

EXPERIENCES OF WOMEN WITH DIABETES: A STUDY IN WEST JAINTIA HILLS DISTRICT, MEGHALAYA

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DECLARATION

I hereby declare that the thesis entitled **“Experiences of Women with Diabetes: A Study in West Jaintia Hills District, Meghalaya”** is the result of doctoral fieldwork undertaken by me at the Department of Humanities and Social Sciences, Indian Institute of Social Sciences, Indian Institute of Technology Guwahati, under the supervision of Dr. Daksha Parmar. The present research work has not been submitted to any other university or institution, in part or whole, for the doctoral degree.

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CERTIFICATE

This is to certify that Ms. Alacrity Muksor has compiled the thesis entitled **“Experiences of Women with Diabetes: A Study in West Jaintia Hills District, Meghalaya”** for the degree of Doctor of Philosophy at the Indian Institute of Technology Guwahati. The research work was undertaken under my supervision while following the guidelines either in whole or part as set by any other university/institution for research purposes. The thesis is the outcome of her exploration and has not been submitted either in whole or in part to any other university/institution for a research degree.

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Abstract

Over the years, there has been an increase in the prevalence of diabetes in rural and tribal areas, which was previously known to be common in urban areas and among rich populations. Qualitative studies on women's experiences with diabetes have been conducted globally and in India. These studies show that diabetes is more challenging for women as it requires extensive self-management and prolonged treatment. This is mainly due to gender discrimination, inequality, and social roles and norms prevalent in society. Due to this, women often neglect their own health as they tend to prioritize the needs of their family members. There are limited studies on understanding the experiences of women living with diabetes in tribal areas, particularly from the northeastern states of India. The present study, therefore, attempts to understand the lived experiences of Pnar women with Diabetes in the West Jaintia Hills District of Meghalaya. The Pnar tribe is the major inhabitant of West Jaintia Hills, and almost eighty percent of the population resides in rural areas. Given that Meghalaya is the state with the largest matrilineal culture, the study focuses on understanding women's health status, especially in the context of diabetes.

The present study is qualitative in nature as it aims to provide an in-depth understanding of multiple factors and processes intersecting at various levels in shaping the health of women. The study combines the approaches of ethnography, narrative inquiries of women documenting their illness experiences, and an in-depth case study on the implementation of the non-communicable diseases' prevention and control program. The program is implemented at the district and the state level, and the views and perceptions of different healthcare providers for diabetes were explored. Further, it also attempts to understand the diabetes care provided by private and traditional medicine providers.

Findings from the present study reveal that women in rural areas of West Jaintia Hills have limited knowledge about diabetes, resulting in complications due to diabetes. There is also inequality in self-management of diabetes among the different groups of women, which was exacerbated with the outbreak of the COVID-19 pandemic. Healthcare providers face numerous barriers in providing care related to diabetes at public health facilities.

Women access different types of healthcare facilities for the treatment of diabetes, such as traditional tribal healers, public health services, and private super-specialty hospitals in Shillong. The challenges faced by women from the low-income group in terms of the everyday struggle for livelihood also shape the development and progression of diabetes. This is due to the chronic stress about their life and the needs of their children. Moreover, the caregiving role the youngest daughter has to undertake adds more to the burden and stress of women in the matrilineal society of Meghalaya. Further, most women in the study also suffer from other diseases along with diabetes, such as hypertension, chronic kidney diseases, eye complications, etc. This increases the likelihood of hospitalization, leading to exorbitant treatment costs, thereby pushing women further into poverty.

Contents

Abstract.....	vii
List of Tables.....	xi
List of Figures	xii
List of Abbreviations:	xiii
Chapter One	1
Introduction.....	1
1.1 Chapterization of the Thesis:	4
Chapter Two.....	6
A Review of the Literature.....	6
Introduction:.....	6
2.1 Diabetes as One of the Major NCDs:.....	6
2.2 Women's Health, NCDs, and Diabetes:.....	17
2.3 Social Determinants of Health:	27
2.4 Beliefs and Cultural Practices Related to Illnesses in General and Diabetes in Particular:	31
2.5 Response of the Health System in the Prevention and Control of Diabetes in India:	36
2.6 Rationale for the Study and Conclusion:	42
Chapter Three.....	45
Conceptualization of the Study	45
Introduction:.....	45
3.1 Conceptualization and approaches adopted for the Study:	46
3.2 Research Objectives and Questions:	56
3.3 Definitions of Concepts used in the Study:.....	57
3.4 Summary:	58
Chapter Four	59
Context of the Study	59
Introduction:.....	59
4.1 Brief Overview of Meghalaya:	59
4.2 Socio-Demographic and Economic Profile of West Jaintia Hills District:	74
4.3 Methodology:	76
4.4 Limitations of the Study:.....	97
4.5 Summary:	98
Chapter Five.....	100
Diabetes in a Matrilineal Society: Experiences of Pnar Women.....	100
Introduction:.....	100

5.1 Socio-demographic Characteristics of Pnar Women Living with Diabetes:	100
5.2 Lay Explanations about Diabetes in the Community:.....	102
5.3 Knowledge and Perceptions Related to Diabetes:	108
5. 4 Cultural Beliefs and Practices Related to Diabetes and its Management:	118
5.5 Barriers to Self-Management of Diabetes:.....	131
5.6 Summary:	142
Chapter Six.....	145
Diabetes Care and Management: Availability of Services and Healthcare Providers' Perspectives.....	145
Introduction:.....	145
6.1 Provisioning of Diabetes Care Services in Public Health Facilities- NPCDCS Program.....	146
6.2 Services Available for Diabetes at Private Health Facilities:	188
6.3 Perspectives of Healthcare Providers on Diabetes and its Management:	196
6.4 Summary:.....	213
Chapter Seven.....	216
Utilization of Health Services for Diabetes: Narratives of Women from Field	216
Introduction:.....	216
7.1 Framework of Medical Care Utilization:	216
7.2 Treatment Seeking Sources for Diabetes and Experiences of Women:	217
7.3 Treatment-Seeking Behaviour among Women: Decision When and Where to Seek Treatment for Diabetes:	227
7.4 Factors Influencing Utilization of Health Services for Diabetes among Pnar Women:.....	231
7.5 Barriers to Utilization of Healthcare Services for Diabetes During the COVID-19 Pandemic:	252
7.6 Summary:	262
Chapter Eight	264
Syndemic Suffering in Matrilineal Society: Poverty, Stress, and Diabetes	264
Introduction:.....	264
8.1 Adverse Childhood Experiences:	265
8.2 Poverty and Diabetes:	266
8.3 Gender Relations and Women's Status:	274
8.4 Food Insecurity, Diet Management, and Diabetes:	284
8.5 Access to Social Support: Role of Primary Caregivers:.....	284
8.6 Views from the Health System, Representatives from Civil Society and International Development Organizations:	294
8.7 Summary:.....	302
Chapter Nine	305

Summary and Conclusion	305
9.1 Summary of Findings from Analysis Chapters:	306
9.2 Policy Recommendations and Scope for Further Research:	318
9.3 Conclusions:.....	327
Bibliography:	331
LIST OF ANNEXURES:	362
Annexure 1 Health Indicators of Meghalaya according to National Family Health Surveys	362
Annexure 3: Semi-structured interview guide for different category of healthcare professionals and traditional tribal healers	365
Annexure 4 Semi-structured interview guide for respondents with diabetes.....	381
Annexure 5 Semi-structured interview guide for caregivers of respondents with diabetes.....	387
Annexure 6: Focus Group Discussion guide with members from the community, ANMs and MLHPs ..	387
Annexure 7 Semi-structured interview guide for representative from Civil Society Organization	388
Annexure 8 Semi-structured interview guide for representative from international developmental organization.....	389
Annexure 9 Letter from the Senior Medical and Health Officer's Nartiang PHC requesting permission from village headmen for fieldwork in villages.....	390
Annexure 10 Entering the Field: A note on participant observations at public health facilities and study villages:	392
Annexure 11 Informed consent form for Women with Diabetes	395
Annexure 12 Informed consent form for Healthcare Professionals	396
Annexure 13 Background characteristics of healthcare officials, providers, and frontline workers	397
Annexure 14 Background characteristics of healthcare providers at private health facilities	399
Annexure 15 Background characteristics of caregivers.....	400
Annexure 16 Illness narratives of five selected women.....	401
Annexure 17 Background characteristics of health officials associated with the MHIS-PMJAY	424
Annexure 18 Field Photos captured during fieldwork	425
Annexure 19 Publications, conferences and workshops attended.....	421

List of Tables

Table 4.1 Key health indicators of Meghalaya in comparison to India (2019-2021)	63
Table 4.2 Disease profile of Meghalaya, 2016	64
Table 4.3 Growth of public sector health institutions and services in Meghalaya between 1972-2015-16	67
Table 4.4 District-wise distribution of public health facilities in Meghalaya (2018)	69
Table 4.5 Names of private health facilities in Meghalaya and their district-wise distribution.....	70
Table 4.6 HWCs visited under Nartiang PHC and Ummulong CHC	87
Table 4.7: Gender-wise distribution of health officials and healthcare providers interviewed at public and private health facilities	89
Table 4.8 Respondents-Women Living with diabetes and caregivers	90
Table 4.9 Background characteristics of village headmen interviewed from select villages.....	91
Table 4.10 Demographic structure of select villages representing other 15 villages.....	92
Table 4.11 Summary fieldwork phases and data collection methods adopted.....	80
Table 5.1 Socio-economic characteristics of women.....	100
Table 5.2 Presence of comorbidity and multimorbidity among women	138
Table 5. 3 Access to antidiabetic medicine during the COVID-19 pandemic lockdown	140
Table 6.1 Packages of services for NCD at each level of health facility	147
Table 6.2 General information on the HWCs Visited.....	153
Table 6.3 Findings from the population-based screening conducted by HWCs	156
Table 6.4 Human Resources at PHC (2020-2021).....	158
Table 6.5 Human Resources at NCD clinic (2020-2021)	159
Table 6.6 Criteria for diagnosis of T2DM using venous blood samples according to WHO definition 1999	161
Table 6.7 No. of men and women newly diagnosed with NCDs during 2019-20 at Public Health facilities (PHCs/CHCs/District Hospital) in West Jaintia Hills, District.....	162
Table 6.8 No. of men and women newly diagnosed with NCDs during 2020-21 at Public Health facilities in Meghalaya.....	162
Table 6.9 Human Resources at the state and district NCD Cell (2020-2021)	168
Table 6.10 People from West Jaintia Hills District admitted in a private hospital, Shillong.....	193
Table 7.1 Sources of initial diagnosis for diabetes among women.....	219
Table 7.2 Sources of treatment follow-up for diabetes among women	219
Table 7.3 Phases in the implementation of MHIS.....	239
Table 7. 4 Brief information about Women with diabetes who incurred high OOPE.....	241
Table 8.1 HbA1c as a measure of treatment outcome for diabetes.....	291

List of Figures

Figure 3.1 Social-economic position and diabetes.....	53
Figure 4.2 Map of Meghalaya.....	61
Figure 4.3 Structure of the Study	77
Figure 4.4 Map showing the location of health facilities visited for fieldwork in West Jaintia Hills.....	88
Figure 4.5 Map showing the number of respondents in each of the 20 villages visited in thadlaskein block, West Jaintia Hills District	93
Figure 4.6 Data analysis process.....	95
Figure 6.1 Structure of the NPCDCS program in India	147
Figure 6.2 A poster on diabetes displayed in one of the HWCs in English language.....	150
Figure 6.3. Checking of Random Blood Sugar (RBS) Using a Glucometer.....	152
Figure 6.4 Process of fund flow for the NPCDCS program	172
Figure 6.5 A graph depicting the number of patients who attended the NCD clinic between January and August 2020.....	187
Figure 6.6 Summary of perspectives of the herbalists on diabetes and its management	200
Figure 7.1 Treatment-seeking sources of women living with diabetes in rural areas of West Jaintia Hills, District, Meghalaya.....	218

List of Abbreviations:

ABP- Ayushman Bharat Program
ADA- American Diabetes Association
AIDS- Acquired Immuno Deficiency Syndrome
ANMs- Auxiliary Nurse Midwives
APDs- Accredited Practising Dietitians
APL- Above Poverty Line
ASHA- Accredited Social Health Activist
ATMs- Automatic Teller Machines
AWC- Anganwadi Centre
AYUSH- Ayurveda Unani Siddha and Homeopathy
BA- Bachelor in Arts
BAMs- Bachelor of Ayurvedic Medicines
BMI- Basal Metabolic Index
BP- Blood Pressure
BPL- Below Poverty Line
C&RD- Community and Rural Development Block
CAM- Complementary and Alternative Medicine
CAQDAS- Computer-Assisted Qualitative Data Analysis Software
CBAC- Community-Based Assessment Checklist
CCU- Coronary Care Unit
CHC- Community Health Centre
CHDs- Chronic Heart Diseases
CHOs- Community Health Officers
CKD- Chronic Kidney Diseases
CMA- Critical Medical Anthropology
COPD- Chronic Obstructive Pulmonary Diseases
COVID-19- Corona Virus Diseases- 2019
CPHC- Comprehensive Primary Health Care
CSDH- Commission on Social Determinants of Health
CSO- Civil Society Organization

CT Scan- Computed Tomography Scan
CVDs- Cardio Vascular Diseases
DEO- Data Entry Operator
DH- District Hospital
DHS (MI)- Directorate of Health Services (Medical Institutions)
DHS- Directorate of Health Services
DM&HO- District Medical and Health Officer
DMHS- Doctor of Medicine and Herbal Sciences
DNO- District Nodal Officer
DPC- District Program Coordinator
DSO- District Surveillance Officer
DTM- Doctor of Traditional Medicine
DVDMS- Drug and Vaccine Distribution Management Systems
ECG- Electrocardiogram
ECHO- Echocardiogram
ENT- Ear, Nose and Throat
FBS- Fasting Blood Sugar
FLC- Finance-cum-Logistic Consultant
FRU- First Referral Unit
GHL- Glycated Haemoglobin Level
GI- Glycaemic Index
GNMs- General Nurse and Midwives
GoI- Government of India
GoM- Government of Meghalaya
HbA1C- Glycated Haemoglobin
HDR- Human Development Report
HIV- Human Immuno Deficiency Virus
HPSR- Health Policy and Systems Research
HR- Human Resource
HSR- Health Systems Research
HWC- Health and Wellness Centres

ICMR- Indian Council of Medical Research
ICU- Intensive Care Unit
IDF- International Diabetes Federation
IDO- International Development Organization
IDSP- Integrated Disease Surveillance Program
IEC- Information Education Communication
IFG- Impaired Fasting Glucose
IGNOU- Indira Gandhi National Open University
IGT- Impaired Glucose Tolerance
IIPS- International Institute of Population Sciences
IUCD- Intra Uterine Contraceptive Device
IMR- Infant Mortality Rate
INR- Indian National Rupee
IPHS-Indian Public Health Standard
JCH- Jowai Civil Hospital
JHADC- Jaintia Hills Autonomous District Council
KFT- Kidney Function Test
KHADC- Khasi Hills Autonomous District Council
LFT- Liver Function Test
MBBS- Bachelor of Medicine and Surgery
MCH- Maternal and Child Health
MFC- Medico Friend Circle
MHIS- Megha Health Insurance Scheme
MHSSP- Meghalaya Health System Strengthening Project
MLHPs- Mid-Level Healthcare Providers
MNT- Medical Nutrition Therapy
MoHFW- Ministry of Health and Family Welfare
MoU- Memorandum of Understanding
MPW- Multipurpose Worker
MRI- Magnetic Resonance Imaging
MS- Medical Superintendent

NCCP- National Cancer Control Program
NCDIs- Non-Communicable Diseases and Injuries
NCDs- Non-Communicable Diseases
NDCP- National Diabetes Control Programme
NE- North Eastern
NEIGRIHMS- North Eastern Indira Gandhi Regional Institute of Health and Medical Sciences
NFHS- National Family Health Survey
NHPS- National Health Protection Scheme
NHSRC- National Health Systems Resource Centre
NGO- Non- Governmental Organization
NITI- National Institute of Transforming India
NPCDCS- National Program for Prevention and Control of Cancer, Diabetes Cardiovascular Diseases and Stroke
NPHCE- National Program for Health Care of Elderly
NQAS- National Quality Assurance Standard
NRHM- National Rural Health Mission
NS- Nursing Superintendent
OHAs- Oral Hypoglycaemic Agents
OOPE- Out-of-Pocket Expenditure
OPD- Out-Patient Department
PBS- Population Based Screening
PFMS- Payment Financial System
PHC- Primary Health Center
PHFI- Public Health Foundation of India
PHFI- Publicly Funded Health Insurance Scheme
PHN- Public Health Nurse
PIP- Program Implementation Plan
PMJAY- Pradhan Mantri Jan Arogya Yojana
PPA- Pre Payment-Receipt
PPBS- Post Prandial Blood Sugar
PPP- Public-Private Partnership
RBS- Random Blood Sugar

RCHP- Reproductive and Child Health Programme
RoP- Record of Proceedings
RSBY- Rashtriya Swasthya Bima Yojana
SCs-Sub-Centers
SDGs- Sustainable Development Goals
SDH- Social Determinant of Health
SHCs- Sub-Health Centre
SM&HO- Senior Medical & Health Officer
SNA- Single Nodal Account
SRH- Sexual and Reproductive Health
SRS- Sample Registration Survey
STs- Scheduled Tribes
TB- Tuberculosis
TFR- Total Fertility Rate
TMS- Transaction Management Software
UHC- Universal Health Coverage
UMP- Unqualified Medical Practitioner
UN- United Nations
UPHC- Urban Primary Health Centre
UPSC- Union Public Service Commission
USA- United States of America
USD- United States Dollar
USG- Ultrasonography
VCMC- Village COVID-19 Management Committee
VHAM- Voluntary Health Association of Meghalaya
VHC- Village Health Council
VHND- Village Health and Nutrition Day
VHSNC- Village Health Sanitation and Nutrition Committee
WHO- World Health Organization

Chapter One

Introduction

The Goal three of the United Nation's Sustainable Developmental Goals (SDGs), calls for ensuring healthy lives and the promotion of well-being for all at all ages. It also focuses on health equity to ensure that no one is left behind in the right to enjoy good health and well-being (RamPrakash & Lingam, 2021). To address health inequities which refer to differences in health deemed unfair and preventable, there is a need to understand health inequalities across population subgroups (Hosseinpour et al., 2018). In recent years, with increasing life expectancy and an ageing population, there has been an increase in the prevalence of chronic illnesses in the population. The change in the morbidity and mortality pattern reflects an epidemiological transition characterized by a shift from the predominance of infectious, communicable diseases to that of Chronic and Non-Communicable Diseases (NCDs) (Omran, 2005; Gulati & Pandey, 2015). The distribution of diseases is different across population groups. For instance, the prevalence of NCDs was earlier known to be higher in urban areas and among wealthy individuals and therefore known as a disease of modernity. However, by the early 2000s, this myth of NCDs being a problem of the urban population was busted, as mortality due to NCDs in rural areas was also high and increasing rapidly, even among people of poor socio-economic status (Jeemon et al., 2019).

The long-term nature of NCDs creates a significant economic burden for individuals and households due to increased expenditure for their treatment and loss of wages owing to disabilities (Srivastava & Bachani, 2011; Islam et al., 2014; Bloom et al., 2014; Barik & Arokiasamy, 2016). In India, approximately 63 million households are impoverished yearly because of catastrophic healthcare expenditures (RamPrakash & Lingam, 2021:2). This is a significant concern for health policy makers, given that more than three-fourths of the population earn less than \$2 per day and barely survive, living a precarious life in poverty (Subramanian et al., 2013). NCDs also lead to other diseases in older adults, discrimination against women and the elderly owing to the high cost of treatment, and complications as they can be asymptomatic and insidious (World Health Organization, 2011a; Jeemon et al., 2019).

To a large extent, studies on women's health have been restricted only to reproductive and sexual health, and limited focus has been given to women's health throughout their life cycles (Lewis & Kieffer, 1994; Inhorn, 2006). Given that the prevalence of NCDs is increasing even in

rural areas and among tribal populations (Government of India (GoI), 2018a), there is a need to understand how the tribal population experiences NCDs. Cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes are the major contributors to mortality among NCDs. Of these four significant NCDs, “diabetes requires intensive and continuous self-care” (Weaver, 2018:5). Diabetes and its risk factors present unique challenges and complications in women’s health and well-being, given the unequal status of women and gender inequality (Kapur & Sheshiah, 2017).

The prevalence of diabetes is increasing even among the indigenous population,¹ especially among women (International Diabetes Federation’s (IDF) Diabetes Atlas, 2021). Tribal women face numerous challenges in accessing healthcare services, such as poor public transportation, negative attitude of healthcare providers towards them, and so on (Kumar et al., 2016a; Boro & Saikia, 2020). This has created numerous challenges when it comes to diabetes, thereby reinforcing health inequalities across social groups (Anderson, 2015; Mini & Thankappan, 2017).

The present study conducted in the matrilineal society of Meghalaya, predominantly inhabited by an indigenous or tribal population, aims to explore the lived experiences of women with diabetes and their interactions with the health system. Studies on the health status of tribal communities have found that tribal communities in India suffer the worst health status compared to all social groups (GoI, 2018a; Ravindran et al., 2022). To a large extent, it is vital to understand the social, economic, and cultural contexts of diabetes as they are the main determinants of the disease. This study was carried out amongst women of the Pnar tribe, which predominantly inhabits the West Jaintia Hills district of Meghalaya. The study explores the experiences and challenges in self-management of diabetes, the treatment-seeking behaviour of women, and sources of treatment for diabetes, especially in the context of the COVID-19 pandemic. It also analyzes the perspectives and responses of the health system and healthcare providers in the prevention and control of diabetes in the state.

¹The term “indigenous peoples” has been used predominantly in literature, but other terms such as tribes, first peoples/nations, aboriginals, or minority ethnic groups also exist. However, the Government of India considers “tribals” a separate demographic entity in the Census (Albert, 2014:42-43). In Clause 1 of Article 342 of the Constitution of India, tribal ethnic groups are notified as scheduled tribes (ibid). The word “tribal” is a colonial construction that earlier had a pejorative meaning of being uncivilized and backward (ibid). However, the word now has been widely used and accepted. The three terms *adivasis*, “tribals,” and “indigenous peoples” have been used at different points of time in the history of India for different reasons. *Adivasis*, which is the oldest term and it means original inhabitants (ibid). However, the term *adivasis* has not been widely accepted in northeast India as in the region, it is meant to address the specific tribal communities in central India. Instead, people in the northeast who claim indigenous status prefer the term “tribal” or “indigenous peoples” (Albert, 2014:43).

The Meghalaya State Legal Services Authority (2015) (as cited in the Meghalaya Mental Health and Social Care Policy, Government of Meghalaya (GoM), 2022:29) “suggested that one-third of the state’s population is living below the poverty line, and poverty in rural areas is two times higher than that of the urban.” Meghalaya suffers from complex challenges such as widespread substance abuse, increased number of childbirths at home, fragmented medical help-seeking patterns, and high fertility levels. All these challenges contribute to health concerns such as the increasing prevalence of cancers, poorer health outcomes for women, and lower life expectancy (GoM, 2022:31). Tribal society, however, is a dynamic society where numerous changes are taking place, and as a consequence, social stratification has been developed. Due to this stratification, women in a tribal society are not a homogenous group, and there is differentiation among women. While a few women are privileged, most belong to the lower stratum of society (Xaxa, 2007).

Meghalaya follows a culture of matriliney. Under this system the children take the lineage of the mother. In Meghalaya, matriliney is constructed “as a system that privileges the youngest daughter, called in the local language *ka khadduh*, as the custodian and not the owner of the ancestral property” (Subba, 2008:51). Scholars and activists working on matriliney in Meghalaya, such as Nongbri (2008) and Mukhim (2019), have argued that matriliney does not guarantee higher status for women in Meghalaya. This is because women do not have a say in the public domain, such as the Village Durbar² and even the State Legislative Assembly. The rate of divorce or abandonment is high in the state and has led to increased burdens on women. This is attributed to the matrilineal culture where women are granted custodial rights over their children; thus, all the responsibilities of raising their children fall on their shoulders (Nongbri, 2008). The experiences of women with diabetes were thus explored within this socio-cultural context of Meghalaya through the present qualitative research work.

² In Meghalaya the local traditional institution or village council is known as Village Durbar and is headed by Village Headmen (Gassah, 1994; Thomas, 2004; Oosterhoff et al., 2015).

1.1 Chapterization of the Thesis:

The present thesis is organized into eight chapters. The first chapter, entitled “Introduction,” briefly provides an overview of the research study.

The second chapter, “A Review of the Literature,” discusses the previous studies on diabetes, diabetes among women, and health system responses related to preventing and controlling NCDs.

The third chapter discusses the “Conceptual Framework” used for the study. This chapter also covers the different approaches adopted for the study besides the framework of social determinants of health, such as the medical anthropological and intersectionality approaches. In addition, the concept of syndemic is discussed briefly in the chapter.

The fourth chapter explains in detail the methodology adopted for the study. Selection of study sites and participants was also discussed in the chapter.

The fifth chapter “Diabetes in a Matrilineal Society: Experiences of Pnar Women” presents the findings from the field after describing the socio-demographic background of the women. The chapter focuses on women’s experiences with diabetes in terms of their knowledge about the risk factors for diabetes, its signs and symptoms, and the care and management of diabetes. Further, the chapter also covers the beliefs and cultural practices related to diabetes and the barriers faced by women in the self-management of diabetes.

The sixth chapter on “Diabetes Care and Management: Availability of Services and Healthcare Providers’ Perspectives” describes and analyzes the different kinds of services available for diabetes at the healthcare facilities in the district and the state. It also focuses on the implementation of the National Programme for the Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases, and Stroke (NPCDCS) at different levels of the public health institution. The perspectives of healthcare providers in the care and management of diabetes are also covered in this chapter.

The seventh chapter entitled “Utilization of Healthcare Services for Diabetes: Narratives of Women from Field” discusses the different treatment sources that women access in seeking preventive and curative care for diabetes. The chapter covers the factors that influence the utilization of healthcare services for treating diabetes among women. In addition, the chapter also explains the experiences and challenges women face while seeking treatment for diabetes at

different healthcare facilities, especially the ones they faced during the COVID-19 pandemic and the subsequent lockdown.

The eight chapter, using narratives of different women is entitled “Syndemic Suffering in Matrilineal Society: Poverty, Stress and Diabetes.” The chapter analyzes the intersection of social determinants of diabetes in women with the co-occurrence of multiple factors like poverty, marginalization, deprivation, and weak health system provisioning. The chapter also analyzes and discusses the perspectives of healthcare officials, representatives from civil society, and international development organizations on the status of women and the provisioning of healthcare services in the state.

The ninth chapter on “Summary and Conclusion” summarizes all the findings from the study based on research objectives and research questions proposed in the present research work. The chapter also highlights some key policy recommendations drawn from the present research findings. It also describes the scope for further research based on findings from the thesis, after which the conclusion of the study is drawn.

Chapter Two

A Review of the Literature

Introduction:

The present chapter discusses various studies and literature pertinent to understand diabetes from socio-economic perspectives with a focus on women's health and diabetes. The chapter is divided into six major sections. Section 2.1 describes diabetes as one of the major NCDs. Section 2.2 focuses on women's health and diabetes. Section 2.3 discusses the relevant literature on social determinants of health and diabetes. Section 2.4 reviews the studies on beliefs and cultural practices related to diabetes. Section 2.5 explains the health system's response to the increasing prevalence of NCDs in general and diabetes in particular. Section 2.6 provides the rationale for the study and conclusion.

2.1 Diabetes as One of the Major NCDs:

Communicable diseases can be transmitted from one person to another, e.g. tuberculosis (TB), diarrheal diseases, and Human Immunodeficiency Virus/Acquired Immune Deficiency Syndromes (HIV/AIDS). NCDs do not spread from person to person and usually last longer. Most NCDs are chronic and have many causes encompassing genetic, physiological, environmental, and behavioural factors (WHO, 2018). About 41 million people die annually due to NCDs, accounting for 74 percent of all deaths worldwide.³ “Cardiovascular diseases, cancers, diabetes, and chronic respiratory diseases” are major NCDs (WHO, 2018:10). These four major types of NCDs share common risk factors, which are an unhealthy diet, physical inactivity, and tobacco and alcohol use, and together contribute to higher mortality (WHO, 2018). They contribute about 80 percent of NCD deaths. Given the large proportion of deaths attributed to the four NCDs, they are considered the major NCDs. Diabetes alone contributes to 2.0 million deaths annually.⁴ The present research

³ Available at <https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases> accessed on 30th June 2023

⁴ Same as footnote number 2

work attempts to study one of these major NCDs, which is diabetes. Hence, the following subsection will briefly define diabetes and its types.

2.1.1 Definition and Types of Diabetes:

Diabetes is a chronic disease that results from a poorly functioning pancreas that fails to produce enough insulin, a hormone that regulates blood glucose. It can also be due to the failure of the body to use the insulin that the pancreas produces effectively.⁵ Uncontrolled diabetes can lead to hyperglycaemia or increased blood glucose/sugar level. If left untreated for a long time, hyperglycaemia can seriously damage the body's organs, particularly the nerves and blood vessels.⁶ Further, diabetes if not well-managed, can lead to serious consequences due to complications such as heart attack, stroke, kidney failure, vision impairment, and limb amputation (Phillips, 2020).

Diabetes is classified into four main types depending on its causes. These are – type 1 diabetes, type 2 diabetes, gestational diabetes, and impaired glucose tolerance or impaired fasting glucose. Type 1 diabetes mainly occurs among children, although it can also occur at any age and cannot be prevented. Insulin injection is needed for people with type 1 diabetes to survive (IDF Diabetes Atlas, 2021). Type 2 diabetes, which accounts for over 90 percent of diabetes cases globally, can be prevented or delayed. Gestational diabetes, as the name suggests, occurs during pregnancies. Impaired glucose tolerance or impaired fasting glucose is also known as prediabetes and indicates a higher risk of developing type 2 diabetes and its related complications (IDF Diabetes Atlas, 2021). In the present research work, the term “diabetes” refers to type 2 diabetes, which is the focus of the study. Since diabetes is considered one of the “fastest-growing global health emergencies in the 21st century” (IDF Diabetes Atlas, 2021:5), understanding the disease burden and prevalence is important.

2.1.2 Burden and Prevalence of Diabetes:

In 2021, it was estimated that 537 million people in the age group of 20-79 years suffered from diabetes. By 2030, this number is projected to reach 643 million and 783 million by 2045. (IDF Diabetes Atlas, 2021:30). Around 6.7 million adults aged 20-79 died in 2021 due to diabetes

⁵ Available at <https://www.who.int/news-room/fact-sheets/detail/diabetes> accessed on 20th March 2023

⁶ Same as footnote number 4

and its complications. This accounts for 12.2 percent of deaths globally from all causes in the same age group (IDF Diabetes Atlas, 2021:55). Diabetes presents several challenges when it comes to everyday management, symptoms, and disability due to its chronic nature. Further, a delay in diagnosis and absence of care could result in increased sugar levels in the blood, thereby leading to complications of heart and kidney diseases, stroke, and blindness (WHO, 2016). Diabetes as a disease also impacts the economy as it is widely prevalent in the young working-age population, imposing several restrictions related to regular monitoring of the disease, adjustments in living, and prolonged treatment costs. For instance, around 32.6 percent of diabetes-related deaths are estimated to occur in people of working age, i.e. in those below 60 years of age (IDF Diabetes Atlas, 2021:55).

India accounts for the highest number of people living with diabetes worldwide. For instance, one in seven adults with diabetes is in India (IDF Diabetes Atlas, 2021:94). In South Asia, with 61.3 million cases, India has the highest number of people with diabetes in the age group of 20-79 years. India also accounts for over one million deaths attributed to diabetes and its related complications (IDF Diabetes Atlas, 2021:95). With 0.6 million deaths annually, India has the third highest number of deaths due to diabetes, after China and United States (IDF, 2021:55). Owing to the highest number of diabetes cases, India is termed the diabetes capital of the world (Prajapati & Kedia, 2015; Pradhan et al., 2018).

Studies on the prevalence of diabetes have been widely conducted, and brief findings from previous studies conducted in India are discussed as follows.

2.1.2.1 Previous Studies on the Prevalence of Diabetes:

In epidemiology, the prevalence of a disease is defined as the total number of old and new cases in a population at a given time (Gordis, 2014). Ahuja (1979) (as cited in Mohan et al., 2007: 218) stated that in India, the first national study on the prevalence of type 2 diabetes was conducted by the Indian Council of Medical Research (ICMR) between 1972 and 1975. The study found that the prevalence of type 2 diabetes among individuals aged 40 years and above was 5 percent in urban and 2.8 percent in rural areas. Subsequently, numerous surveys were carried out in India, and the results show the rising prevalence of diabetes both in urban and rural areas. Bharati et al. (2011), in their study conducted in Puducherry, India, estimated the prevalence of diabetes there to be 8.47 percent. Kundap et al. (2015) conducted a cross-sectional study in a village in Pune

district and estimated the prevalence of diabetes to be 10.5 percent. A study conducted by Tripathy et al. (2017) in Punjab found that the prevalence of diabetes was 8.3 percent. Numerous studies have also been conducted in rural areas to estimate the prevalence of diabetes. Agarwal et al. (2017), in their community-based study conducted in rural Agra, estimated the prevalence of diabetes to be 7 percent. Studies conducted in rural areas also give male-female differentials in the prevalence of diabetes. For example, a study conducted in a rural block of Haryana by Jangra et al. (2019) estimated the prevalence of diabetes to be 9.2 percent, where it was 10.8 percent among females and 7.6 percent among males. Singh et al. (2017), assessed the prevalence of diabetes mellitus in the rural population of Western Uttar Pradesh and concluded that the prevalence of diabetes is high at 8.03 percent (9.91 percent among females and 6.79 percent among males). Zaman and Borang (2014), in their study among hilly villages of Arunachal Pradesh, found the prevalence of diabetes there to be 19.78 percent. The prevalence of diabetes among females (22.04 percent) was higher than among males (16.06 percent).

In a study conducted by Yadav et al. (2019), using the 60th (2004) and 71st (2014) rounds of the National Sample Survey, they found that the prevalence of diabetes varies across gender and socio-economic characteristics. For example, it was higher among men than women and higher among those in the most affluent category living in urban areas. Yadav et al. (2019) also found that the prevalence of NCDs among men and women in rural areas is less than in their urban counterparts. The explanation given for their findings was the urban consumption of highly processed foods which are rich in fats and carbohydrates, environmental pollution leading to chronic respiratory illnesses, and a sedentary lifestyle in urban areas. However, diabetes was common even in rural populations, as was evident in the study conducted by Zaman & Borang (2014) in the rural hilly areas of Arunachal Pradesh (19.78 percent). Also, Jeemon et al. (2019) argued that since 2003, the mortality due to NCDs has been as high as 41 percent in rural areas and had increased to 47 percent by 2010-13. The rise in the burden of NCDs in rural areas, according to Jeemon et al. (2019), is due to increased life expectancy, growing population, urbanization, and changing lifestyle and food habits.

The results from a random survey conducted by Syiem et al. (2012) in Meghalaya found that the prevalence of diabetes amongst the urban tribal Khasi and Jaintia populations was 9.89 percent and 12.5 percent, respectively. The findings from the fourth National Family Health Survey

(NFHS-4) (2015-16) showed that the percentage of women and men in the age group of 15-49 years in Meghalaya with random blood sugar levels of more than 140mg/dl was 6.1 and 9.3 percent respectively. In the district of Jaintia Hills,⁷ the percentages were 5.9 and 5.3 for women and men, respectively (International Institute of Population Sciences (IIPS) & ICF, 2017). In NFHS-5 (2019-21), the percentages were 9.5 and 13.9 percent for women and men, respectively, for all of Meghalaya. However, the NFHS-5 (2019-21) district fact sheet for the West Jaintia Hills district shows that the percentages of women and men (15-49 years) whose random blood sugar level was more than 140 mg/dl were 8.8 and 7.8 percent respectively (IIPS & ICF, 2021). Thus, we can infer from the aforementioned two rounds of NFHS that over the years, the percentage of individuals in the age group of 15-49 years with high random blood sugar levels has increased at the state and district level in Meghalaya. The increase in the prevalence of risk factors for NCDs, such as diabetes among the tribal population, has been documented to some extent in quantitative studies (Ganie et al., 2020; Hazarika & Babu, 2023; Chinnayan et al., 2023). However, limited qualitative research has been conducted on diabetes among the tribal population, particularly in Meghalaya (Government of India (GoI), 2018a). According to the 2011 Census of India, about 80 percent of the population in Meghalaya resides in rural areas and is predominantly tribal. The Disease Burden Profile (DBP) of Meghalaya estimated that the proportion of total disease burden from NCDs is the highest at 52.3 percent among all diseases in Meghalaya (Indian Council of Medical Research, Public Health Foundation of India, and Institute for Health Metrics and Evaluation, 2017).

The report of an expert committee on tribal health published by the Ministry of Health and Family Welfare and Ministry of Tribal Affairs, Government of India, in 2018, mentioned that the tribal population is facing a triple burden of disease (GoI, 2018a:33). According to the report, the three burdens include: firstly, malnutrition and communicable diseases such as malaria and tuberculosis that are still rampant secondly, a rise in the prevalence of NCDs such as cancer, hypertension, and diabetes due to rapid urbanization, environmental distress, and changing lifestyles; and the third is the burden of mental illness and addiction (GoI, 2018a). The increase in the prevalence of NCDs among the indigenous population is due to the shift from a traditional to a modern lifestyle as well as due to poverty and malnutrition (GoI, 2018a; Medico Friend Circle, 2017). This has important implications for Meghalaya, with its poor health indicators and weak

⁷ Although the district was bifurcated into East and West Jaintia Hills in 2011, in NFHS-4, the district factsheet was available for Jaintia Hills as a whole.

infrastructure. This is because, according to WHO (2016), diabetes has close links with other NCDs and their risk factors, resulting in lifelong illness and prolonged treatment periods for multiple morbidities. As a consequence, this leads to huge treatment expenditure. The next sub-section will briefly discuss the socio-economic burden pose by diabetes and its complications.

2.1.3 Socio-Economic Burden of Diabetes:

The rising epidemic of diabetes and its chronic nature have a long-term impact on the economy of a country and its health status. For the prevention and control of diabetes, the health systems of different countries are responding by introducing related health programs. For instance, as early as 1987, the Government of India introduced the National Diabetes Control Program (NDCP) in the selected districts of Tamil Nadu, Jammu & Kashmir, and Karnataka to ensure screening for early detection and treatment of diabetes (Das, 2013). However, given the weak and fragmented nature of diabetes care in public health systems, most patients living with diabetes in India are forced to seek care from private health facilities resulting in high out-of-pocket expenditure (OOPE) for treating diabetes. Most patients living with diabetes in developing nations such as India experience a substantial burden from the cost of care for diabetes out-of- their pocket. Moreover, the poor coverage and functioning of insurance schemes further escalates the cost of care for diabetes (Oberoi & Kansra, 2020). The economic consequences of diabetes are calculated in two ways: direct costs, and direct costs plus indirect costs. The number of physician visits, medicines, and diagnostic tests constitute the direct costs. Transportation costs while seeking treatment, loss of wages due to morbidity, and premature mortality leading to societal loss constitute indirect costs. Patients and their families usually bear the costs of diabetes care (Bjork, 2001; Oberoi & Kansra, 2020). In addition, another cost is added to the expenses known as “intangible costs,” which comprises the cost of being pushed into poverty, social isolation, dependence, having poor mental health, and behavioural disorder, leading to a poor quality of life (Oberoi & Kansra 2020:468).

In a review of literature conducted by Yesudian et al. (2014), it was observed in a study in Delhi that the average annual direct cost of type 2 diabetes was Indian National Rupee (INR) 6,212.40 (United State Dollar 143.14)⁸ in 2005, of which more than half of the amount was spent on drugs (INR 3,324; USD 76.59) (Yesudian et al., 2014:3). With complications, the costs of

⁸ One Dollar is equivalent to Indian National Rupee 82/-

diabetes increased further. Yesudian et al. (2014) also found that in Chennai, the total cost for patients with diabetes complications between 2008 and 2009 was INR 14,691.75 (USD 301.32) whereas, for patients without complications, the cost was INR 4,493 (USD 92.15) (Yesudian et al., 2014:11). Among all the complications of diabetes, foot complications were the costliest, as patients had to spend four times more than those without complications. This was followed by patients with renal or kidney disease, and those with cardiovascular and retinal complications, who spent three times more than patients without complications. Similarly, consultations and hospitalization costs were higher for patients with complications, with an average of INR 1,085 (USD 22.25) and INR 5,256.40 (USD 107.80), respectively. However, for patients without complications, the costs for consultation and hospitalization were INR 350 (USD 7.18) and INR 1,083 (USD 22.21) respectively (Yesudian et al., 2014:14). The cost of drugs for diabetes represents more than 50 percent of a household's total direct costs. Large-scale dataset studies reveal that drug costs for diabetes accounted for 58 percent of out-of-pocket expenditure on diabetes treatment (Yesudian et al., 2014:15). Diabetes alone exhausts an average of 5 percent to 25 percent of household earnings in India, posing an economic burden to households (Oberoi & Kansra 2020). Khongrangjem et al. (2018), in their study in Meghalaya, in estimating the cost of care for diabetes without complications, revealed that the total median cost of diabetes per month was INR 5,375 (USD 64.79), out of which INR 3,816 (USD 46) was the direct cost and INR 1,559 (USD 18.79) was the indirect cost (Khongrangjem et al., 2018).

In rural areas and among low-income populations, there is lower expenditure on diabetes. This is attributed to problems of access and affordability and not to a lower need for diabetes among people from lower-socioeconomic groups in rural areas (Yesudian et al., 2014). However, detecting diabetes at a later stage among low-income groups often leads to catastrophic household expenditure (ibid). The high-income population in urban areas incurs more expenditure on diabetes care, leading to better outcomes. In contrast, poor people living in rural areas tend to have the worst health outcomes due to difficulties accessing diabetes care, thereby spending less on diabetes care (ibid).

Existing literature shows that the economic burden of diabetes is borne largely by the patients and their families, therefore indicating the need for better health coverage. The serious adverse effects of high out-of-pocket expenditure for diabetes care leads to impoverishment due

to catastrophic spending. Further, the high cost of care in case of complications is a barrier to universal health coverage (UHC) (Yesudian et al., 2014; Oberoi & Kansra, 2020). Numerous barriers and difficulties pose challenges in managing diabetes and its comorbidities in India. This includes limited awareness about diabetes- its risk factors, prevention strategies, poor quality of healthcare for diabetes, non-adherence to medication, and irregular blood glucose monitoring (Oberoi & Kansra, 2020).

2.1.4 Awareness and Knowledge about Diabetes:

Awareness and knowledge about diabetes are crucial for the early identification of symptoms, diagnosis, and timely treatment. Previous studies have shown that increasing knowledge about diabetes and its complications facilitates compliance with treatment, thereby reducing the risk of complications associated with diabetes (Deepa et al., 2014; Amankwah-Poku, 2019). In a study conducted by Deepa et al. (2014) to assess the knowledge and awareness about diabetes in urban and rural India as part of the Indian Council of Medical Research India Diabetes Study, it was found that only 50 percent of their study population had heard about diabetes. Further, the study also found that awareness in rural areas was significantly lower compared to urban areas. Their study also found that about 56.3 percent of the general population and 63.4 percent of people with diabetes knew that diabetes could be prevented. Concerning awareness about complications, about 51.5 percent of the general population and 72.7 percent of people with diabetes knew that diabetes could affect other organs. The study concluded that knowledge and awareness about diabetes, especially in rural areas, are poor, indicating the need for “large-scale diabetes awareness and education programs” (Deepa et al., 2014:379). In a cross-sectional study conducted by Kamath et al. (2015) to assess the knowledge and awareness about oral health among diabetic patients in Mangalore city, it was found that about 63 percent of their respondents were unaware of the type of diabetes they had. They also found that 48.1 percent of the respondents were unaware of the systemic complications associated with diabetes, and only 22.5 percent knew about gum disease caused by diabetes.

In northeast India, the first rural survey for diabetes was conducted by Lau et al. (2009) in Tripura to determine the level of awareness and knowledge about diabetes in the community and to identify the risk factors for diabetes. About 91 percent of their study population had heard about diabetes, 44 percent were concerned about getting diabetes in the future, and only 37 percent knew

that diabetes required long-term treatment. The study concludes that in rural areas, there is “low baseline knowledge and awareness about diabetes” despite the significant prevalence of diabetes (Lau et al., 2009:305). The study emphasizes the need for health education and reducing risk factors in northeast India. Similar findings are noted from a study by Singh et al. (2012) in Arunachal Pradesh on awareness about diabetes. Their study found that only 21.4 percent of their population knew that a disease known as diabetes even existed, and only six percent were aware of its symptoms.

While the greatest strength of quantitative studies is in the generalization of findings across similar settings, it fails to reason out findings and, in most cases, the recommended action might not be possible for the study populations. For instance, in terms of limited awareness about diabetes, the action recommended such as generating awareness and improving health education programs alone are not enough as there are other social factors that act as barriers to following the advice related to diabetes even if a person have adequate knowledge about diabetes.

2.1.5 Risk Factors of Diabetes:

NCDs, including diabetes, have common risk factors. These risk factors include tobacco smoking, excessive alcohol consumption, unhealthy dietary practices, physical inactivity, environmental pollution, and stress (Gupta et al., 2018; WHO, 2018). The aetiology or the cause of diabetes is thus believed to be multiple. These individual-level risk factors can be modifiable or non-modifiable. “Modifiable risk factors include sedentary lifestyle, lack of physical activity, overweight or obesity, unhealthy diets (increased consumption of refined grains, fat, sugar, and sweetened beverages and low consumption of fruits and vegetables) and habits (smoking and alcohol addiction), exposure to environmental pollutants, altered intrauterine environment and mental health (stress/depression), short sleep duration and the built environment. Non-modifiable risk factors include genetic, age, ethnicity, and family history” (Pradeepa & Mohan, 2021:2936).

The rise in the prevalence of diabetes in India is attributed to a genetic predisposition, considered a high-risk factor among Asian Indians. A certain unique clinical, biochemical characteristic of Asian Indian ethnic groups known as the “Asian Indian Phenotype” (Hussain, 2018:69) is considered a strong risk factor that contributes to the higher rates of diabetes among Asian Indians. This phenotype results in a large waist circumference and waist-to-hip ratio, even

with a low Body Mass Index (BMI), leading to a greater degree of central obesity and increased resistance to insulin hence diabetes (Okram, 2016; Hussain, 2018).

The biomedical explanation of diabetes limits itself to risk factors, such as genes, obesity, age, ethnicity, high blood pressure, and high blood cholesterol. It ignores the structural factors outside the individual's control (Weaver, 2018; Mendenhall, 2019). However, socioeconomic factors such as class, caste, gender, education, income, working conditions, food, and nutrition also determine the exposure to risk factors and the development of diabetes (Kapur, 2001; Arutselvi, 2018a). To a large extent, many biomedical studies have focused only on individuals suffering from diabetes in isolation from the broader social context. However, studies have also documented that socioeconomic status, place of residence, gender, access to health services, transportation, dietary habits, employment, and deprivations also have a tremendous impact on the development and everyday management of diabetes (Raphael et al., 2003; Brown et al., 2004; Arutselvi, 2018b).

Further social epidemiologists also argue that social and emotional pathways cannot be disconnected from biological risk. Krieger (2005) argues: “we live embodied “genes” do not interact with exogenous (that is, outside the body) environments— only organisms do, with consequences for gene regulation and expression” (Krieger, 2005:351). She defines embodiment as a multi-level phenomenon as it encompasses the interplay between bodies, components of bodies, and the world in which the body lives (ibid:351). Thus, in epidemiology which explains population health, it is crucial to explain all levels: micro-phenomena, meso-phenomena, and macro-phenomena. The experiences of being born into a certain ethnicity, early childhood deprivation, the environmental condition where one lives, and racial discrimination, according to Krieger (2005), are not separated from the body. All of them interact and act as risk factors for uncontrolled hypertension leading to comorbidity with diabetes, for instance, worsening a person's health conditions. The concept of embodiment is important in epidemiology and the study of social inequalities (Krieger, 2005).

2.1.6 Poverty, Malnutrition, and NCDs:

Due to their chronic nature, NCDs often take many months to develop. Further, the development of the symptoms of NCDs is a slow process, and many times people suffering from NCDs are asymptomatic. This makes early diagnosis of NCDs a major challenge. Once diagnosed,

NCDs also need proper treatment for a long time. Further, the conditions necessitate that it must be regularly monitored so that it does not lead to complications. Often the treatment for chronic illnesses is very long and spans the individual's lifetime (Boutayeb & Boutayeb, 2005). Given the epidemiological transition that India witnessed in the last three decades, there has been an increase in the prevalence of NCDs in the population. One of the dominant ways of understanding the NCDs was mainly through the adoption of certain "lifestyles" such as high consumption of fried oily and processed foods, sedentary lifestyles, and absence of physical activities (Medico Friend Circle, 2017). Given this, NCDs were considered to be largely prevalent amongst the population belonging to better socio-economic status and mostly in the urban areas or cities. This assumption that NCDs are widely prevalent in rich and urban areas often fails to consider the growing evidence that these diseases are also widespread amongst populations belonging to poor socio-economic groups. It is only in the past few decades that the prevalence of diabetes has been increasing across all socioeconomic levels of the population worldwide (Singer et al., 2022).

By the early 2000s, there was a growing recognition that NCDs also caused an increasing disease burden for poor and socially marginalized communities (Jeemon et al., 2019). Studies have also documented that people belonging to disadvantaged socio-economic groups were disproportionately affected by the burden of NCDs (Manderson & Jewett, 2023). In rural areas, the increasing prevalence of chronic illnesses, including diabetes, is attributed to increased life expectancy, growing population, urbanization, poverty-related everyday stress of life, malnutrition, and changing lifestyle and food habits (Jeemon et al., 2019). By the end of 2015, The Lancet constituted a Commission entitled Non-Communicable Diseases and Injuries (NCDIs) Poverty Commission with an affirmation that "NCDIs are important, yet an under-recognized and poorly-understood contributor to the death and suffering of this vulnerable population" (Bukhman et al., 2020: 991). The Lancet Commission submitted its report in 2020 and observed that a diverse and heterogeneous set of conditions are associated with NCDI and poverty. It reported that the poorest of the poor acquire NCDIs at a much younger age group, and NCDIs are more lethal amongst people living in extreme poverty coupled with poor access to quality health services (ibid: 992).

In India, studies have also documented poverty, deprivation, poor sanitation, and malnutrition as important determinants of chronic illnesses. For instance, a rural secondary

hospital in Ganiyari operated by the Jan Swasthya Sahyog, which caters to the health needs of the poorest of the poor tribals in the forest villages of Chhattisgarh it was observed that majority of tribal communities diagnosed with diabetes are undernourished and had a BMI of less than 18.5kg/m², and often lived in poverty. Thus, a close relationship that was also observed between deprivations associated with poverty and high levels of malnutrition also leads to diabetes (Patil et al., 2017a). Apart from this, there is also a high consumption of salts, tobacco, and alcohol in tribal areas which further increases the risks of co-morbidities such as hypertension and other chronic illnesses (SAMA, Undated). Further, in rural areas, studies have documented that people suffer from uncontrolled levels of blood sugar due to delays in screening and preventive care, poor adherence to treatment, irregular access to medications, and late diagnosis, resulting in the early onset of complications and multi-morbidities (Ramachandran et al., 2008; Little et al., 2017; Arutselvi, 2018a). Diabetes also affects both men and women. However, women are negatively impacted by diabetes and its severe consequences. Worldwide, more women suffer from diabetes, its complications, and increased vulnerability due to the gender roles, norms, and inequality that shape exposure to risk factors, access to health services for diabetes care as well as self-management of diabetes (Kapur & Seshiah, 2017). In addition, it was also observed that rural women were more vulnerable to the risks of NCDs compared to rural men and urban women (MFC, 2017). Hence, the next section discusses some key issues concerning women's health and diabetes.

2.2 Women's Health, NCDs, and Diabetes:

Gender is one of the most important determinants in studying health inequality. Gender as a factor varies across cultures and even from family to family (Bhasin, 2003). All cultures value girls and boys differently, allocating different roles and positions to them among families and communities (Bhasin, 2003; Hendriks, 2017). The roles assigned to girls mostly confined to the domestic or the private sphere, and for boys, the public sphere. Thus, both genders are treated differently in society. This has led to inequality in their social status. Men and their needs are often prioritized in the allocation of scarce resources. To a large extent, the research focus on women's health has been largely restricted to the domain of reproductive health (Lewis & Kieffer, 1994; Inhorn, 2006). Historically, efforts were directed at improving maternal and child health, given the high mortality of women and children during pregnancy and childbirth. Further, women's health

became central to the debates on nation-building as a healthy population symbolized power and a resource (Hodges, 2006). This focus resulted in prioritizing family planning services. The emergence of the women's health movement at the global level in the 1970s highlighted the coercive nature of family planning policies which disproportionately targeted women's bodies to control fertility rates (Rao, 2004). By the 1980s and 1990s, the focus shifted to safe motherhood and reproductive health issues to redefine women's health concerns, mainly in response to the advocacy measures undertaken by the women's movement (Kumar et al., 2016b). Over the years, there has been an emergence of critical feminist scholarship on women's health that focuses on understanding gender relations as well as women's role in production and reproduction. The classical works of Doyal (1995) highlighted the broader socio-economic, historical, political, and cultural factors that shape women's health within capitalist development in a patriarchal society.

In a context where women do not have access to resources such as good education, employment, income, and nutritious food, gender discrimination results in adverse health outcomes (Arber & Thomas, 2001). Gender inequality within households varies and may differ across socioeconomic groups or cultures. The division of labour between men and women within the household determines how to a large extent, women are mainly engaged in unpaid work at the household level, such as domestic responsibilities and caring for children, husbands, and family members (ibid). Despite this burden of work, women's contribution to the economy is often neglected (Neetha, 2010). The role played by women in providing care to families and communities as part of women's social reproductive function has been well acknowledged (Leslie et al., 1988). Nonetheless, societies worldwide perceive and treat women in such a way that it harms their health. In some contexts, girls are not provided with adequate nutrition, are denied access to education, and their mobility is restricted, which is not the case for boys (Lewis & Kieffer, 1994). Women's occupations are largely underpaid, uncertain, and informal, which is relatively not the case for men. Despite greater work burdens and responsibilities, women often do not have access to land, wealth, or any other form of property (Gribbin & Sadana, 2010). The caretaking role that women mostly undertake is unpaid due to the assumption that it is natural (Piang et al., 2010).

Women are biologically stronger than men, but their health is compromised because of existing gender inequalities based on gender discrimination, the absence of economic

independence, and the lack of access to wealth and property making women poorer. This structural inequality significantly impacts women's health (Doyal, 1995, 2000). Feminist scholarship has highlighted gender differentials in morbidity and mortality and the necessity to focus on equity to ensure good health and well-being for women (Sen & Ostlin 2010). Socioeconomic factors such as poverty, income, and gender bias determine who has access to treatment and whose lives are more valued.

Lewis and Kieffer (1994) argue that the focus on women's health has always been on the reproductive process during the childbearing period, i.e. when a woman is between 15-44 years old. Their overall health is hardly considered, and when considered, it is only about ensuring their reproductive and children's health. However, these efforts do not consider the non-reproductive facets of women's health status, even though the major and significant proportion of women's lives and activities occur outside the facet of reproduction. In addition, the social, economic, and political factors which influence women's daily productive and reproductive activities are also not considered. Thus, there is a need to expand the focus and understand the health status of women throughout their life cycle, encompassing physical, mental, social, and economic health (Lewis & Kieffer, 1994). Understanding the kinds of working spaces available for women is crucial in studying how they pose a risk to women's health. Understanding woman's daily activities and time allocation for these activities is also crucial. Time allocation studies conducted in rural areas of developing countries show that women spend more time on both market and home production (ibid). However, compared to paid productive activities, women spend more time in home production and work longer than men (ibid). Women's time allocation for work changes over their life cycles (Leslie et al., 1988). Women's health must also be viewed from the seasonal nature of their agricultural activity and their extra burdens at harvest and pre-harvest, which affects their health. In developing countries, women actively engage in agricultural activity by assisting men in cultivating the food necessary for consumption. Moreover, women are also engaged in trade and marketing activities (Lewis & Kieffer, 1994).

It is important to note that the burden of caring of the young and the old is disproportionately borne by women in Indian societies as they are often considered to be the main provider of care. Even when women work outside and are engaged in economic activities, due to their caregiving role and other domestic responsibilities, women tend to spend more hours working

at home than men (WHO, 2006; Neetha, 2010). This has an adverse impact on the health and well-being of the women as often they cannot prioritize their own health (Arber & Thomas, 2001). In a situation where women perform paid and unpaid work, it is important to understand how this “double shift” affects women's health and its variation across socioeconomic groups (ibid).

Even when women live longer, they suffer from different health problems. Most of them are alone because they are widows and often do not remarry. Ageing of women, to a large extent, increases the burden of work on young women as aging is often accompanied by ill health, and they need more care. The care work that women undertake within homes is largely unpaid, and they are often alone in discharging their care duties as they often do not have any support. They are expected to sacrifice their own health to care for others. Many women have also internalized these values and often neglect their health. All this has an impact on health practices, access to health services, and also health-seeking behaviours (Sen & Ostlin 2010: 3). Thus, there are a number of social and economic constraints that restricts women's access to health care.

In the Indian context, given the poor socio-economic context and widespread gender discrimination, poor health outcomes were reflected in the high mortality of girl children, adverse sex ratios, poor nutritional status of girls, and high rates of maternal deaths in the country. Qadeer (1998), in an important paper, highlighted how there had been a selective focus only on women's reproductive health even when communicable diseases have disproportionately affected women's health and complicated their reproductive health as well. The notion of “safe motherhood” and not “safe womanhood” as selective primary health care ignores the need for non-reproductive health problems which women face (Lewis & Kieffer, 1994:122).

Recent literature has documented the burden of NCDs among women to some extent. In the last three decades, NCDs have constituted the major proportion of deaths among women. Globally, NCDs account for two out of three deaths among women yearly (Bonita & Beaglehole, 2015). For instance, in 2019, about 765,860 women died of diabetes which is higher than the number of men, with 730,234 (WHO, 2020a). NCDs affect women as much as men and more in the post-menopausal age group (WHO, 2011; Jeemon et al., 2019). The prevalence of risk factors varies across women from rural and urban areas. The prevalence of behavioural risk factors (tobacco and alcohol consumption, inadequate physical activity, lack of fruit and vegetable consumption, and frequent consumption of salt and processed food) for NCDs is higher for urban

women. However, the prevalence of biological risk factors such as “being overweight, obesity, high blood pressure, high glucose, and high cholesterol levels is higher among women in rural areas” (WHO, 2020b: vii). The discrimination women face worldwide regarding accessing economic resources and decision-making creates more challenges as far as NCDs are concerned. NCDs thus reinforce health inequality across social groups (Anderson, 2015; Gowani et al., 2016; Mini & Thankappan, 2017).

Unlike people with other NCDs who can take their medication and carry out their daily activities, people living with diabetes must take extensive care of themselves. Weaver (2018:6), in her study on diabetes among women in Delhi, argued that women in the Indian context are expected to practice self-sacrifice, the ideology of feminine virtue, which has a direct link with the role of women in providing domestic care for others. This eventually leaves no space for women to take care of their own health and thus they have to suffer complications caused by diabetes. “Across their life course, women with diabetes have unique health needs and concerns, including preconception health, pregnancy, postpartum care, and the menopausal transition” (Han et al., 2019:2). A diagnosis of gestational diabetes mellitus (diabetes-related pregnancy) sometimes results in a change in or loss of identity as a healthy person with a “perfect” or “normal” pregnancy. Due to the pressure to conform to this ideal expectation of “normal pregnancy,” women sometimes have to hide their diagnosis (Ryswyk et al., 2015:112). While both men and women are equally affected by diabetes, the consequences of diabetes severely impact women (Kapur & Sheshiah, 2017:553). Pregnancy may worsen pre-existing diseases and result in complications due to diabetes (Han et al., 2019). In all countries, women tend to receive less intensive care and treatment for diabetes compared to men (Kapur & Sheshiah, 2017:553). Previous studies on diabetes among women have largely been conducted on gestational diabetes mellitus (Morrison et al., 2014; Mithal et al., 2015; Morampudi et al., 2017; Nguyen et al., 2018), with limited studies being conducted on diabetes among women beyond their reproductive age. Nonetheless, these studies revealed numerous challenges that women face in accessing diabetes treatment. Recently in India, studies on women and diabetes have been carried out particularly in Delhi (Weaver, 2018; Mendenhall, 2019). Previous studies shows that diabetes is also associated with other NCDs including mental disorders particularly among women, as discuss in the following sub-section.

2.2.1 Diabetes and its Association with Other NCDs:

The prevalence of cardiovascular diseases among individuals with diabetes is two to four times higher than among those without diabetes (Fradkin, 2012). Thus, the risk of having cardiovascular diseases is closely associated with diabetes. Occurrences of two diseases at the same time in an individual are known as co-morbidities (WHO, 2016; Pati & Schellevis, 2017). As an individual age, he or she is prone to many other diseases, and this condition where more than two diseases exist in an individual is known as a multi-morbidity (Barnett et al., 2012). Further studies have also shown that diabetes is also associated with mental disorders such as depression.

2.2.1.1 Stress, Depression, and Diabetes:

Studies have documented that people with diabetes in general, and women in particular, are more likely to suffer from depression than those without diabetes (Pan et al., 2010; Deischinger et al., 2020). Often given the complex determinants of diabetes, its prolonged nature coupled with the constant demand to manage the outcomes of diabetes results in tremendous stress for women (Weaver & Hadley, 2011:212). Further, diabetes and its associated co-morbidities, such as hypertension, often negatively affect women's mental health (Mendenhall et al., 2012; Weaver et al., 2015). In the Indian context, to a large extent, given the stigma associated with mental illness, there is a high chance of a poor diagnosis of depression associated with diabetes. Hence, depression among women with diabetes is largely untreated in India (Mendenhall et al., 2012).

In their work on "Social Pathways in the Comorbidity between Type 2 Diabetes and Mental Health Concerns in a Pilot Study of Urban Middle and Upper-Class Indian Women," Weaver and Hadley (2011:222) found that women with diabetes consider the symptoms related to mental health "as part of their experiences." Women with diabetes used the word "tension" to describe their life problems. Some women also attributed the onset of diabetes to "tension." Further, in her work on "Sugar and Tension: Diabetes and Gender in Modern India," among women from various socio-economic groups in Delhi, Weaver (2018:92) argue that the word "tension" is a "vague" term that women use to express their distress in "culturally acceptable way."

In her study conducted in Delhi that focused on Stress and Diabetes, Mendenhall (2019) observed a huge variation across different socio-economic groups about the sources of stress. For instance, there were multiple sources of stress or life stressors among women from low-income groups. They were often worried about the future of their children, the perpetual conflicts within the family, concern for the health of the family members, financial burden, stress of living in joint families, work-related stress, loneliness as well as job stress, interpersonal abuse, and old age (Mendenhall, 2019:71). Like, Weaver (2018), Mendenhall (2019: 76) describe the word “tension” expressed by her respondents as “idiom of distress.” Social problems such as financial struggles due to poverty further increase tension among people with diabetes, manifesting the impact of psychological suffering in somatic symptoms. Thus, tension due to social factors is linked to somatic symptoms such as “insomnia, racing thoughts, loss of appetite and raised blood pressure” (Mendenhall, 2019:78). The word tension, therefore, is a broad term that describes the way “everyday stress becomes embodied” (ibid).

A delay in seeking treatment can also lead to co-morbidities and multi-morbidities, resulting in diabetic complications. Besides having a close link with other NCDs, the complications due to diabetes are numerous. Neuropathy, Coronary Heart Disease (CHD), cataracts, retinopathy, cerebrovascular accident, and peripheral vascular disease are common complications of diabetes in India (Vaz et al., 2011). Thus, hospitalization risk is three times higher among people with diabetes compared to those without diabetes (Bjork,2001). Co-morbidities and multi-morbidities pose a major challenge to the health system’s service delivery, especially the public health system, due to poor infrastructure and shortages of human resources because of an inadequate budget allocated for health (Barnett et al., 2012).

2.2.3 Women’s Access to Healthcare Services for the Treatment of Diabetes:

Women with diabetes encountered numerous challenges due to gender discrimination and the inability to access care (Bajaj, 2017). Gender-based family roles strictly appropriated by society increase the vulnerability to disease and women’s access to health services and determine women’s health-seeking behaviour. This is due to the restrictions on their mobility and autonomy in access to health care, which could intensify both short and long-term complications of diabetes (Bhojani et al., 2013; Kapur & Sheshiah, 2017). Weaver (2018) argues that a cultural context in which women are meant to be confined to the domestic sphere and care for other members of their

families makes diabetes management more challenging for them. Women in India considered other family member's health a priority, neglecting their own health and well-being. Kapur and Sheshiah (2017) argued that it is a well-known fact that women from low-income countries have to bear the burden of economic, political, and social discrimination. Consequently, they have a low level of education, are mainly unemployed, and have a poor health status. Further, a study by RamPrakash and Lingam (2021) found that poor and marginalized women face numerous difficulties while accessing healthcare insurance schemes during hospitalization.

If a woman is diagnosed with diabetes, there will be more repercussions, such as a fear of remaining unmarried, or if married being abandoned or divorced. Findings from the study conducted by Little et al. (2017) show that women are afraid to let their diagnosis of diabetes be known even to their spouse or to be spouse. The reason is due to the notion that women with diabetes will face complications during pregnancy and hence are not desirable spouses (Little et al., 2017). The stigma associated with women living with diabetes, as it is a disease considered to be inherited, was also discussed by Tattersall (2009). These fears thus act as crucial barriers to seeking treatment, leading to complications and reducing the chance of arriving at positive health outcomes, which is not the same with men.

Women's choices and opportunities within household interactions and healthcare access are limited by the interplay of gender norms, poverty, and patriarchy (Theobald et al., 2017). Gender roles and relations are linked to poverty and other equity stratifiers in complicated ways and are also determined by the context (Theobald et al., 2017). RamPrakash and Lingam (2021), in their study on the utilization of health insurance in Tamil Nadu, found that the likelihood of utilization of services at public health facilities is higher among the poor and women. This is despite the poor-quality services that are available at public health facilities. Natasha Agnes D'Cruze (2020), in her ground-level survey conducted in Jharkhand to understand the implementation of the Pradhan Mantri Jan Arogya Yojana (PMJAY), argues that despite the poor quality of services provided at public health facilities, the poor have no other choice but to be content with the "government-like" treatment (D'Cruze, 2020:2).

Women in Meghalaya have limited access to advanced diagnostic tests as these are only available in the private sector and are often very expensive and beyond the reach of women from low-income households. Similarly, health care for more complicated ailments and even some

medicines are unavailable in public health facilities (Mukhim, 2005). Increased treatment costs further increase the economic burden on women as they have to work harder and for longer hours to increase their wages and income. Consequently, they have to spend the wage they earned on healthcare services. This hard labour is passed on to women's daughters, who have to drop out of school, thereby assuming the care-giving role of their mothers (Smith, 2001).

It is well-documented that women in a matrilineal society have greater mobility compared to their sisters in a patrilineal society (Schivers & Postel-Coster, 1977; Jeffrey, 2005). However, the household responsibilities of women in both matrilineal and patrilineal societies are almost the same. Therefore, understanding the health status of women in a matrilineal society is important, as the present study is contextualized within Meghalaya's matrilineal society. The next sub-section, therefore, briefly presents the literature on women's health in a matrilineal society.

2.2.4 Tribal Women's Health in a Matrilineal Society:

It is important to note women are not a homogenous group, and there are significant differences based on the socio-economic, cultural, and historical context. Thus, women belong to different social class, caste, occupations, ethnicity, religion, and region (Xaxa, 2007). The structural inequalities shape and influence women's life and health in India. Tribal women constitute an important section of India's society. Tribals are often known as Adivasis, Indigenous people, and Scheduled Tribes in India. It is estimated that around 90 percent of tribal communities in India have lived near forests, rural areas, river valleys, or mineral-rich regions and in remote interior habitations, which are often isolated, inaccessible, and have harsh environmental conditions (GoI, 2018a). Historically tribals have depended on the forests for their livelihoods, food, and, most often, also for their medicines in case of illness (Jan Swasthya Sahyog, 2016). It is important to note that there are huge diversities and differences within the tribal communities based on occupations, region education, wealth, land, language, region, etc. There are different sub-tribes as well. High levels of poverty, social exclusion, and marginalization mark the lives of tribal communities in India (Xaxa, 2007). As reported by various studies, the socio-economic development programs and policies such as massive displacement, restrictions in access to forests and their produce, poor rehabilitation policies, food insecurity, unemployment, ethnic conflicts, etc. have resulted in the increased marginalization of tribal communities in India (GoI, 2014; Mohanty, 2005). These larger structural factors play an important role in determining the health

status of the tribal population. With respect to health problems, tribal communities are facing a triple burden of communicable and infectious diseases, chronic illnesses, as well as reproductive and child health problems (GoI, 2018a).

There is a dominant perception that tribal women enjoy better social status than other Indian women. For instance, tribal women are considered to have greater freedom in marriage, divorce, remarriage, physical mobility, work participation, access to property, or decision-making (Mitra, 2008). However, it is important to note, as Xaxa (2004) argues, that the higher status of women in tribal societies is a myth, and there is pervasive gender inequality even in tribal societies. This is clearly reflected in the poor health status of tribal women, which is worst compared to women belonging to other social groups. Given the low levels of education, poor employment opportunities, increasing poverty, and marginalization, food insecurity has thus resulted in extreme deprivations and hardships in the life of tribal women, which is also reflected in their poor health status (SAMA, Undated).

A matrilineal society is one where the lineage or descent of a person is traced through the mother (Nongbri, 1988). Given the rights that women in a matrilineal society have over property and their ability to make household decisions, their health and nutritional status are expected to be better than those in a patrilineal society. Nonetheless, the literature says otherwise, and there is a debate on the benefits of matriliney. While some literature argues that it benefits women, others have argued against it, arguing that it is not helping women. For instance, a study conducted by Ene-Obong et al. (2017) in their study to understand the interplay between gender roles and nutrition among women in Ohafia matrilineal society observed that even when women have access to agricultural land and actively participate in agriculture and food grains production, it did not contribute to improvement in their nutritional status. Both women and young children suffer from malnutrition and food insecurity. However, another study conducted by Bhanbhro et al. (2020), they found that “matrilineality empowers and allows women to make decisions during pregnancy about nutrition and the management of household resources” (Bhanbhro et al., 2020:12). Nonetheless, even in their study they found that women from low-income groups, have no government support and have limited access to nutritional information, leading to negative impacts during pregnancy, such as anaemia, giving birth to babies with low birth weight, and pre-term birth. Matrilineal societies worldwide are transitioning, with some becoming extinct, as in the case

of the Nair Community in Kerala, India (Jeffrey, 2005). Meghalaya's matrilineal society is considered "one of the world's last matrilineal societies" (Rathnayake, 2021). Much of the literature on the health status of women in a matrilineal society revolves around maternal and child health, with limited literature on women's health conditions beyond reproductive health.

Besides gender, other social determinants of health impact the causes and self-management of diabetes. The literature on social determinants of health and diabetes is discussed briefly in the following section.

2.3 Social Determinants of Health:

The Institute of Health Equity defines "social determinants of health" as a "term used to describe the social and environmental conditions in which people are born, grow, live, work, and age, which shape and drive health outcomes."⁹ The social determinants of health are also known as the "causes of the causes" (Marmot, 2005:1101). Seiglie et al. (2021) argue that the importance of social determinants of health has been recognized since the nineteenth century by the pioneers of the field, such as Rudolf Virchow. Throughout the twentieth century, social factors have highlighted working and living conditions as the main determinants for shaping and influencing the health of populations. However, in 2008 the publication of the CSDH report critically highlighted why there is a gap between different communities that persists despite health interventions (WHO, 2008). The report aimed to close the health gap within a generation by tackling health inequalities and addressing the social determinants of health (ibid).

2.3.1 Studies on Social Determinants of NCDs, including Diabetes:

Numerous studies have been conducted on the impact of social determinants of health on diseases, including NCDs (Hargreaves et al., 2011; Walker et al., 2014; Adgoy, 2019). These studies' findings showed that people from disadvantaged social groups suffer the most. Brewer and Cooper (2014) argued that mortality due to CVDs is higher among Blacks as compared to Whites in the United States (US). They mentioned the relationship of stress due to exposure to discrimination with the occurrence of CVDs, a conventional risk factor for NCDs. The Black community, being historically marginalized, faces discrimination even in healthcare settings,

⁹ Available at <https://www.instituteofhealthequity.org/about-our-work/action-on-the-social-determinants-of-health-> accessed on 12th May 2022.

thereby being deprived of quality care. In their study based on a review of the literature, Lumagbas et al. (2018) observed that apart from the common risk factors of diabetes, the exposure to air and noise pollution, lack of safety and security, stress, and female abuse intensified the prevalence of diabetes.

Hill et al. (2013), in their work in the context of the US, gave a detailed explanation of the social determinants of diabetes. Their explanation goes beyond a simplistic explanation of risk factors. Social determinants of health “such as income, education, housing, and nutritious food are central to the development and progression of diabetes. Individuals with lower income and less education are two to four times more likely to develop diabetes as compared to individuals belonging to better socioeconomic status” (Hill et al., 2013: 68). This is because individuals with lower income are deprived of the resources which are prerequisites to good health. Further, they have to struggle to make ends meet. The constant struggle leads to high levels of chronic stress which eventually trigger both psychological and biological responses (ibid). As a result of psychological responses such as depression, anxiety, and reduced self-esteem and motivation, an individual could resort to harmful behaviour such as excessive tobacco and alcohol consumption and also consumption of unhealthy foods. “Biological responses include increase in blood pressure, cortisol, and blood glucose levels” (ibid:68). Both physiologic and psychological responses increase the likelihood of obesity and type 2 diabetes (ibid).

Professor Emily Mendenhall (2019), in her pioneering work conducted across four countries (Chicago, Delhi, Soweto and Nairobi), stated that diabetes is a “disease of poverty” (Mendenhall, 2019:135). This was based on her findings from qualitative interviews with women who narrated their experiences. In her work, women’s narratives also reflect a more nuanced understanding of what drives their illness and how they perceive and experience illness (Mendenhall, 2019). For instance, her findings from Nairobi showed that her respondents associated diabetes with stress, which was mostly associated with physical problems, such as body aches, vision problems, numbing of the legs and fatigue. In her study, women in Nairobi cited the “impact of AIDS, deaths in the family, interpersonal abuse, financial stress, diabetes stress, the needs of children including schooling, food insecurity, physical abuse, violence, feeling unsafe, robbery or theft, neighbourhood discord, family conflict, emotional abuse, alcoholic spouse, death

of a friend, child drug abuse, land conflict and verbal abuse” as life stressors (Mendenhall, 2019:118).

In India, there are some studies to understand the prevalence of diabetes in rural areas and its social determinants. Little et al. (2017) conducted in-depth interviews with both men and women above 20 years of age across 14 villages in Tamil Nadu. A total of 54 individuals living with diabetes were selected using convenience sampling, equally represented by both men and women. The findings from the study contribute to the understanding of the cause of the increase in the prevalence of diabetes in rural India. For instance, in rural areas, respondents mentioned the rise of new shops selling soft drinks, and chips as the cause of diabetes, which is due to the aggressive marketing of a high-fat and high-sugar diet in rural areas. The Public Distribution System was also cited as one of the causes of diabetes. Farmers who used to consume the traditional crops they used to cultivate earlier, such as finger millet, sorghum, pulses, and vegetables, have now started selling them and replacing them with subsidized rice, oil, and sugar from the fair-price shop. They do this in the hope of saving some money, which they get when they sell these traditional crops that they cultivated. Tension, family history, lack of exercise, fate, and drinking too much tea are the other causes mentioned in the study. Smith-Morris (2004) argues that a decrease in farming activities has created avenues for the diabetes epidemic among the Pima Indians of North America. One of the causes is the shift in occupation from agriculture to wage labour leading to a sedentary lifestyle. The other cause is the decline in food production through farming activity, thereby increasing the dependence on commodities provided by the government including processed foods. These processed foods initially provided by the government and gradually through markets in the form of fast foods negatively impact the health status of the Pima Indians.

To prevent diabetes complications, there is a need for proper self-management. The ability to self-manage diabetes is determined by numerous factors. The next sub section therefore focusses on the factors that influences self-management of diabetes.

2.3.2 Factors Influencing Self-Management of Diabetes:

People living with diabetes are usually advised to follow a strict diet plan, undertake regular exercises, and maintain sound mental health for good glycaemic control (Verma et al., 2021a). In addition, regular monitoring of blood glucose levels and strict adherence to medications is also

necessary (Grabowski et al., 2021; Verma et al., 2021b). Thus, they have to take extensive care of themselves, affecting them psychologically and financially (Verma et al., 2021b; Pardhan et al., 2021). The social determinants of health thus have a strong impact on the management of diabetes and its complications. There are numerous social and cultural factors that influence the self-management of diabetes and these include “low socioeconomic position, food insecurity, health system factors, sociocultural factors, neighbourhoods and transport” (Basu & Garg, 2017:2-73).

Medical anthropologist, Weaver (2018:5) argued that “people with diabetes are ideally never allowed to forget- even for an hour- that they have the disease.” Diabetes demands intensive self-care, and so Weaver’s work explored how women from different social groups in the context of India deal with the disease in the urban areas of New Delhi. Findings from her ethnographic work reveal that in a rapidly changing social and economic system, with increasingly precarious jobs and fast urbanization, women have to first fulfil their role of taking care of the family. This often leads to “tension” which eventually makes women suffers from diabetes and its complications (Weaver, 2018: 67). Women recruited in Weaver’s study were from different social groups – impoverished, lower middle class, upper middle class, and upper class. Some women mentioned the cause of “tension” is a consequence of living in a joint family which is a cultural practice of Indian society. Women belonging to the lower socio-economic strata mentioned about the dual burden from their family and employer, causing them more tension and also depression thereby hampering the management of diabetes (Weaver, 2018).

Arutselvi (2018b), in her case study conducted in urban areas of Chennai compared two women who were living with diabetes. One was 65 years old, housewife who belonged to the most backward community –Vanniyar– with no formal education and who was from the working class. The other woman was 71 years old, pensioner, a well-educated professional who belonged to a backward community– the Nadar– from the upper middle class. Contrasting the social backgrounds of the two women identified by the author shows the existence of inequality in the management of diabetes. This is evident in terms of the types of health services accessed by the two women, dietary practices, and regularity in health check-ups, ability to purchase a glucometer, insurance, support structure and financial status. The woman who belonged to the Vanniyar community was deprived of all the above-mentioned privileges, thereby suffering from complications arising due to diabetes, and had to undergo eye surgery. The woman from the upper

middle-class background had a good health outcome and did not suffer from any complications as she could afford to eat the diet prescribed by her physician, go for regular check-ups and also had her family's social support: her son, daughter-in-law and her grandson who helped her in managing diabetes.

“Social support, defined as one's own perception that they are being cared for and that assistance would be available when needed,” has been shown to have a greater influence on health outcomes (Mo et al., 2022: 2). Social support, mainly provided by family members, close friends, or the community, helps in reducing stress and provides protective psychological resources such as self-control, self-efficiency, mastery, and other health promotive behaviours (Mo et al., 2022:2). Studies have shown that adequate social support is associated with good diabetes management. Those having fewer social ties especially among individuals from poor household's leads to poor blood sugar control due to high level of stress (Brown et al., 2004). Lack of social support and allied depression can influence the quality of self-management for diabetes (Walker et al., 2016). Studies have shown that individuals belonging to racial minorities such as non-Hispanic Blacks in the United States of America (USA) suffer disproportionately when it comes to the management of diabetes. Given the low-income conditions in which they live, known as the “neighbourhood factors,” there is lack of access to healthy food, health care facilities and other recreational spaces needed for physical activity (Walker et al., 2016: 8-9). Other factors that determine self-management of diabetes include psychosocial support and behavioural factors such as smoking, irregular blood glucose monitoring and physical inactivity (Brown et al., 2004).

Diabetes is shaped differently across cultural and societal context. Understanding the beliefs and cultural practices related to diabetes and how these influence the self-management of diabetes is also necessary (Scheets & Placek, 2020). This brings us to the next section on beliefs and cultural practices related to diabetes. Beliefs and cultural practices also influence the self-management of diabetes as discussed in the following section.

2.4 Beliefs and Cultural Practices Related to Illnesses in General and Diabetes in Particular:

2.4.1 Beliefs and Cultural Practices Related to Illnesses:

A learned collective human behaviour known as culture. It is “a complex system in which a group acquires, shares, and holds traditions, attitudes, beliefs, and values. It affects every aspect of people’s lives, including illness, health status, and health-related behaviours” (Chacko, 2003: 1088). Beliefs and practices, language, social norms, behaviours and values shared by members of society are all part of culture, which can either enhance or act as a barrier in adapting to a healthy lifestyle, treatment-seeking, and compliance with the advice given by healthcare providers (Nayak et al., 2012; Zeh et al., 2014). Undoubtedly, culture has an impact on the occurrence of diseases (Ahmed, 2003). Cultural adherence with respect to food, physical activity and social interaction, commitment to religious beliefs, differences in language, poor health literacy, and beliefs about causation have been widely studied (Rovner et al., 2013; Zeh et al., 2014; Patel et al., 2015; Elliott et al., 2016). In a study conducted by Nayak et al. (2012) in the district of Udupi in Karnataka, India, it was found that there are numerous perceptions about health and illnesses in the villages. These include: “illness or diseases are caused by the wrath of god or goddess, venereal diseases are caused due to illicit sexual intercourse, HIV/AIDS is caused among poor socio-economic people, leprosy and tuberculosis are caused due to their past sins, children are most susceptible to the effect of evil eye, childhood diseases are attributed to the anger of god, hysteria or epilepsy (fits) are due to ghost intrusion” and many others as listed in their study (Nayak et al., 2012: 65).

The source of treatment for different kinds of illnesses in general, including diabetes, are also influenced by cultural practices. Haque et al. (2018), in their qualitative study in Bangladesh found that the first treatment source for people from the lower strata of society was traditional healers. It was only when this failed that they approached modern medicine, and if modern medicine failed, they again approached traditional healers. Similarly, studies on traditional healing practices have been conducted in almost all the north eastern states of India, including Meghalaya. A qualitative study conducted by Albert et al. (2019) in Meghalaya among the Khasi traditional healers found that the healers in the Hills perceived themselves to be less knowledgeable than biomedical doctors. As a result, healers only treated the illnesses which they believed they could cure; otherwise, the healers would refer their patients to biomedical doctors for further treatment. However, people approached them for an infantile disease known as *niangsohpet* (literally *niang* refers to insect and *sohpet* to the navel) in Khasi –which is not clearly explained by biomedicine. People also sought treatment for burns and fractures from traditional healers, which they found to be efficacious. Findings from the study conducted by Ramashankar et al. (2015) in northeast India

reveal that traditional healers attributed their skill of diagnosis to inheritance and also considered it as God-gifted. The traditional healer believes that it is a skill given to them by God to help the poor who are sick.

Traditional healers have been part of tribal society since time immemorial. In their study on the different kinds of healthcare services accessed by the Santhals in Odisha, Sonowal and Praharaj (2007) found that the consultation of traditional healers was not necessarily due to the inaccessibility of government hospitals. It was rather because of the belief that certain diseases can be better cured by these healers, for instance jaundice (Sonowal & Praharaj, 2007:143). Tribal populations resorted to different types of therapies such as biomedicine, ayurveda and other indigenous healing practices for treatment of illnesses, either simultaneously or when one system fails, they will resort to the other (Sonowal & Praharaj, 2007). In Meghalaya, traditional healers from the Khasi and the Garo tribes provide substantial healthcare services apart from those provided by the government especially in rural areas. This is authorized by the Act passed by the governance body known as the Khasi Hills Autonomous District Council (KHADC) and was affirmed by the United Nations General Assembly on the rights of indigenous peoples to their traditional system of medicine (Albert et al., 2019).

Nayak et al. (2012) argued that even the smallest decisions taken by an individual are influenced by his or her cultural background. Socio-cultural factors play a vital role in determining the health and illnesses in a population (Caballero, 2010; Nayak et al., 2012; Alves & Oliveira, 2018). The ways in which diseases are perceived and coped with differ from culture to culture. Evidence suggests that culture determines how NCDs such as hypertension and diabetes are interpreted and managed in a particular society, through the individual's perception of health and illnesses (Airhihenbuwa & Iwelunmor, 2012).

2.4.2 Beliefs and Cultural Practices Related to Diabetes:

Individuals have various beliefs about the causes and treatment of diabetes and these beliefs are shaped by the socio-cultural practices of the individual (Shilubane et al., 2016). Some social groups believe that diabetes is caused by heredity, eating sweets, stress, and emotional instability, which includes episodes of fear and anxiety (Caballero, 2010). Similarly, Abdulrehman et al. (2016) in their ethnographic study conducted in coastal Kenya found several beliefs regarding the causes of diabetes which include: consumption of ice water, stress, the presence of toxic chemicals

such as pesticides in foods, vaccinations, and transmission through mosquito bites and/or sexual intercourse. A recent ethnographic study among Javanese diabetic patients by Sari et al. (2022) explored their cultural beliefs and practices, and misconceptions related to self-management of diabetes. For instance, respondents shared numerous that walking barefoot is good for people with diabetes, and that prolonged consumption of oral hypoglycaemic drugs can affect the kidney.

In a cross-sectional study conducted by Patil et al. (2017b), they found that people believed that diabetes only occurs in old age, it cannot be prevented, and it is a contagious disease. Misconceptions, often shaped by culture, are barriers to prevention and treatment of a disease. Misconceptions are mainly attributed to poor knowledge and awareness about diabetes among people (Patil et al., 2013).

However, it is not only culture that determines the health status of the population. Acculturation, which is the adoption of the culture of one group of the population by another cultural group who has migrated to another country also influences health status (Caballero, 2010). Acculturation can be either low or high. High acculturation includes adopting a diabetogenic lifestyle which includes heavy consumption of foods rich in fats and carbohydrates, and also leading a sedentary lifestyle (Caballero, 2010). Diabetes is considered to be a penalty of advanced civilization as the increase in its prevalence is attributed to the lifestyle adopted in the modern centuries (Mohan, 2007; Tattersall, 2009). Example of low acculturation is not integrating oneself as part of the local health system, having no insurance coverage, and low levels of education (Caballero, 2010). However, it is also important to note that this can also be due to the underlying social determinants of health where a disadvantaged groups especially migrants is deprived of social security schemes and only has access to insurance schemes with poor coverage and also engage in low-paid jobs (ibid).

Robert Tattersall (2009), a Special Professor of Metabolic Medicine at the University of Nottingham, argues, the rise in the prevalence of diabetes among the Pima Indians of Arizona is due to westernization. According to him, during the early twentieth century, European settlers in Arizona diverted the water and irrigated the desert to create productive farms. This has led to the collapse of the Pimas' agricultural system and driven away from a subsistence economy, and made them dependent on welfare benefits. Thus, their traditional high-fibre diet of beans and vegetables was replaced by fat and a highly refined diet. This has led to a loss in employment opportunities

as well as resulting in excessive alcohol consumption, spending their time sitting idly, and driving old cars. Tattersall (2009) argues that diabetes was rare among them in the 1930s and early 1950s as only three percent of the population was affected. However, due to this transition, the rates of diabetes and obesity started increasing among them and by the 1990s, “the Pimas had become very fat, with diabetes affecting 37 percent men and 54 percent women!” (Tattersall, 2009:186).

2.4.3 Cultural Practices Related to Prevention and Treatment of Diabetes:

Culture plays an important role in management illnesses. The cultural beliefs of patients can also become a barrier to effective treatment of illnesses as it shapes patients’ preference for a particular treatment source. Misconceptions about diabetes, beliefs related to its cure, a reliance on herbal remedies to cure the disease, rituals, and values practised by a particular community can also influence the management of diabetes (Abdulrehman et al., 2016). Some patients would prefer a traditional healer whose treatment efficacy is not certain, thereby delaying treatment (VanHoutum, 2005). One of the examples of how culture impacts diabetes management comes from a study conducted in Sudan, where it was found that “false beliefs, religious practices, cultural misconceptions, family and gender issues, and cultural dietary practices have a negative effect on the management of diabetes” (Ahmed, 2003: 227). Van Houtum (2005) also argues that religion can dictate a lifestyle or habits proven to be harmful to the health of an individual or complicate existing illnesses.

The traditional beliefs of a community regarding diabetes influence how and where treatment is sought by the families (Airhihenbuwa, & Iwelunmor, 2012). In the Middle Eastern region, the use of traditional medicine to reduce the blood glucose levels is common despite advancements in the modern medicine. Herbal plants commonly used to treat include fenugreek and acacia (Alibeji & Stewart, 2016). Haque et al. (2018), in a study conducted in Bangladesh argue that due to the beliefs concerning diabetes, even with the advancements made in modern medicine, traditional healing practices are still widely used by people from the lower socio-economic groups. The use of herbal medicine among patients who suffer from diabetes is also widely prevalent in Jordan (Gharaibeh & Tawalbeh, 2017). An ethnographic study conducted by Abdulrehman et al. (2016) in coastal Kenya found that there was a pervasive use of non-biomedical remedies such as aloe vera and papaya leaves for the treatment of diabetes. The study also found that there was fear and mistrust of medications (biomedical therapies) due to rumours that the

medicines were fake; that once taken, they have to be taken every day; and that one should only to dietary restrictions.

Several studies have been conducted globally and in India on the utilization of traditional medicine for all illnesses in general and diabetes in particular (Sidhu & Thakur, 2015; Haque et al., 2018; Bhat & Mulgund, 2019; Gawai, et al., 2020). Lyngdoh et al. (2014) found that a preference for home remedies is high in the East Khasi Hills District of Meghalaya and showed that people still believe in their efficacy. Findings from a study conducted in Northeast India by Hynniewta and Yogendra (2008), Sarmah (2011), Shankar et al. (2012), and Das & Prashad (2019) showed that numerous herbal plants have been used for the treatment of both short-term and long-term illnesses. The main reasons for the utilization of traditional medicine are due to its easy availability, accessibility and cost-effectiveness, especially in rural areas (Kasole et al., 2019). It is also due the trust of the people, or compulsion of people to utilize it due to their poverty. Herbal therapies are also used to treat diabetes and its comorbidities as well (Sarmah, 2011; Kasole et al., 2019; Das & Prashad, 2019). Mihsill and Keshan (2017) also explored the use of animals in traditional medicine in Meghalaya. While numerous studies have been conducted globally on the treatment of diabetes by traditional health practitioners, studies on the same studies are absent in Meghalaya. These studies, mostly conducted in African countries, reveal that traditional health practitioners used different modalities and herbal preparations for the treatment of diabetes. These include prayers, acupuncture, laying hands on patients, sand fortune-telling, use of feathers and animal skin and so on (Keter & Mutiso, 2012; Atwine & Hjelm, 2016; Hammond et al., 2019).

In biomedicine, the health system plays an important role in the prevention and control of diabetes as discussed in the following section.

2.5 Response of the Health System in the Prevention and Control of Diabetes in India:

As discussed earlier, given the increasing prevalence of NCDs in the country, the Government of India has implemented national programs for the prevention and control of diabetes at public health facilities. The history of the implementation of the program is discussed in detail in the following sub-section.

2.5.1 National Programme for the Prevention and Control of Diabetes:

According to Das (2013), India already passed the stage of diabetes becoming an epidemic in the 1980s. This is evident from the efforts made in 1987 when the National Diabetes Control Program (NDCP) was initiated. The program was started by the Government of India during its seventh Five Year Plan in some districts of Tamil Nadu, Jammu and Kashmir, and Karnataka on a pilot basis. However, due to funding constraints, the program could not be scaled up. But in the years 1995-96 and 1997-98, allocation of funds improved and the program was again implemented (Das, 2013). The objectives of the program were: prevention of diabetes and its complications through early diagnosis and timely treatment, and provisions of treatment for people living with diabetes and the rehabilitation of people handicapped due to diabetes (Verma et al., 2012). However, as the prevalence of other NCDs in general increased, in 2008 the Ministry of Health and Family Welfare (MoHFW) launched the National Programme for Prevention and Control of Diabetes, Cardiovascular Diseases and Stroke (NPCDCS). “The objectives of the program were prevention and control of NCDs, awareness generation on lifestyle changes, early detection and capacity building of health systems to tackle NCDs” (Verma et al., 2012: 313). In 2010, this program was integrated with the existing National Cancer Control Programme (NCCP) and a new program known as the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) came into existence. The rationale for the integration of all NCD-related interventions into the NPCDCS is for optimization of scarce resources and to ensure uninterrupted services to patients; at the same time ensuring sustainability of interventions under the program (GoI, 2013). Health promotion, opportunistic screening, capacity building, diagnosis and treatment are the main objectives of the NPCDCS (GoI, 2013). Although the program was launched in 2010, it was implemented in only 100 districts across 21 states on a pilot phase. After the pilot phase, the program was re-strategized and scaled up to other districts in the country.¹⁰

The NPCDCS operational guidelines emphasizes health promotion through awareness generation at the community level, screening, diagnosis and treatment for NCDs, establishment or strengthening of health infrastructure, human resource development, outreach services and other services such as procurement of screening devices, essential drugs, consumables, etc. (GoI, 2013). According to the operational guidelines of NPCDCS, the different levels of health facility are to

¹⁰ Website of the National Health Mission, Ministry of Health and Family Welfare, Government of India. Available at <https://nhm.gov.in/index1.php?lang=1&level=2&sublinkid=1048&lid=604> accessed on 20th September 2021

provide packages of services. In the Sub Centre (SC) or Sub Health Centre (SHC), the services include health promotion for behaviour change and counselling, screening for diabetes and hypertension, awareness generation and referral of suspected cases. This is to be carried out by the Auxiliary Nurse Midwives (ANMs) (ibid). In the Primary Health Centre (PHC), along with the above services, the other services include clinical diagnosis and treatment of common NCDs, identification of early warning signals of common cancers, and referral of suspected cases. In the PHC there is supposed to be at least one Medical Officer who would be able to carry out the above services (ibid). At the Community Health Centres or the First Referral Unit (FRU), along with the above services, laboratory investigations are also expected to be carried out. Emergencies and advanced care are to be provided at the district hospitals and medical colleges (ibid). In 2017, population-based screening for NCDs was introduced under the NPCDCS in selected districts of India. In the initial years themselves, only opportunistic screening was provided to people above 30 years of age at various public health facilities (GoI, 2016).

Over the years, several states have been implementing the NPCDCS program. Based on a review of the literature, some of the major challenges observed in the implementation of this program are the huge shortage of health workers in public health facilities, vacant posts, inadequate training on NCD care, irregular supply of medicines, conflicting timings of screening and work, inadequate information education materials, etc. (Kashyap & Shivaswamy, 2019; Ainapure et al., 2018). There are studies that discuss the implementation of the program in various states of India (Bhagyalakshmi & Kodali, 2019; Lall et al., 2019). For instance, Lall et al. (2019) studied the challenges of implementation in terms of providing primary care for diabetes and hypertension in rural areas of the district of Kolar in Karnataka and identified many challenges in terms of training and availability of information. Another study conducted in Karnataka by Raghuveer et al. (2020) mentioned that overburdened staff, logistical and documentation issues, and inadequate training were barriers to the implementation of the program.

The NPCDCS program is one of the national health programs implemented at the SCs as well to address the growing burden of NCDs in India. However, the effectiveness of the program implementation is largely determined as a part of the general health services. Studies have observed that public health infrastructure are often absent or largely dysfunctional in remote rural and tribal areas with severe shortage of health workers (Jain, 2017a). Further, the absence of proper

roads and the sheer lack of transportation facilities to reach the health facilities and the geographical terrain increases the vulnerability of the tribal communities in seeking health care (Kumar et al., 2016a). Often people from rural or tribal areas are forced to travel long distances to access healthcare in the private facilities in cities and towns. All this results in high out-of-pocket expenditure, which further aggravates the cycle of debt and poor health outcomes (SAMA, Undated). Despite its poor functioning, the tribal communities to a large extent are depended on public health facilities for both outpatient and inpatient care given their poverty (GoI, 2018b).

Given the epidemiological transition and the increasing burden of NCDs in India, in 2018, the GoI launched an important initiative to provide comprehensive health care services at the primary level by transforming SHCs/PHCs in to HWCs implemented under the Ayushman Bharat scheme. It was envisioned that the HWCs will provide improved access to different kinds of health services with a focus on meeting the health needs of people for chronic illness (GoI, 2018b). Hence, the following sub-section briefly discusses about HWCs.

2.5.2 Comprehensive Primary Health Care through Health and Wellness:

The Ayushman Bharat Program was launched by the Government of India on 26th September 2018. It has two major components- the National Health Protection Scheme (NHPS) and the HWCs. The NHPS provides financial assistance to 10 crore families in India who are categorized as poor and vulnerable (Verma, 2019). The other component is aimed at providing comprehensive primary health care through the HWCs. Existing Sub Centres and Primary Health Centres which covered a population of 3,000-5,000 and 20,000-30,000 each respectively were upgraded to HWCs. Primary healthcare is crucial to reduce morbidity and mortality in the population. It also reduces treatment expenditure due to exigency for secondary and tertiary care (GoI, 2018b). Recognizing the importance of primary health care in providing care for NCDs, the National Health Policy 2017 envisages the setting up of HWCs through which service delivery for primary health care will be strengthened. The purpose of the HWCs is to provide comprehensive services which range from preventive, promotive, curative, rehabilitative, and palliative care. HWCs aim to provide an expanded range of services beyond maternal and child healthcare, especially related to chronic illnesses (Hooda, 2020). As per the requirements in the operational guidelines for comprehensive primary health care through HWCs issued in 2018 by the Ministry of Health and Family Welfare, the HWCs will provide twelve expanded packages of services. One

of the elements of the twelve packages is on Screening, Prevention, Control and Management of NCDs (GoI, 2018b). To enable the service delivery of these twelve packages of services in HWCs, a new cadre of healthcare providers known as the Community Health Officers (CHO) was introduced in 2017 in some of the states to function as Mid-Level Health Care Providers (MLHPs) (GoI, 2018b). MLHPs are a new cadre of health workers introduced in 2017 to enable service delivery in HWCs. The cadre is a group of health care providers with basic qualifications such as Bachelor of Science in Nursing (BSc. Nursing) or General Nurse and Midwifery (GNM) and Bachelor's degree in Ayurvedic Medicine and Surgery (BAMS) (GoI, 2018b). They are also supposed to undergo a six-month “bridge course” certificate program rolled out by Indira Gandhi National Open University (IGNOU) to equip them with the skills for providing comprehensive health care services.¹¹ Owing to the rise in the burden of NCDs across all states in India, HWCs offer an avenue for their early detection and treatment and will thereby help in achieving the Sustainable Development Goals (SDGs) of mitigating the effects of NCDs (Verma, 2019).

2.5.3 Diabetes in the Context of COVID19 Pandemic:

The novel coronavirus posed a threat to the entire human population globally as everybody was at risk due to its infectiousness (Nair & Raveendran, 2020). It has been well documented that with the outbreak of COVID-19 pandemic, the vulnerabilities of people living with diabetes increased since they were at a higher risk of being infected and of suffering from worse complications and mortality due to COVID-19 (Pal & Bhadada, 2020; IDF Diabetes Atlas, 2021). Studies have also shown that having diabetes makes it harder for the immune system to resist a COVID-19 infection (Ateino, 2020). Thus, patients diagnosed with NCDs were advised to be extra cautious (Pal & Bhadada, 2020) so as to protect themselves from the risk of getting infected and also from complications. People with diabetes were 3.6 times more likely to be admitted to the hospital due to COVID-19 compared to those without diabetes (IDF Diabetes Atlas, 2021). The differential impact which COVID-19 has on socially vulnerable people living with diabetes has highlighted the fact that tackling health inequalities is very crucial (Seigle et al., 2021). One of the important challenges that people with chronic illness suffered from during the pandemic was

¹¹ After IGNOU was approached by the MoHFW, to develop the Bridge Programme (Certificate) in Community Health for Nurses (BPCCHN), a MoU was signed between the two on 16th March 2016. The programme launched by IGNOU in January 2017 is funded by the NHM and is associated with the Ayushman Bharat (Website of IGNOU, available at <http://www.ignou.ac.in/ignou/aboutignou/school/sohs/programmes/detail/674/2> accessed on 18th February 2021).

the severe disruptions in the provision of a continuum of care for their illness, resulting in a worsening of their complications in the absence of regular medicines (Ateino, 2020). Further, the lockdown also impacted people as most of them were locked in their homes without much physical activity and an increase in stress levels due to loss of incomes, rising unemployment and increased vulnerability to COVID-19 (Verma et al., 2021b). People from low-income group face numerous challenges in accessing health facilities due to scarcity of vehicle, raised travel fares and fear of COVID-19 mandatory test at public health facilities. Whereas, high-income population were able to access health facility using their own vehicles and also monitor their blood glucose regularly as they could afford to purchase the glucometer (Muksor & Parmar, 2022).

2.5.4 Approach of the Health System to Women's Health:

Doyal (1995) argues that the biomedical approach to health has reduced women's problems only to physiological causes while not taking into consideration the other underlying social and cultural factors. Noting the consequences of diabetes for women, policies should be formulated in such a way that they are sensitive towards the needs of women. Further, for a long period of time, women's health in many of the low and middle-income countries was largely restricted and focused only on provisioning of healthcare through sexual and reproductive health services. As women live longer there is a need to address the health needs of women throughout their life span (Inhorn, 2006). It is important that health systems respond to the ageing women's population suffering from various chronic health conditions as the life expectancy increases. This can be done through policy transformations, such as integration of maternal and child health services with NCD prevention and care, along with health promotion (Kapur & Sheshiah, 2017). The inefficiency of public health-care systems, lack of female doctors and privacy, lack of expertise of health-care professionals, hence lack of confidence in health professionals, are a matter of concern for women seeking care for diabetes (Stenhouse et al., 2013; Bhojani et al., 2013; Morampudi et al., 2017; Suresh & Thankappan, 2019). Public health centres usually lack medicines and diagnostic tests which forces women to depend on private clinics or hospitals where the services are expensive (Bhojani et al., 2013; Parsons et al., 2018; Suresh & Thankappan, 2019).

Women have to visit several health facilities even when they needed only a single episode of primary care for diabetes. This is due to the lack of facilities for blood glucose tests in government health facilities. Even in most private clinics, there is an absence of diagnostic tests and or a pharmacy within their clinics (Bhojani et al., 2013; Ryswyk, 2015). The fragmented

healthcare system has been identified as a barrier, coupled with long waiting times (Suresh & Thankappan, 2019). Seeking care for diabetes and other chronic illnesses at different levels of health facilities is challenging for women (Bhojani et al., 2013). Thus, poor infrastructures in the public health facilities hamper the free delivery of medical care services to the population living in rural areas and forces them to seek care from private health facilities.

The private sector has demonstrated a rapid growth in the last few decades and presently, it is the dominant player in the healthcare sector providing more than 70 percent of healthcare services (Lall et al., 2019). The dominant private health sector claims to provide comprehensive care for diabetes and its complications. Nonetheless, the literatures have documented the poor quality of services available for diabetes even in private health facilities due to poor regulation (Bhojani et al., 2014; Lall et al., 2019). The costs of care at the private for-profit sector are undoubtedly high given their objective is for maximization of profit. However, since the 1990s due to the phenomena of commercialization the cost of healthcare services is increasing even in the non-profit institutions (Baru & Kapilashrami, 2019). This is due to the increase in user charges for doctors' consultation and even in diagnostics with limited subsidies being provided to the poor (ibid). In order to address the rising costs of medical care in the private sector, the Government of India has also introduced a number of publicly funded medical insurance schemes for poor and vulnerable households. However, studies have pointed out that publicly financed health insurance does not provide adequate financial protection to individuals belonging to households below the poverty line (BPL) (Nandi & Schneider, 2019; D' Cruze 2020; RamPrakash & Lingam, 2021).

2.6 Rationale for the Study and Conclusion:

Based on the detailed review of literature on NCDs, diabetes and women's health, it becomes clear that there are multiple factors that intersects at various levels to determine health status of women in the society. Further, to a large extent when it comes to NCDs, most of the studies have been conducted either in urban areas or amongst urban poor in cities and towns. Studies have also observed that the prevalence and risks factors of diabetes goes beyond individual level factors and there is a need to situate the diabetes within the larger social context (Weaver, 2018; Mendenhall, 2019). Over the years, there has been growing recognition of the fact that NCDs in general and diabetes in particular are also increasingly prevalent in rural and tribal areas and amongst population living in conditions of poverty and are often undernourished (GoI, 2018a;

Jeemon et al., 2019; Mandersen & Jwett, 2023). Though there are important studies on women and diabetes in India, they are also restricted to cities such as Delhi or amongst the developed states or states in southern India which underwent early epidemiological transition in the country (Mendenhall et al., 2016; Weaver, 2018). Further, there are limited qualitative studies that have explored the experiences of women with diabetes in their socio-economic context. Most importantly there are hardly any studies on women and diabetes within a social context from the north eastern states of India. Findings from the present review also shows that there are limited studies on tribal women and diabetes, their perspectives and beliefs as well as health-seeking behaviour. While there are quantitative studies on understanding the knowledge and attitudes of women, studies on the costs of treatment and barriers and challenges to seeking medical care for diabetes, there are hardly any studies that document and explore the lived experiences of women living with diabetes. It is in this context; the present study attempts to explores the experiences of tribal women with diabetes in matrilineal context of Meghalaya. As discussed, earlier Meghalaya, which is predominantly inhabited by tribal population follows matrilineal culture. Under this system, women have some autonomy regarding mobility outside the house, work and ownership of property (Oosterhoof et al., 2021). According to NFHS-5 (2019-2021), about 92.3 percent of women in Meghalaya made their own decisions related to healthcare. However, the household responsibilities of both women in matrilineal and patrilineal society are almost the same (Schivers & Postel-Coster, 1977; Jeffrey 2005). Given the rights that women in a matrilineal society have over property and their ability to make household decisions, it is expected that their health and nutritional status would be better compared to women in a patrilineal society. However, the literature on the reproductive health status of women in matrilineal societies says otherwise. For instance, with respect to reproductive health, women of Meghalaya lags behind in comparison to women from other north eastern states (Oosterhoof et al., 2021). Thus, there is a debate on the benefits of matriliney. Some studies argues that it is beneficial for women (Ene-Obong et al., 2017), and others have argued that women still suffer from unequal social status which is reflected in their poor reproductive health, malnutrition, and high level of anaemia (Bhanbhro et al., 2020; Oosterhoof et al., 2021). Further, the matrilineal culture in the state is also undergoing transformation given the rapid transition that the society of Meghalaya is witnessing with urbanisation, expansion of educational facilities, increasing economic and social impacts of mining in the state as well as development policies (Mukhim, 2019; Dutta, 2022). In recent years,

Government of Meghalaya has also recognised the poor performance with respect to its health indicators particularly in respect of reproductive and child status. Given the weak capacity and poorly functioning health systems in the state, the GoM has also collaborated with the World Bank in 2021 to implement the Meghalaya Health Systems Strengthening Project (MHSSP) in order to provide quality health care to its population (GoM, 2021b). Apart from this in 2021, the Government has also declared Meghalaya Health Policy, that aims to invest adequately in health by raising healthcare expenditure, address gender inequality and improve the overall health status of Meghalaya. It is within this broader socio-economic, cultural and epidemiological and policy transitions that the present study makes an attempt to explore and understand experiences of women living with diabetes in West Jaintia Hills District of Meghalaya. The study aims to explore the beliefs, perceptions, myths, causes and knowledge about diabetes within the socio-cultural context of matrilineal society of Meghalaya. Secondly, it also makes an attempt to understand the response of the health system to diabetes and women's interaction with health care facilities for seeking care for diabetes.

Conclusion:

This chapter discussed in details the review of literature with respect to diabetes as a major NCD, the rising prevalence of diabetes in India as well as the socio-economic factors determining diabetes. The chapter also made an attempt to highlight the debates on women's health and NCDs as well as the social determinants of health and diabetes. Further, response of health system towards women's health and NCDs was undertaken. Based on the detailed review of literature the studies identify the research gap to understand the experiences of tribal women living with diabetes in the state of Meghalaya. With this broad rationale of the study, the next chapter discusses the Conceptualization and Methodology adopted in the present research.

Chapter Three

Conceptualization of the Study

Introduction:

This chapter discusses the conceptualization of the study as well as its research questions and objectives. The present study is qualitative in nature, given its focus to understand the beliefs and perceptions of women living with diabetes and their interactions with the health system. Qualitative studies help in explaining the social world of the people in their natural settings by understanding their actions and behaviours and the meanings they attached to their worldviews and social phenomenon (Bryman, 1988; Denzin & Lincoln, 2018). Given the limited number of studies on women and diabetes, especially in the context of tribal populations, the present study is exploratory in nature.

Shelton et al. (2022) have highlighted the importance of qualitative research in formulating research questions related to health equity and chronic diseases. According to them, qualitative research also enables us to understand and capture the experiences of population groups severely affected by health inequities and largely underrepresented in research. To explore how people in the community understand diabetes and the implementation of the program for its prevention and control, it is essential to consider how they perceive diabetes and its causes, as well as document their experiences and treatment-seeking behaviour. Lobo (2010), argues that health problems cannot be solved only through biomedical interventions without considering social factors. Thus, Lobo (2010) found sociology and social anthropology as the most relevant approaches to studying health and illness in general and malaria in particular within a social context. Similarly, in the present study, I applied an interdisciplinary approach to understanding diabetes within the socio-cultural context of the Meghalaya state, as it will help to understand the health problems in its broader socio-economic context.

The present qualitative study adopts ethnography as an important approach within qualitative studies using data collection methods such as participant observations, everyday conversations, informal group discussions, and in-depth interviews with different categories of respondents. Narrative inquiry with women living with diabetes enabled them to share in detail

their illness experiences and everyday life. A case study of the National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases, Cancer and Stroke (NPCDCS) program was also conducted to understand the functioning of the program at various levels of the public health systems. In qualitative research, the most notable methods used for data collection are participant observations, in-depth and unstructured interviews. These methods are crucial for gaining insights from the perspectives of the people being studied (Bryman, 1988:61). Thus, information for the present research work was gathered in multiple ways by undertaking empirical field data collection as well as a detailed review of literature and document analysis by undertaking:

- 1) In-depth interviews to understand the lived experiences of women with diabetes by documenting their life narratives in detail.
- 2) Semi-structured interviews with healthcare service providers both at public and private health facilities as well as informal health providers.
- 3) In-depth interviews of key informants such as healthcare officials at the state, district, and block levels, as well as activists and scholars working in the area of gender and health in Meghalaya.
- 4) Review and analysis of health programs, policies, modules, and guidelines and
- 5) Health information collected and analysed from the State and District Health Department.

The chapter is divided into three major sections. Section 3.1 briefly explains the conceptualization and approaches adopted for the present study. Section 3.2 highlights the research objectives and questions asked in the present study. Section 3.3 explains concepts used in the study and Section 3.4 summarizes the Chapter.

3.1 Conceptualization and approaches adopted for the Study:

Given the focus of the present study to understand diabetes in the social context amongst women in the state of Meghalaya, it integrates different perspectives and approaches. The history of the “social origins of illnesses” can be traced back to the work of Friedrich Engels, Rudolf Virchow, and Salvador Allende, who contributed significantly to the field of traditional medical sociology in the 18th century (Waitzkin, 1981:77). Over the years, there has been a growing interest

in understanding the linkages between the health and social conditions. Some of the important approaches included in the present study are discussed sequentially below.

3.1.1 Medical Anthropological Approach to Understand Diabetes in Social Context:

An important branch known as medical anthropology has developed from social and cultural anthropology. Medical anthropology was professionalized in the early 1960s with a broad mandate to understand and interpret human beings by studying their behaviour, their experiences of illnesses and diseases, and the medical systems within their sociocultural context (Singer & Erickson, 2011). In anthropology, every aspect of social life of people, such as culture, customs, norms, values, beliefs, rules, myths, worldviews, and languages, are studied in detail (Lobo, 2010). Depending on the social hierarchy and differences, there is variation in culture, beliefs, values, norms, occupation, education, awareness, accessibility, and utilization of various resources among different social groups (ibid). Medical anthropology is based on two important foundations of medicine and social behaviour relating to medicine and health (Lobo, 2010). Therefore, studying the problem of diabetes can also be considered within the medical anthropology framework, given the focus of the study to understand diabetes within a matrilineal society of a tribal state, namely Meghalaya, in northeast India. For instance, the description of local knowledge of disease and variables influencing treatment-seeking behaviour can be explained through medical anthropological research. According to Lobo (2010:24), “this description is critical for health education, delivery of health services, and sustainability of intervention programs, both for community-based primary healthcare programs as well as vertical control programs.”

One of the most important scholarly works in the field of Medical Anthropology is that of Prof. Arthur Kleinman in 1988. The study aims to explain the experience of “chronic pain” by individuals and how this chronic pain is expressed in the form of symptoms indicating the need for medical treatment. The present research also draws from the work of Kleinman (1988) in an attempt to understand the meanings women give to their personal experiences of living with chronic illnesses like diabetes through their narratives.

Marcia Inhorn (2006:346), a medical anthropologist stated the importance of listening to women’s voices regarding their health and well-being as it is of “vital importance to policy making.” She argues that anthropology can significantly contribute to the field of biomedicine and public health in multiple ways. According to her, it can help in “problem definition in women’s

health research,” as well as by considering the context of women’s health while planning health interventions. The third is evaluating health care delivery for women to help provide insights while formulating “new policies and best practices” (Inhorn, 2006:348). Research on women’s health using a medical anthropological approach focusing on diabetes has been conducted globally and in India by Prof. Lesley Jo Weaver (2018) and Prof. Emily Mendenhall (2019). In this present study, I also draw significantly from their scholarship.

Prof. Emily Mendenhall, a medical anthropologist used the term “syndemic” to define “the synergistic interaction of social, psychological, and biological factors” and the manifestation of these interactions together in a rather complex way than by a single disease (Mendenhall, 2019:23). The term “syndemic” was first conceived by Merrill Singer, a Critical Medical Anthropologist, in the “early 1990s in his work on substance misuse, violence, and HIV” in the context of the United States (Mendenhall et al., 2022:1). Singer and Clair (2003) defined syndemics as the interactions of diseases or unfavourable health conditions such as malnutrition, substance abuse, and stress that results from social condition detrimental to health, for example, harmful living and working environmental conditions, or a society where one suffers from oppression (Singer & Clair, 2003: 428-429). The relationship between poverty, poor childhood nutrition, and heart diseases in the later stages of life is a dangerous synergism. For instance, one of the routes in which social conditions and inequality impacts health is through a poor diet which further acts synergistically to worsen an individual’s health conditions (Singer & Clair, 2003:430). In addition, stress resulting from poverty, discrimination, or other forms of social suffering is a significant pathway where oppressive social conditions are expressed as symptoms of illnesses (ibid). The medical anthropology approach is important in syndemic research as it is bio-culturally/bio-socially oriented to health social sciences research (Singer & Clair, 2003).

As argued by Inhorn (2006:361), in medical anthropology, where ethnographic methods are used to collect rich information, there is a need to explore the intersectionality of different forms of oppression. These oppressions in women’s lives can be on the basis of “gender, race, class, age, nation, religion, sexual orientation, disability, or appearance.” Thus, the other approach that I adopted is the intersectionality approach, given the context in which the present study was conducted among tribal women in Meghalaya. The intersectionality approach is discussed briefly below.

3.1.2 Understanding Health Inequality among Tribal Women Using Intersectionality Approach:

Feminist scholarship argues that to study and understand health inequities, it is imperative to move beyond giving priority to only one single category. It is extremely critical to consider the multiple axes of oppression, such as gender, class, and race to address health inequalities (Ravindran et al., 2022:21). This approach is known as the “intersectional approach” to the study of health inequities (ibid). Thus, the present study attempts to draw from another critical approach known as Intersectionality as given by Prof. Kimberly Crenshaw. Crenshaw (1991) argues that the category of women is not homogeneous but has many layers or strata, creating an identity that leads to either getting privileges or being discriminated against. The entire approach of homogenization of social groups was largely challenged by the intersectionality approach, where the focus was on considering variations within and between categories such as women, non-whites, or heterosexuals. Intersectionality asserts that the different axes of stratification/differentiation/oppression interact to produce something “unique and distinct” from any single category acting alone (Ravindran et al., 2022:21). In the study of tribal population in India, there is a dominant presumption that they are a homogenous group. However, there are different sub-tribes and differentiation based on region, culture and socio-economic status. In his seminal work “Women and Gender in the Study of Tribes in India,” Xaxa (2007:184) argues that tribal women are not a homogeneous group as there is a division even between women, with few of them belonging to the “well-off section” enjoying numerous advantages. In contrast, most belong to the “lower stratum,” suffering from multiple disadvantages and deprivations.

The importance of gender as a critical determinant of health is widely acknowledged. In the “sociology of health and illness, medical anthropology, and the political economy of health, gender is one of the most commonly used categories for analysis to understand the complexities of the health of women” (Keane, 2014:180). Inequities in health are often understood as avoidable and unfair differences in health (Hosseinpour et al., 2018; Ravindran et al., 2022). There is a significant difference in women’s health depending on the socio-economic context. Thus, poverty, inequality, educational status, access to food and nutrition, utilization of health services, availability of economic resources, geographical isolation, and social exclusion are some of the key factors that shape the health status of women during their life course (Ravindran et al., 2022).

In the Indian context, tribal women continue to suffer from increased vulnerabilities and risks of developing communicable and chronic illnesses as well as dying during childbirth. Thus, health and gender inequities intersect to produce poor health outcomes among tribal women in India (ibid).

According to Ravindran et al. (2022), there are other pathways to health inequities, known as “life course events.” The life course approach is a model in public health that has prevailed since the first half of the twentieth century (WHO, 2000) and is discussed briefly in the following sub-section, given its significance in understanding chronic illnesses, such as diabetes.

3.1.3 Life Course Approach:

The present study also draws from the life course approach, an important public health model for understanding the current pattern of health and diseases in individuals and populations. It aims to understand and look for factors over a person’s life experience or across generations to understand their health status (WHO, 2000). Most importantly, this approach attempts to recognize that an individual’s health is influenced by their past and present experiences shaped within the larger socio-cultural context in which they live. Within epidemiology, the life course approach enables one to understand how chronic disease risk and health outcomes in the later phase of an individual’s life are also interrelated with an individual’s experiences of physical and social hazards during the gestation period, childhood, adolescence, young adulthood, mid-life and old age (WHO, 2000: 4). As argued by Ben-Shlomo and Kuh (2002:285), the main objective of the life course approach is to study and identify the underlying biological, behavioral, and psychological processes that shape and operates across the life span of the individual.

The life course approach incorporates Barker’s (1998) “fetal origins hypothesis” but is much broader (WHO, 2000:4). Critical periods of growth encompass both in utero and early infancy and during childhood and adolescence (ibid). The life course approach also encompasses the long-term health consequences of biological and social experiences in early and mid-adulthood. Socio-economic conditions throughout the life course also shape adult health and disease risks (ibid). Research on social inequalities in health and women’s health has adopted the life course approach to study the impact of experiences and exposures at different life stages after accumulating social inequalities in morbidity and mortality among the middle and older population (ibid).

Ravindran et al. (2022:18-19) argue that there are three ways in which health inequities are created. The first one is that regardless of any incidents that take place in the life stages of an individual, the experiences they had gone through during the gestational period and early childhood impacts their health status in adulthood. The environment that individuals live in during their early life affects their life trajectory and health, is the second way that creates health inequities. The third way that affects an individual's health is the "cumulative effect of exposure" to a harmful environment that worsens when the exposure is more intense and of longer duration. Further, Krieger (1999) argues that people's experiences of discrimination on an everyday and an accumulation basis have a tremendous impact on their health and treatment-seeking behaviour.

For critically understanding the differences in the population's health status across social groups, the social determinants of health framework given by the WHO in 2010 has emerged as an important approach. Thus, the next section briefly explains the Social Determinants of Health.

3.1.4 Social Determinants of Health and Diabetes:

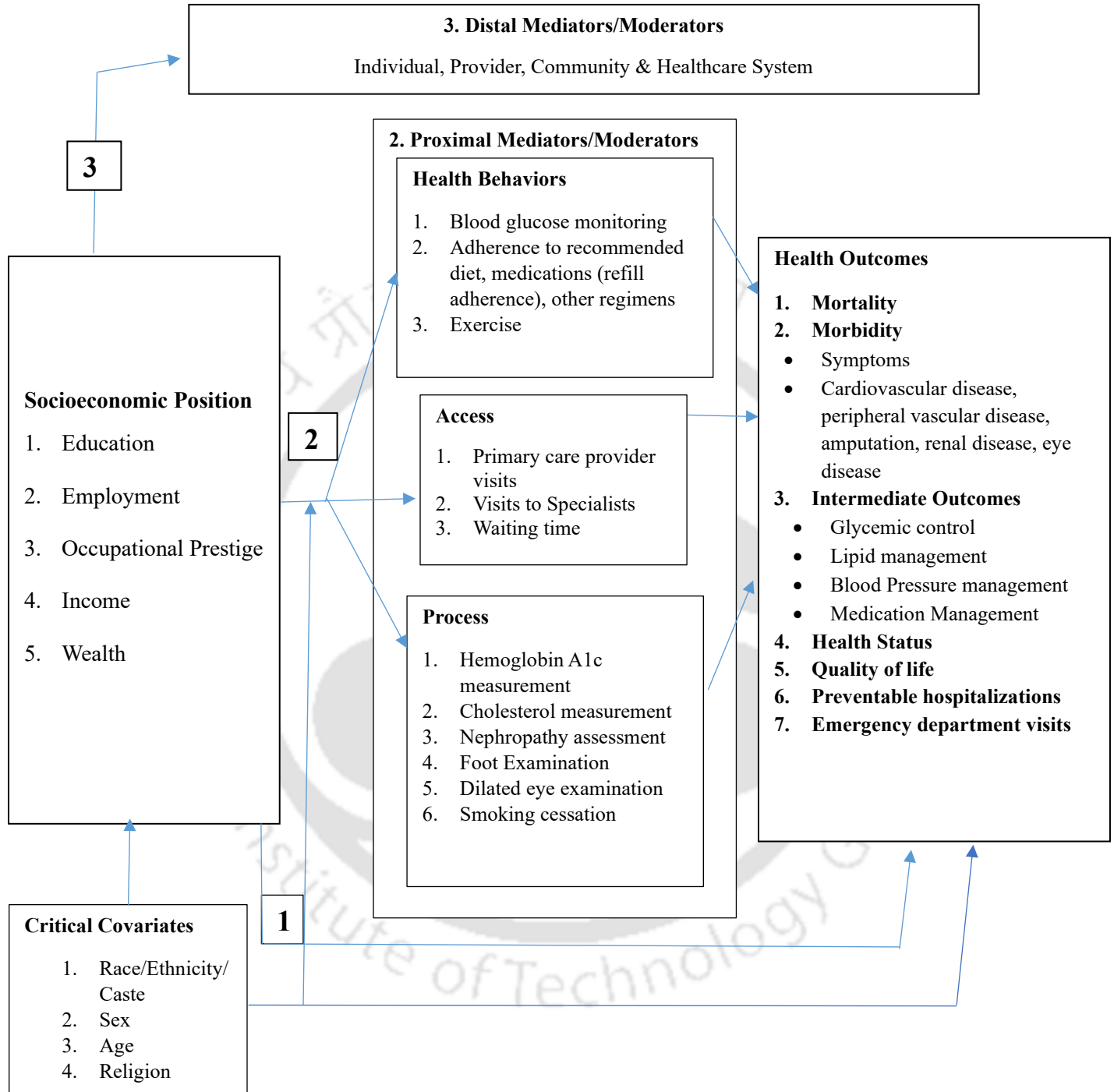
In simple terms, the social determinants of health refer to the conditions in which people "live, work, and age."¹² According to the Social Determinants of Health (SDH) approach, it is important to understand that health and disease are mainly determined and influenced by non-medical factors such as income and employment, education, income, food security, access to health care, housing, and working conditions. These factors operate and interact at different levels, from individual and family to community and structural level. Healthcare services are an intermediary factor determining healthcare services utilization (WHO, 2010). These factors shape and influence the population's health by exposing them to multiple levels of an interconnected axis of vulnerabilities and insecurities in life (ibid).

It is important to note that diabetes as a chronic illness is also influenced by structural factors beyond the individual's control. For instance, consuming a highly fatty and sugary diet due to a lack of policy to regulate the sale of these food products increases risks to the population (Weaver, 2018:7). The broader structural determinants also play an important role in impacting the care and management of diabetes. For instance, for people belonging to low-income households, it is extremely difficult for them to access treatment services for diabetes due to the

¹² Available at <https://www.instituteofhealthequity.org/about-our-work/action-on-the-social-determinants-of-health-> accessed on 12th May 2022.

high costs of care (Mendenhall, 2019). Literature on social determinants of diabetes has documented the association between socioeconomic position and the health of persons with diabetes. A lower socioeconomic position has been associated with developing chronic diseases such as diabetes (Raphael et al., 2003; Brown et al., 2004). The factors shaping the socioeconomic position at the individual level include – race or ethnicity, sex, age, education, employment, or occupation prestige; at the household level, it includes income and wealth (Brown et al., 2004), as shown in Figure 3.1. Demographic characteristics such as age, sex and race or ethnicity are considered “critical covariates” by Brown et al. (2004:64) as they can influence health outcomes independently. The socioeconomic position of persons determines their health outcomes (Pathway 1). For instance, in the case of diabetes, the general outcomes include – “health status, quality of life, and mortality.” The specific outcomes are intermediate outcomes, such as “blood sugar control, blood pressure management, lipid management, and medication management” (ibid:64). Socio-economic status influences health outcomes through individual health behaviors, access to care, and processes of care, also known as “proximal mediators or moderators” (Pathway 2) (ibid:64). Individual health behaviors encompass regular monitoring of blood glucose, adherence to recommended diet, regular medications, and exercise. Access to care involves visiting healthcare providers at the primary level and specialists. The care process carried out at healthcare facilities to monitor and prevent complications of diabetes include – measurement of HbA1c or glycated hemoglobin (as the name suggests, it is a fraction of hemoglobin in the RBCs, which has glucose attached to it), cholesterol measurement, nephropathy assessment, foot examination, eye examination, and counseling related to tobacco smoking cessation (ibid).

Figure 3.1 Social-Economic Position and Diabetes



Source: Adapted from the work of Brown et al. (2004:64)

Further, individual levels characteristics also play a critical role in determining the health of the population living with diabetes at different levels of the socio-economic hierarchy (Pathway 3). These factors include “communication between patients and providers, health literacy, language barriers and culture, stress, mental health and social support, social integration, and competing demands” (Brown et al., 2004:67-68). Apart from this, the nature of care provided by health workers, shaped by their knowledge, skills, and experiences, also influences the outcome of diabetes in the population. The other factors that influence general health outcomes, including diabetes, are – availability and accessibility to healthy foods, access to parks and public spaces for exercise and safety of the neighborhood, transportation, and environmental exposures (ibid). Further, healthcare organization systems, known as the intermediary determinant of health, also play a significant role in influencing the outcomes of diabetes (ibid). All the three factors – Individual, provider, and community and healthcare system are known as the “distal mediators or moderators” (ibid:64). Against this backdrop, I also attempt to study the health system using the Critical Medical Anthropology (CMA) approach and the Health Policy and Systems Research (HPSR) approach.

3.1.5 Critical Medical Anthropology (CMA) and Health Policy and Systems Research (HPSR):

In her critical work, Mishra (2013) puts forward a research method where disciplines such as medical anthropology and public health intersect. The intersections lie in their common quest to understand health, illness, and suffering. According to Mishra (2013), two liberating developments have developed in medical anthropology and public health. “These developments relate to the emergence of critical medical anthropology (CMA) and health system research (HSR) or health policy and systems research (HPSR) in public health” (Mishra, 2013:1).

The turn toward political-economic approaches in anthropology in general and the effort to involve and expand the political economy of health approaches is due to the emergence of CMA in the 1990s (Singer & Baer, 2018). Singer (1995:81) defines CMA as a “theoretical and practical effort to explore the challenges related to health, illness, and treatment with regard to their interactions at different levels of the health system and community.” At the micro level, illness is experienced, given meaning to, and determines the behaviour of individuals towards the illness. The micro level also encompasses the physiology of the human body and environmental factors.

These micro-level phenomena do not occur in isolation but interact with community-level factors, such as popular and folk beliefs prevalent in the community and measures adopted by community members to prevent and treat illnesses. Similarly, the phenomena in the community also interact with other external factors: the health institution level. The other level of interaction is the national level which determines how the health systems should operate based on the nation's political structure or priorities. However, the macro level or global political economy shapes interactions at all these levels. Mishra (2013:2), therefore, critically pointed out that due to these interactions that occur at multiple levels, there is a need to move beyond the "traditional medical anthropological" approach of studying the local conceptions of health, illness, and health-seeking behaviour only at the micro or local level. To understand these interactions, there is a need for a CMA approach that examines the relationship between local phenomena and national and global ones. In CMA, the unit of analysis thus shifted from restricting only at the micro level to interactions and interfaces at different levels."

The second development in medical anthropology and public health, as proposed by Mishra (2013), is the coming up of Health System Research (HSR) or Health Policy and Systems Research (HPSR). This is because of the adoption of a multidisciplinary research approach in public health. The emergence of HSR is due to the recognition that technocratic solutions alone cannot address the issues of disease prevention and control, and it is insufficient to address the issues of equity, access, and quality of care. Therefore, the HSR endeavours to understand the health system to address equity, access, and quality of care (Mishra, 2013).

Thus, the present study also draws from both these approaches, where I attempt to explore not only the experiences of women with diabetes and their local understanding of diabetes at the individual level but their interactions at the community level and health institution. Further, my study also aims to understand the nature of services provided at different levels of health institutions. In this case, the implementation of the national NCD prevention and control program was also explored.

Based on the combination of all the above approaches, my study aims to critically understand women's experiences of living with diabetes in Meghalaya. Lewis & Kieffer (1994) argues that women's health needs to be conceptualized in the context of their reproductive function, their engagement in economic activities such as agricultural production, formal and

informal sectors, social reproduction, and any other household-related activities that are not well-defined but necessary for the sustenance of the household. The present study also asks questions such as what women do, where, when, and why questions related to their daily economic activities. These questions will help us understand the various health risks women face due to these activities. As women are not homogeneous groups, age, educational level, ethnicity, and other factors are also considered. Further, my study also attempts to understand the availability of healthcare services for promoting health, controlling diseases and women's health-seeking behavior. Apart from this, the study also attempts to explore women's interactions with the health systems. There are very limited studies in the context of Meghalaya which have explored women's experiences within their socio-economic and cultural context, their health-seeking behaviour, and the health system's response to diabetes care. Thus, this study aims to understand the intersection of individual, family, community, and health services level factors and the social, cultural, psychological, and economic factors.

With this conceptualization, the present research study aims to explore the following objectives and questions:

3.2 Research Objectives and Questions:

- 1. To understand the experiences of women with diabetes in West Jaintia Hills District, Meghalaya.**
 - i. How do women in the study area perceive the causes of diabetes?
 - ii. What are women's knowledge and perceptions related to symptoms, management, and treatment of diabetes?
 - iii. What are the cultural beliefs and practices related to diabetes and its management?
 - iv. What are the barriers to self-management of diabetes among women?
 - v. What are the experiences and barriers faced by women suffering from co-morbidity or complications due to diabetes?
- 2. To explore the different types of health services providing care for diabetes**
 - i. What are the services provided for diabetes at public, private, and alternative healthcare facilities?
 - ii. What are the challenges faced by various healthcare providers in these facilities?

- iii. What are the perspectives of healthcare providers about the risk factors and management of diabetes in the study area?

3. To understand the utilization of health services by women for diabetes care

- i. What are the various sources women access for the prevention and treatment of diabetes?
- ii. What are the experiences of women while accessing different sources?
- iii. What medical insurance schemes are available for women suffering from diabetes, and whether it is easing the burden of treatment expenditure for hospitalization?
- iv. How did women seek care for diabetes, especially during the COVID-19 pandemic?

4. To understand the intersections of various determinants of diabetes among women

- i. How does poverty affect the risks and management of diabetes?
- ii. How does everyday stress act as a barrier to managing diabetes?
- iii. What are the different sources of social support available to different women groups?

3.3 Definitions of Concepts used in the Study:

In the present study, I used a few terms that need definition within the context of the study. These include:

Women living with diabetes: The term women refer to women respondents living with diabetes, both newly diagnosed at health facilities visited and those who have lived with it for years and identified by the health workers at the HWCs level.

Diabetes: It refers to type-2 diabetes which is the most common type of diabetes.

Tribal: Refers to the tribal community living in Meghalaya as documented in the Constitution of India and categorized as Scheduled Tribes (STs). The term tribal also refers to the Pnar tribe that predominantly inhabits West Jaintia Hills District. According to Census of India, 2011 they constitute 78.17 percent of the total population in West Jaintia Hills.

Pnar Woman: Pnar woman refers to a woman who speaks the Pnar language and resides in the Pnar region of West Jaintia Hills District.

Traditional Healers: Refers to the providers of Pnar medicine or *Dawai Pnar*. They are also known as *Kombiraij*.

Traditional Medicine: Traditional medicine refers to Pnar medicines provided by *Kombiraij* (also known as *Doktor Pnar* in local terms) in the form of herbs or mixed with other allopathic and ayurvedic medicines.

Given the outbreak of the COVID-19 pandemic in 2020, which overlapped with the fieldwork of the study and the restrictions imposed by the District Administration, it was extremely challenging to visit the villages and interact with community members directly without going through proper channels. Hence, first, I decided to study the health system as the public health systems have been at the forefront in responding to the pandemic and I was able to visit and access the public health facilities. Through the health system, I accessed the community for fieldwork when restrictions were little eased and hence could collect data for the remaining three objectives.

Before discussing the methodology in detail, in the next section I will briefly provide an overview of the Meghalaya state, and also discuss the status of health infrastructure and health care services in Meghalaya. Further I will also provide an overview of the study district, i.e. West Jaintia Hills.

3.4 Summary:

This chapter provides an overview of the conceptualization and approaches adopted in the study. These approaches and frameworks were applied in the study after fieldwork has been conducted, as an analytical tool. It also discusses the objectives and research questions explored in the study. Lastly, the chapter also explains the concepts used in the present study.

Chapter Four

Context of the Study

Introduction:

The chapter discusses the larger context of the study by focusing on the socio-demographic profile of the Meghalaya state as well as the West Jaintia Hills District, where the study is located. The chapter also makes an attempt to briefly discuss the health systems in the state and described the study settings. The present chapter is divided into four sections. Section 4.1 provides a brief overview of Meghalaya in terms of its geography, demography, economic and health status. Section 4.2 discusses the socio-demographic and economic profile of West Jaintia Hills which is the study district. Section 4.3 explains the methodology of the study in terms of selection of study sites, and study participants, the data collection tools and techniques, access to the study settings, self-reflexivity, data analysis and ethical consideration. Section 4.4 discusses the limitations of the study and Section 4.5 summarizes the Chapter.

4.1 Brief Overview of Meghalaya:

4.1.1 Socio-Demographic Status:

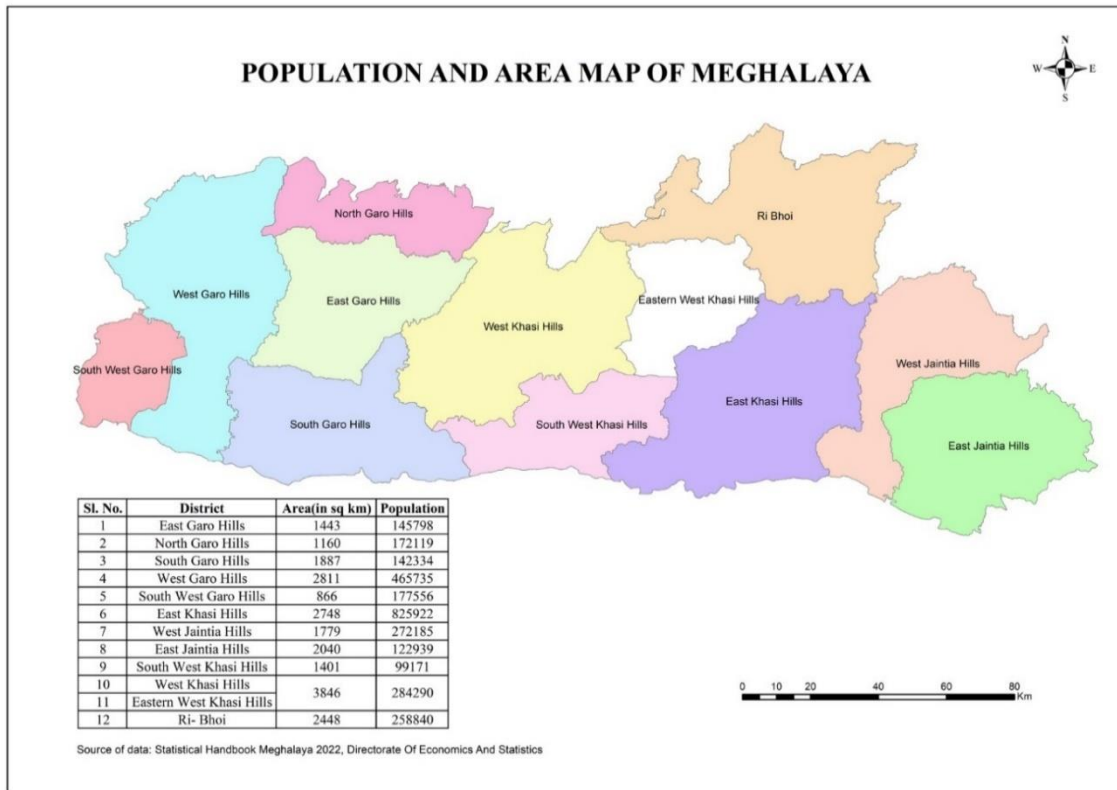
The word Meghalaya means “Abode of Clouds” due to the nature of its climate (Dutta, 2022:47). Meghalaya, one of India’s eight northeastern (NE) states, was formed after being carved out of Assam in 1972 (ibid). It is divided into twelve districts (GoM, 2022a), as shown in Figure 4.2. It has a total population of 2.9 million, of which 79.9 percent live in rural areas and the remaining 20.1 percent reside in urban areas (GoM, 2022a). Meghalaya is predominantly (95%) inhabited by the tribal population (Dutta, 2022). The state’s literacy rate was 74.4 percent (76 percent-males and 73 percent-females) (Census of India, 2011). Geographically, the state is largely mountainous, with hills, valleys, plains, and flood-prone areas in the foothills. In the north and northwest, Meghalaya is bounded by the Brahmaputra valley of Assam, in the east by the Cachar area of Assam, and in the south and partly southwest, it is bounded by the Surma valley of Bangladesh. The border shared between Meghalaya, and Bangladesh is approximately 443km (GoM, 2022a). About seventeen tribes notified as Scheduled Tribes by the Government of India inhabit Meghalaya. The Khasi, the Jaintia, and the Garo are the three major tribes that inhabit Meghalaya, apart from a number of other sub-tribes such as Hajong, Koch, Rabha, Boro, and Mann

(GoM, 2009). However, other communities, such as Nepalese, Bengalis, Punjabis, and others, constitute a small proportion of Meghalaya's population, particularly in Shillong (Bijukumar, 2023). Earlier, all these communities co-existed in harmony with the Khasis, the major inhabitants of Meghalaya, until recent times when the state observed inter-ethnic conflicts. The most recent conflict was between Dalit Sikhs and the Khasi community in 2018 (ibid). People from other communities are seen by the local people as “outsiders” and a threat to their resources (ibid:23).

The Khasi and the Jaintia, traced their descent from common ancestors called the *Ri Hynniewtre* (the Seven Families). Thus, they are ethnically the same (Bareh, 1964). It has been theorized that the Khasis and Jaintias originated from Southeast Asia while the Garos from Tibet. The Khasis and the Jaintias are similar culturally and physically and speak the common Khasi dialect (ibid). Scholars use the word Khasi to mean both Khasi and Jaintia collectively. The term “Khasi” means “born of a mother,” where “Kha” means born, and “Si” means ancient mother (Bareh, 1964:12-13). All three tribes follow a matrilineal social system where lineage and inheritance are traced through women (Gassah, 1994; Griffin et al., 1995). Women's status is considered higher, although not equal to men's (Mukhim, 2019). However, recent literature has documented a gradual shift from matrilineal to patrilineal social structure in the state (Dutta, 2022). As distinct from other NE states in India, a large proportion of the tribal population in Meghalaya are Christians (Dutta, 2022).

Meghalaya falls under the Sixth Schedule of the Constitution of India that empowers the state to create new political institutions known as District Councils (Gassah 1994; Oosterhoff et al., 2015). District Councils are established at district level, for instance the Khasi Hills Autonomous District Council (KHADC) in Khasi Hills District and Jaintia Hills Autonomous District Council (JHADC) in Jaintia Hills District. The District Council are empowered to make laws related to land, forest primary level education administrative matter in the district (ibid).

Figure 4.1 Map of Meghalaya



Source: The official web portal, Government of Meghalaya¹³

Meghalaya is considered one of the economically backward states, given its low per capita income and slow growth over time (Nayak & Thomas, 2007). Before the advent of mining as an important economic activity, people's main occupation in Meghalaya has been agriculture (Dutta, 2022). Based on the National Multi-dimensional Poverty Index published by the National Institute of Transforming India (NITI) Aayog in 2023, Meghalaya is among India's top three multidimensionally poor states (GoI, 2023).¹⁴ About one-third of the State's population lives below the poverty line, and poverty in rural areas is two times higher than that in urban (GoM, 2022a).

According to NFHS-5 (2019-21), about 91.9 percent of the population in Meghalaya lives in households with electricity. Despite this, there are frequent power cuts in the villages of Meghalaya. About 79.2 percent live in households with improved drinking-water sources. The percentage of the population living in households that used an improved sanitation facility was

¹³ Available at <https://meghalaya.gov.in/maps> accessed on 12th May 2023.

¹⁴ This is based on the estimates calculated by the NITI Aayog on Multidimensional Poverty Indicator (MPI), a metric, which takes into account indicators related to nutrition and health, availability of clean drinking water, gas, electricity, education, etc.

82.9 percent. About 33.7 percent of households used clean fuel for cooking. The percentage of households with any usual member covered under a health insurance or financing scheme was 63.5 percent (IIPS & ICF, 2021).

The historical and persisting inequities increase the likelihood of the tribal communities in the state to suffer from ill health (GoM, 2022a). The average life expectancy of Meghalaya is 62.3 years, which is significantly lower than the national average of 68.8 (GoM, 2021:2). It is also estimated that around 64.1 percent of all NCD deaths in the State are premature (GoI, 2021).

One of the distinct features of the tribal communities in Meghalaya is that it is a matrilineal society that gives women some control over family, economic, and community resources. Given the Matriline culture, women in Meghalaya are considered to have relatively higher status than women from other states of India (Dutta, 2022). However, matriliney in Meghalaya is also considered to be “patriarchal matriliney” as women are bound to submit to the control of their brother’s and maternal uncle’s and, at the same time, have to undertake huge domestic responsibilities (Dutta, 2022:60). Women in the state have no say in traditional political decision-making processes, even when they have access to economic resources, particularly the youngest daughter (Nongbri, 1988). Mukhim (2021) argues that, akin to other tribes of the Northeast, the Khasi traditional institutions are male-centric. The fact that women are not allowed to participate in the traditional institutions such as the Village Durbars makes it difficult for them to enter politics, as these institutions serve as means for people who aspire to be in politics. Citing the works of a Renowned Historian and Former Chairman of the Union Public Service Commission (UPSC) from Meghalaya, Prof. David Syiemlieh (2004) (as cited in Kharkongkor, 2021:26) argues that the patriarchal base in Christianity accommodates tribal traditions where women are expected to perform a secondary role in the local administration. Thus, gender discrimination is not absent in the state. This is also evident from the poor health status of women in the state, as discussed in the next section.

4.1.2 Health Status of People in Meghalaya:

The health status of the tribal populations is considered poor in the state, given the poverty and geographical location in remote and hard-to-reach areas, forests, or hilly terrains. This results in their isolation, poor implementation of policies and programs, and lack of economic opportunities, among other problems (GoM, 2009; GoI, 2018a; Ravindran et al., 2022). Compared

to the urban areas, the condition in rural areas is far worse as “rural areas in NE states are very backward,” they lack connectivity and have poor public health infrastructure (Singh, 2017:101). Among the northeast states of India, Meghalaya has the worst health conditions after Assam. For instance, according to NFHS-5 (2019-21), the infant mortality rate of Assam and Meghalaya was 31.9 and 32.3 per 1,000 live births, respectively. According to the Disease Burden Profile conducted by the Indian Council of Medical Research, Public Health Foundation of India, and Institute for Health Metrics and Evaluation in 2016, life expectancy has increased in Meghalaya from 63.1 years to 72.4 years among females and 59.8 years to 66.8 years among males during the period from 1990 to 2016. Meghalaya’s total fertility rate (TFR) is still higher than the replacement level at 2.9 children per 1000 live births. Apart from this, the unmet needs for contraception are also very high at 26.9 percent (IIPS&ICF, 2021). Table 4.1 below depicts some of the health indicators of Meghalaya. The details of Meghalaya’s health indicators between 1992-2020 are enclosed as Annexure 1.

Table 4.1 Key health indicators of meghalaya in comparison to India (2019-2021)

Health Indicators	Meghalaya	India
Total Fertility Rate (Children per woman)	2.9	2.0
Sex Ratio at birth	989	929
Female Literacy Rate	87.6	71.5
Percentage of unmet needs for Family Planning services	26.9	9.4
Percentage of unmet needs for spacing of births	18.3	4.0
Percentage of pregnant mothers who had at least four Antenatal visits	52.2	58.1
Percentage of births attended by Doctors/Nurses/LHV/ANM/other health personnel	64.0	89.4
Percentage of Institutional Births	58.1	88.6
Percentage of Children 12-23 months fully immunized	63.8	76.4
Percentage of children under five years who are stunted	46.5	35.5
Percentage of children under five years who are wasted	12.1	19.3
Percentage of children under five years who are underweight	26.6	32.1
Percentage of children 6 - 59 months who are anemic	45.1	45.1
Infant Mortality Rate (IMR)	32.3	35.2

Percentage of non-pregnant women aged 15-49 who are anemic	54.4	57.2
Percentage of pregnant women aged 15-49 who are anaemic	45.0	52.2
Percentage of men aged 15-49 who are anaemic	25.5	25.0
Percentage of women aged 15-49 whose body mass index is below normal	10.8	22.9
Percentage of men age 15-49 whose body mass is below normal	9.0	16.2
Percentage of women age 15-49 who are overweight and obese	11.5	24.0
Percentage of men age 15 -49 who are overweight and obese	13.9	22.9
Percentage of currently married women who usually participate in household decisions	92.3	88.7

Source: Data compiled based on NFHS-5 (2019-2021, various page numbers)

Meghalaya also has a high burden of communicable diseases such as Malaria, Tuberculosis (TB), and Human Immunodeficiency Virus (HIV). Further, NCDs such as cancer, hypertension, and diabetes are also rising (GoM, 2021). The disease profile across different age groups is presented in Table 4.2.

Table 4.2 Disease profile of Meghalaya, 2016

Age Group	Percentage out of total deaths	Major causes of deaths
Children (0-14 years)	15.3 %	• Diarrheal disease, Lower Respiratory Tract Infections, Common infectious diseases (38.4%) • Neonatal disorders (30.4%) • Neglected Tropical Diseases (NTDs) and malaria (11.2%)
Individuals (15-39 years)	15.7 %	• Other causes [not mentioned in the study] (14.15%) • Diarrheal diseases, lower respiratory tract infections, and other common infectious diseases (13.5%) • HIV/AIDS and tuberculosis (12.8%) • Suicide and violence (10.1%) • Cirrhosis (9%) • Cardiovascular Diseases (CVDs) (8.8%) • Cancers (7.7%) • Unintentional injuries (7.3 %) • Transport Injuries (7%) • Digestive Diseases (5%) • Maternal disorders (4.7%)

Individuals (40-69 years)	37.6 %	• Cancers (24.9%) • Cardiovascular Diseases (20.6%) • HIV/AIDS, tuberculosis, diarrhea, lower respiratory tract infections, and other common infectious diseases (9.4%) • Cirrhosis (8.2%) • Diabetes/urogenital diseases or endocrine disorders (6.5%)
Individuals (70 years and above)	31.5 %	• Cardiovascular diseases (25.7%) • Diarrheal disease, lower respiratory tract infections, or other common infectious diseases (23.4%) • Cancers (10.3%) • Chronic respiratory diseases (9.6%) • Diabetes/ urogenital disease/ endocrine diseases (8.3%) • HIV/AIDS and tuberculosis (6.1%)

Source: Indian Council of Medical Research, Public Health Foundation of India, and Institute for Health Metrics and Evaluation, (2016:1)

Table 4.2 above shows that with 37.6 percent of the total mortality, chronic diseases such as cancers, cardiovascular diseases, and other communicable diseases such as HIV/AIDS, tuberculosis, etc., are the major contributor to mortality in Meghalaya among individuals aged 40-69 years. Further, among individuals aged 70 years and above, infectious and non-communicable diseases such as cardiovascular diseases and cancers contribute significantly to mortality in Meghalaya. In addition, the burden of mental disorders such as anxiety and depression is also on the rise in Meghalaya (GoM, 2022a). This clearly indicates that Meghalaya is suffering from triple disease burden, posing major challenges to the health system in the state.

4.1.3 Health Status of Women in Meghalaya:

Concerning the health status of women, Oosterhoff et al. (2021) argue that despite being a matrilineal society, women's health is poor compared to other women in the northeastern states. Their arguments are based on the indices released by the NFHS-5 (2019-21), mainly on the status of sexual and reproductive health in the state. For instance, only 53.9 percent of pregnant women had an antenatal check-up in the first trimester. Around 45 percent of pregnant women were anaemic. The problem is also acknowledged in the Meghalaya Health Policy 2021, which the Governor of the State notified on 9th March 2021. According to the policy document, although the state has managed to reduce the number of deaths due to malaria and eliminate polio, it still fares poorly with respect to other health indicators. The health policy of Meghalaya compares the indicators with Kerala state to understand the poor health status of the population in Meghalaya and the efforts to be directed to improve the health and well-being of the population. For instance,

Meghalaya's infant mortality rate (IMR) was 34 per 1000 live births, whereas it was 6 for Kerala. The maternal mortality rate is also acknowledged to be “alarmingly high” for Meghalaya, with 197 deaths per 1,00,000 live births. In contrast, for Kerala, it was 43 (GoI, 2021:2), while the all-India maternal mortality rate was 113 (Sample Registration Survey, 2020).

Another major issue confronting the state is the increase in the number of female-headed households, mainly by single mothers. This is because women are either widowed or their husbands deserted the family. This has emerged as a major challenge that women in the state face besides general health issues such as high maternal mortality rates, low awareness of health problems, and high rates of anemia, etc. (GoM, 2022a:41). In certain cases, women also prefer to separate from their husbands due to infidelity, alcohol dependence, or a breakdown in the relationship (ibid). Women then shoulder the responsibility of raising their children for various reasons. Moreover, owing to the matrilineal nature of society, women, especially the youngest daughter, are also expected to take care of their elderly parents. These responsibilities lead to increased work and domestic burden and emotional distress among women (ibid). The next section makes an attempt to understand the healthcare infrastructure and service in Meghalaya.

4.1.4 Healthcare in Meghalaya: A Brief Trajectory

During the pre-independence period, Missionaries played an important role in the setting up modern health facilities in the state. For instance, Welsh Mission at Shillong and Jowai and the Baptist Mission at Tura established several hospitals to provide medical care to the population (GoM, 2009). In 1915, the Pasteur Institute in Shillong was set up by the colonial government to produce vaccines for various diseases such as smallpox, cholera, and anti-rabies.¹⁵ The institute has also emerged as an important research and development institute in the Northeastern region.

Apart from this, the pre-independence period also saw the establishment of hospitals by philanthropists. For instance, the Ganesh Das Hospital was set up with donations provided by Ganesh Das Shri Ram in 1935 (Muksor, 2017). It was only in 1949 that the hospital came under the Director of Health Service, Assam. In 1943, the British Government in Shillong established the Reid Provincial Chest Hospital.¹⁶

¹⁵ Available at https://meghealth.gov.in/dhsr_pasteur_inst.html accessed on 4th June 2020.

¹⁶ Available at <https://theshillongtimes.com/2018/05/20/heritage-hospital/> accessed on 4th June 2020.

After the independence, when Meghalaya was still a part of the erstwhile state of Assam, there was significant growth and expansion in setting up different health facilities such as district hospitals, dispensaries, disease control hospitals, and primary health centres across different districts of the state.¹⁷ Apart from this, there was a massive upgradation health infrastructure in order to reach out to remote health facilities in the state. For instance, a new Government Civil Hospital was established at Jowai, and State Dispensaries were set up in a few accessible villages. Primary Health Centres (PHCs) were also established at all the Block headquarters in Meghalaya. Special Disease Hospitals, for instance, TB hospitals were also established at Tura, and Leprosy Colonies were established in West Garo Hills and Ri Bhoi. To a large extent, the health facilities implemented vertical disease control programs apart from providing preventive, promotive, and curative healthcare (GoM, 2009).

Table 4.3 provides a detailed description of the growth of public health facilities in Meghalaya over the last four decades. It also shows the increase in public health facilities after the National Rural Health Mission (NRHM) was implemented in the state.

Table 4.3 Growth of public sector health institutions and services in Meghalaya between 1972-2015-16

Items	1972	1981	1991	2001	2007	2015-16
Number of Hospitals	7	9	9	6	9	12
Number of Dispensaries	57	58	23	20	14	13
Number of CHCs	0	0	0	12-17	28	28
Number of PHCs	9	23	63	85-88	104	110
Number of sub-centres	0	93	272	401	405	423
Number of Beds	781	1264	1811	2735	3166	4227
Number of indoor patients	3385	40260	342740	97000	158000	NA

¹⁷ India's rural public health system includes three-tier health facilities based on population norms. For instance, one Sub Centre is set up for a population of 5000 in plain and 3000 in hilly and tribal areas. They are manned by ANM and MPWs, and it is the first point of contact. Next on the level are the Primary Health Centres established for 30,000 population in rural areas and 20,000 in tribal and hilly areas. Apart from para-medical staff, a medical doctor at PHC provides inpatient and outpatient care. Above the PHC, there is a CHC for 120,000 and 80,000 population in plain and tribal areas where specialists such as paediatricians, gynaecologists are available. Further in the hierarchy are the District Hospitals in every district of the country with a bed size of 100-500 and often act as the most important site for referral and curative care. The HWC is a new concept introduced in 2018 when the Ayushman Bharat was launched. These HWCs are transformed SCs that provide comprehensive healthcare services ranging from Maternal and Child Health to Non-Communicable Diseases (NCDs), and there is a provision for Community Health Officers or Mid-Level Healthcare Providers (GoI, 2018b).

Number of outdoor patients	90788	2039973	1915790	1511000	1923000	NA
No. of IUCD inserted	485	284	1789	2407	2646	4414
No. of sterilizations	582	257	612	2294	2264	2525
Doctors	113	189	335	389	568	609
Nurses	117	305	318	384	862	835
Health visitors	8	30	45	59	71	67
ANMs	82	227	450	594	687	755
Pharmacists	0	0	137	92	188	189
Lab. Technicians	0	0	45	100	172	163
Vaccinators	0	0	148	148	106	100

Source: Meghalaya Human Development Report (2009:33) & Statistical Handbook Meghalaya 2017, Directorate of Economics & Statistics, Government of Meghalaya (various pages)

Apart from the public and private health facilities, non-governmental organizations (NGOs) such as the Voluntary Health Association (VHA) of Meghalaya and the Bosco-Reach Out along with many others works in the state to provide healthcare to the people. Further, the State of Meghalaya has one of the most important Central Government Medical College and Hospital known as – The North East Indira Gandhi Regional Institute of Health and Medical Sciences (NEIGRIHMS), in Shillong. NEIGRIHMS, established in 1987, is one of the biggest tertiary medical care hospitals catering to the health needs of the people from remote districts of Meghalaya and other northeastern states.¹⁸ Equipped with State-of-the-Art-Technology, for super-specialty teaching and as a referral site, NEIGRIHMS has 531 beds (ibid). The institute imparts nursing and medical education, including super specialty education. Table 4.4 provides an overview of the state's district-wise availability of health facilities.

¹⁸ Available at <https://neigrihms.gov.in/>. Accessed on 10th July 2022

Table 4.4 District-wise distribution of public health facilities in Meghalaya (2018)

Districts	DH	CHCs	PHCs	SCs	UHCs	Dispensary	Total
West Garo Hills	1	5	9	64	3	3	85
South Garo Hills	1	1	6	21	0	1	30
South West Garo Hills	1	1	9	27	0	0	38
North Garo Hills	0	0	10	50	0	0	60
East Garo Hills	1	1	7	0	0	0	9
West Khasi Hills	2	2	15	46	1	0	66
East Khasi Hills	1	7	25	72	13	4	122
South West Khasi Hills	0	2	3	20	0	0	25
Ri Bhoi	1	3	8	32	0	2	46
East Jaintia Hills	0	2	6	35	0	0	43
West Jaintia Hills	1	3	12	46	2	1	65
Total	9	27	110	413	19	11	589

Source: National Health Mission, Government of Meghalaya website¹⁹

DH: District Hospital; CHCs: Community Health Centers; PHCs: Primary Health Centers; SCs: Sub Centers; UHCs: Urban Health Centers

With respect to health infrastructure, Meghalaya is no different from other tribal regions. Table 4.4 shows the skewed distribution of District Hospitals across the state, with North Garo Hills, South West Khasi Hills, and East Jaintia Hills having no District Hospital. Further, the number of CHCs and PHCs also varies across districts, with East Khasi Hills having the largest number of CHCs and PHCs. According to the latest report of the Rural Health Statistics (2019-20), as of 1st July, in Meghalaya, there is a shortfall of 390 (47%) Sub Health Centres, six (5%) Primary Health Centres, and three (10%) Community Health Centres (GoI, 2020). Attracting human resources to the tribal areas is still a challenging task, and lack of connectivity as well as difficult geographical terrain, and hilly and remote locations of health facilities, are major problems in the accessing and delivery of health services by public health institutions (GoI, 2018a).

Despite setting up the health infrastructure, many of the health facilities could not function, given the shortages of health workers and the unavailability of operation theatres or equipment, separate labour rooms, or vehicles for referrals. Thus, referral care was extremely weak and poor in the state (GoM 2009). Given the difficult geographical terrain of the state and poor connectivity in terms of transportation, absences of medical doctors and specialists such as Obstetricians & Gynaecologists, Paediatricians and Surgeons results in poor performance of health care services.

¹⁹Available at <http://nhmmeghalaya.nic.in/health-facilities.html> [last updated-25/09/2018], accessed on 10th March 2023.

This is often attributed to poor programme planning as well as lack of funds for health problems (Oosterhoff et al., 2015). With the implementation of health sector reforms across the country, there was tremendous reduction in the allocation of budgetary funds to healthcare. For instance, in Meghalaya there was a decline in the public health expenditure from 8 percent in 2001-02 to 3.9 percent in 2008-09 (GoM, 2009). Thus, the weak capacities of the public health systems are also one of the reasons for the poor health indicators in the state.

4.1.4.1 Private Health Care in Meghalaya:

The decade of the 1990s witnessed the growth of private hospitals in the state largely missionaries and for-profit hospitals. For instance, Nazareth Hospital- a voluntary non-profit organization was established in 1959, Bethany Hospital (private-for-profit) in 1990, Woodland Hospital (private-for-profit) in 1991, and some others, as shown in Table 4.5. These three major hospitals established in Shillong in East Khasi Hills District have grown over the years, and their bed strength today ranges between 100 to more than 400. These hospitals have also started expanding beyond Shillong to other state districts. For instance, Bethany Hospital has a branch in Nongpoh, and Woodland Hospital recently (2020) established its branch in Jowai, which is in West Jaintia Hills District.

Table 4.5 Names of private health facilities in Meghalaya and their district-wise distribution

Sl. No.	Name of the Hospital	Bed Strength	Services Provided	District
1	Woodland Hospital, Shillong (1991)	160 ²⁰	Multi-Specialty services	East Khasi Hills District (Shillong)
2	Nazareth Hospital (1959)	422 ²¹	Specialty Services	
3	Dr. H Gordon Robert Hospital (1922)	350 ²²	Specialty Services	
4	Supercare Hospital (2005)- private-for-profit	150 ²³	Specialty Services	
5	Bethany Hospital- private-for-profit (1990)	175 ²⁴	Multi-Specialty services	
6	Children's Hospital (NA)- private-for-profit	NA	Specialty Services	
7	Bansara Eye Care Hospital (NA)- private-for-profit	NA	Ophthalmic Services	

²⁰ Available at <https://woodlandhospitals.com/woodland-hospital-shillong/> accessed on 10th July 2022.

²¹ Available at <https://www.nazarethshillong.in/current-hospital-statistics/> accessed on 10th July 2022.

²² Available at <https://robertshospital.com/history-of-the-hospital/> accessed on 10th July 2022.

²³ Available at <https://supercarehospital.com/history/> accessed on 10th July 2022.

²⁴ Available at <https://bethanyhospitals.com/our-history> accessed on 10th July 2022.

8	Bawri Nethralaya Eye Hospital (NA)- private-for-profit	NA	Ophthalmic Services	
9	Hope Clinic (1992)- private-for-profit	NA	Multi-Specialty Clinic	
10	Holy Cross Mairang (NA)- missionary hospital	NA	Secondary Care	West Khasi Hills
11	Holy Cross Tura Hospital (1993)- missionary hospital	100 ²⁵	Secondary Care	West Garo Hills
12	Christian Hospital Tura - missionary hospital	NA	Secondary Care	
13	Dr. Norman Tunnel Hospital (1933)- missionary hospital	165 ²⁶	Secondary Care	West Jaintia Hills
14	Woodland Hospital, Jowai (2020)- private-for-profit	100 ⁷	Multi-Specialty Services	
15	Bethany Outreach (2014)- private-for-profit	NA	Secondary Care	Ri Bhoi
16	Holy Cross Health Centre Umsawkhan- - missionary hospital	NA		

Source: Office of the Chief Executive Officer, State Nodal Agency -Megha Health Insurance Scheme, Department of Health and Family Welfare, Government of Meghalaya

With respect to the location of Health Infrastructure, there is a concentration and growth of health facilities in the East Khasi Hills, where the state capital Shillong is located. Apart from the Civil Hospital, this district also has the advantage of other health facilities such as the Ganesh Das Hospital, which is the Maternal and Child Health Hospital, Meghalaya Institute of Mental Health and Neuro Sciences (MIMHANS), and the Reid Provincial Chest Hospital for tuberculosis. Majority of the private hospitals in Shillong provide multi-specialty and super-specialty services. Therefore, people from rural and remote villages have to travel to Shillong to seek advanced medical care.

4.1.4.2 National Rural Health Mission (NRHM) in Meghalaya:

Given the poor health indicators the state of Meghalaya was one of the high focus states as a part of the National Rural Health Mission which was implemented in the state since 2005-06. Given the objective of NRHM to provide access to quality public health services to the most vulnerable, poor and women and children there has been significant efforts directed towards improving the functioning of the rural health facilities (GoM, Undated). NRHM also resulted in increased allocation of funds for strengthening public health facilities and recruiting health

²⁵ Available at <https://www.holycrosshospitaltura.com/copy-of-about-us> accessed on 10th July 2022.

²⁶ Information collected from a health official during fieldwork

workers across different levels of care. There has been an increase in the appointment and deployment of health workers-medical and paramedical in all the health facilities. One of the most important changes visible was deployment of one ANM in every sub-centre. However, it is important to note that most of the appointments are contractual in nature. Efforts were also directed to ensure the functioning of health facilities 24*7 (ibid). Apart from this, new primary health centres and sub-centres were constructed in the state. With the deployment of ASHAs at the village level, there were intensive efforts undertaken with the community members to increase awareness about ante-natal care, institutional deliveries, and immunization of children (ibid).

Since the implementation of NRHM, there has been an increase in the utilization of OPD and indoor services, institutional delivery, and immunization services in Meghalaya (GoM, 2009). It also enabled the construction of new PHCs, and every Sub Centre was functional with at least one ANM where there was no one earlier. ASHAs have undertaken massive work at the community level, particularly creating awareness about antenatal care, immunization, and institutional deliveries (ibid). As of 2021, the state has a total of around 6,589 ASHAs in rural areas and around 195 ASHAs in urban areas (GoI, 2021).

There has also been an increase in institutional deliveries. For instance, it was only 29.7 percent in 2005-06 as per NFHS-3, which has at least increased to 58.1 in 2019-21 per NFHS-5. The TFR has declined from 3.8 in 2005-06 to 2.9 in 2019-21. However, there is a slow decline in comparison to other states in India. Meghalaya still has a long way to go to improve its health indicators.

4.1.4.3 Public Private Partnerships (PPPs) in Healthcare:

Further, to improve the functioning and performance of public health facilities in the state, the GoM has also undertaken Public Private Partnerships (PPPs) with NGOs to hand over the public health facilities to the NGOs. For instance, the Department of Health and Welfare initiated PPPs in Meghalaya with assistance from the National Health Mission (NHM). In this regard, the poor-functioning PHCs/CHCs were handed over to NGOs in 2009 after signing a Memorandum of Understanding (MoU) with the GoM. Altogether, 57 public health facilities have been outsourced in Meghalaya as on March 2017. These include 35 sub-centers, 19 primary health

centers, one state dispensary, and two community health centers.²⁷The five NGOs that signed the MoU with the Government of Meghalaya include- the Voluntary Health Association of Meghalaya (VHAM), Karuna Trust, Citizens Foundation, Jaintia Hills Development Society, and Bakdil.²⁸

The state's poor maternal and child health indicators, is reflected in the NFHS-5(2019-21) (Table 4.1). People still complain about the absence of doctors, medicines, equipment, overcrowding, and long waiting times in public health facilities (Oosterhoff et al., 2015). Further, the performance of the CHCs needs improvement given the poor status of human resources, particularly specialists at the CHC. Poor connectivity due to the absence of proper transportation also results in poor referrals (GoM, 2011).

Despite significant institutional reforms introduced by the NRHM, NRHM funds were also observed to be poorly utilized, given the low absorption capacity for various program funds provided under the NRHM (GoM, 2009). However, over the years, given the commitment of the state towards achieving universal health coverage (UHC), there have been tremendous efforts directed in the expansion of health infrastructure as well as the appointment of medical manpower across different health facilities to improve the health service delivery in the state.

4.1.4.4 Megha Health Insurance Scheme- Pradhan Mantri Jan Arogya Yojana (MHIS-PMJAY) in Meghalaya:

With the epidemiological transition, there was an increasing burden of infectious, communicable, and chronic illnesses, along with the high burden of poor maternal and child health indicators. Given the poorly functioning health facilities in certain remote districts given the unavailability of manpower and specialized services due to various reasons, people were forced to seek medical care in private health facilities in Shillong. Thus, accessing these facilities in urban areas resulted in high out-of-pocket expenditure for people in Meghalaya. Therefore, the GoM also introduced the Megha Health Insurance Scheme (MHIS) in 2011 with the objective of providing a universal health insurance scheme (UHS) to all residents in the State, including existing categories of Rashtriya Sawasthya Bima Yojana (RSBY)²⁹ beneficiaries but excluding State and

²⁷ Expression of Interest for Integrated Healthcare Project, Department of Health and Family Welfare, Government of Meghalaya. Available at the Directorate Health Services, Government of Meghalaya, accessed during fieldwork.

²⁸ Information collected from the Directorate of Health Services, Government of Meghalaya during fieldwork.

²⁹ Health Insurance Scheme launched by the Ministry of Labour and Employment, Government of India in 2008 Available at <https://www.india.gov.in/spotlight/rashtriya-swasthya-bima-yojana> accessed on 10th June 2022.

central government employees. This makes GoM the first in India to provide universal health coverage to its entire population, irrespective of socioeconomic status (Dutta et al., 2022).

Since 2018, the GoM has also implemented the Ayushman Bharat program and its two components of transformation of SHC into HWCs and the National Health Protection Scheme (NHPS) that ensures financial coverage for medical insurance up to 5 lakhs. As a part of these reforms, the MHIS has been integrated with the NHPS since 2018. As per the information available, as of 2021, the state has upgraded around 114 Primary Health Centres, 460 sub-centres, and 19 Urban Health Centres to HWCs (GoM, 2021b).

A recent development with regards to the health sector in Meghalaya is the implementation of the Meghalaya Health System Strengthening Project (MHSSP). The MHSSP is an agreement made between the GoM and the World Bank in 2021. The project was signed for a period of five years and aims to make quality healthcare accessible to the populations of Meghalaya.³⁰

4.1.4.5 Traditional Medicine in Meghalaya:

Further, traditional medicine is common and widely accepted among indigenous people (Albert et al., 2015). In rural areas of Meghalaya, “the indigenous tribal traditional healers” are the “largest group of healthcare providers outside the public sector” (Albert et al., 2019:160). There are different types of indigenous healers and practitioners in the state who use different medicinal plants and herbal medicines as well as through prayers and touch to diagnose and treat health problems (Albert et al., 2015). There is a higher utilization of tribal medicine in Meghalaya, especially for minor ailments such as diarrhoea, fever, and cough among people in rural areas. This is because awareness about tribal medicine is high in Meghalaya, and people believe in its efficacy.

4.2 Socio-Demographic and Economic Profile of West Jaintia Hills District:

West Jaintia Hills District is one of the twelve districts of Meghalaya. It is bounded in the North by Assam, South by Bangladesh and East Jaintia Hills District, East by Assam, and West by the East Khasi Hills District. As the name suggests, the district is very hilly and has deep, narrow, steep gorges and valleys. These valleys are carved out by the district's three important and

³⁰ Available at <https://theshillongtimes.com/2022/08/25/health-systems-strengthening-project-to-be-a-game-changer/> accessed on 20th April 2023.

major rivers: Umngot, Myntdu, and Myntang.³¹ It was on 31st July 2012 that West Jaintia Hills District came into existence after the erstwhile Jaintia Hills District was bifurcated into two, namely East and West Jaintia Hills.³² Jowai, located 64 km from Shillong, the state capital, is the most important town in the erstwhile Jaintia Hills district (Griffin et al., 1995). At present, Jowai is the headquarter of West Jaintia Hills. All the important institutions and hospitals are located in Jowai town. The district comprises 293 villages (Census of India, 2011).

There have been assumptions that the Jaintia might have migrated from Southeast Asia (Gassah, 1994). They might have started migrating from Mongolia via west Asia, along the Himalayas' foothills to Southeast Asia, then to their present habitat through Burma. As the Jaintias live a settled life, it is assumed that they might be among the earliest groups of migrants to northeast India (ibid).

About 2,70,352 people live in West Jaintia Hills District, of which 1,34,406 are males, and 1,35,946 are females (Census of India, 2011). As per the 2011 census of India, the district's literacy rate was 63.23%, while the state average was 74.43%. The Jaintia people who belong to the Scheduled Tribe category are the major inhabitant of Jaintia Hills District (Gassah, 1994).

The Jaintia mainly inhabits the Jaintia Hills. Jaintia is a “generic term” that “includes the Pnar or Synteng and other subgroups,” which form the major proportion of the district's population (Gassah, 1994:69). The Jaintias belong to the Proto-Austroloid Monkhmer race and have been indigenous in the hills for a long time. Other sub-tribes, known as the Wars, the Bhois, and the Biates, also inhabit the district (Passah & Sarma, 2002). People residing in the central region of West Jaintia Hills are called “Pnars” by those living in the southern and northern regions. However, the “Pnars” called those living in southern and northern regions “Wars” and “Bhois.” The Pnars, Wars, and the Bhois are collectively known as “Jaintias” or “Syntengs” (Passah & Sarma, 2002: xi). The predominant language spoken by the Pnars or Syntengs or the Khasis of the eastern plateau is known as Pnar (Griffin et al., 1995). Although the Jaintia speaks their language and dialects, they do not have their script. In primary and middle schools, Khasi is used as the vernacular language because the Jaintia language and Pnar are yet to develop and replace Khasi as a vernacular (Gassah, 1994). The Jaintias believe their religion is God-given and not founded by

³¹ District Profile of West Jaintia Hills District. Available at <https://westjaintiahills.gov.in/document-category/district-profile/> accessed on 10th July 2020.

³² Same as footnote number 31

man (Griffin et al., 1995:23). According to them, God is omnipotent, omnipresent, and omniscient. With the introduction of Christianity in the mid-nineteenth century, there has been a significant change in the social structure of the tribal society in Meghalaya (ibid). Nevertheless, these traditional religious beliefs and social structures persist even today.

The main occupation of the people in the district is agriculture, with approximately 70% of the people depend on it for their livelihood.³³ The two major food crops grown throughout the district are rice and maize, and the important cash crops include potato, ginger, garlic, and turmeric. Tomato, cabbage, and cauliflower are produced in significant quantities in the district.³⁴ Apart from vegetables, people also grow and sell oranges, pineapples, jackfruit, plums, pear, and peaches. Arecanut and betel vines are also grown in large quantities in the warmer region of the district, such as Dawki, located in the Amlarem Block. Wet and dry rice, varieties of millets, maize, potatoes, varieties of fruits, betel nuts and leaves, bay leaves, and vegetables are the staple crops grown by the Jaintias). Apart from agriculture, the other important occupation of the people in the district is Sericulture which is the rearing of silkworms.³⁵

According to NFHS-5 (2019-21), in West Jaintia Hills District about 75.4 percent of the population lives in households with electricity. About 70.6 percent live in households with improved drinking-water sources. The percentage of the population living in households that used an improved sanitation facility was 75.1 percent. About 20.7 percent of households used clean fuel for cooking. The percentage of households with any usual member covered under a health insurance or financing scheme was 65.6 percent (IIPS & ICF, 2021). There is however limited study that explores the impact of the socio-economic status on the health of the population in Meghalaya and specially their impact on the women's health.

4.3 Methodology:

4.3.1 Structure of the Study:

Fieldwork for the present study was undertaken at multiple levels, from the individual and household levels to the state level. At the individual level, interviews with women were conducted

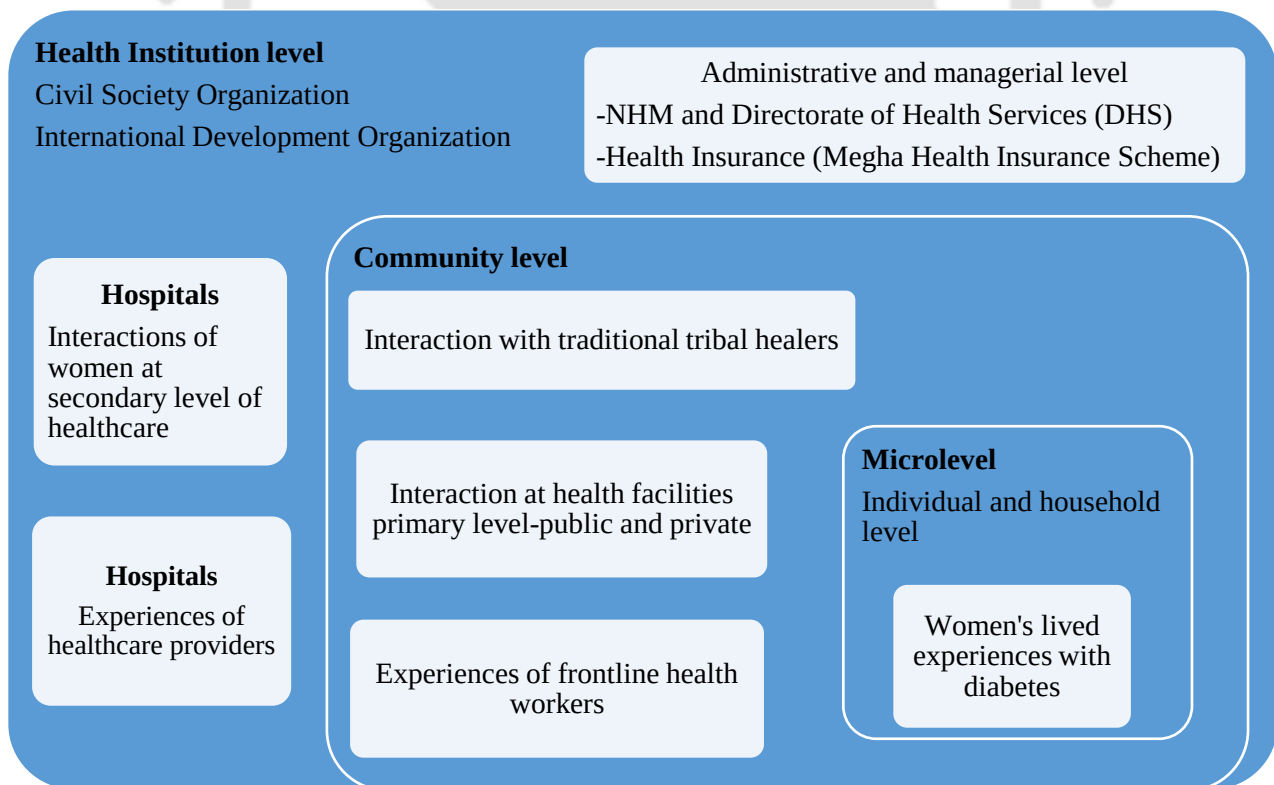
³³ District Profile of West Jaintia Hills District. Available at <https://westjaintiahills.gov.in/document-category/district-profile/> accessed on 10th July 2020.

³⁴ Same as footnote number 33

³⁵ Same as footnote number 33

in their villages. At the community level, interviews were conducted with traditional tribal healers and frontline healthcare providers to understand their interactions with the women. Participant observations were also made to understand women's interactions with the providers in these settings. All the phenomena and processes at the local level, such as health service provision, are determined by other factors, such as government policies and programs. Therefore, another level explored in the study is the health institution level. Further, views and perspectives of representative's Civil Society and International Development Organizations associated with health were also explored. At the health institution level, fieldwork was carried out at public and private health facilities. In addition, fieldwork was undertaken at the District Health Administration Office and the State Health Directorate (Directorate of Health Services) responsible for implementing government healthcare policies and programs. Government healthcare policies and programs determine the provisioning of healthcare services at public health facilities. Figure 3.3 shows the multiple levels explored and their interactions to achieve the study's objectives.

Figure 4.2 Structure of the study



Source: Figure developed based on fieldwork

4.3.2 Conducting Fieldwork and Data Collection: Tools and Techniques:

The inquiry frameworks selected for the study encompass – ethnography, narrative inquiry, and a case study approach. Hence, the present study integrates the three inquiry frameworks commonly adopted in qualitative research. Karen O'Reilly (2005), a sociologist, argues that different techniques need to be adopted while collecting information from different groups of people and in different situations. These techniques may vary from “structured to unstructured, formal to casual, predetermined to open-ended, and free-floating to fixed topics” (O'Reilly, 2005: 126).

Ethnography is an important approach in sociological and anthropological research whose main objective is to study human observations in their natural setting (Berreman, 2004). Ethnography involves systematically applying a range of methods to understand people's everyday lives without compromising its scientific rigor (O'Reilly, 2005:1). In medical anthropology, “data collection methods fall into three broad categories: participant observation, systematic observation, and interview methods” (Gravlee, 2011:81). Of the three, participant observation is the foundation of data collection in ethnographical research, as researchers commonly adopt it (Berreman, 2004; Gravlee, 2011). Participant observation is meant for the more or less purely observational procedures carried out by ethnographers or field researchers (Bryman, 1988). Participant observation has been used widely in health research.

The other inquiry framework adopted for the present study is narrative inquiry. “Narrative inquiry focuses on understanding lived experiences, often based on the temporal or episodic stories of a small number of individuals representing a case grouping of interest” (Shelton et al., 2022:42). Narrative inquiry explores an individual's life through their stories. This approach is widely used in anthropology (Shelton et al., 2022). In the present study, illness experiences were explored through narrative inquiry, and data for the same was collected through in-depth interviews and a review of medical records maintained by the patients.

The case study approach is another inquiry framework adopted for the study. Robert K. Yin (2003:13) defined a case study as “an empirical inquiry that investigates a contemporary phenomenon within its real-life context.” Case studies are a design of inquiry widely adopted across different disciplines and mainly for evaluation (Creswell, 2014). Researchers usually

develop an in-depth case analysis, especially on an individual or group of individuals, a program, event, activity, or process, where different data collection methods are being adopted for a sustained period (Creswell, 2014). In-depth interviews, participant observation, and textual and content analysis of reports and records are the main data collection methods in the case study (Yin, 2003; Shelton et al., 2022). An in-depth case study of the implementation of the national program for preventing and controlling diabetes has also been undertaken in the present research work.

Information such as records, reports, and studies on Meghalaya, its people, culture, and health system were also collected from different offices and libraries. For this, I visited libraries in Shillong, such as State Central Library, Martin Luther Christian University Library, and North Eastern Hills University Library. Jawaharlal Nehru University library was also visited to review literature, access books and records on Meghalaya. Table 3.11 below briefly summarizes fieldwork phases and different data collection methods applied in different settings with different categories of respondents.

Table 4.6 Summary fieldwork phases and data collection methods adopted

Phases of fieldwork	Duration	Settings	Respondents
Pilot Phase	13 th April to 31 st May 2020	District Medical and Health Officer's Office Field visits to JCH, Ialong, and Dr. Norman Tunnel Hospital	Officers, Program Managers Five women from the community
Phase 1	October 2020	District Medical and Health Officer's Office District NCD cell	District Nodal Officer, District Program Manager, NHM, Finance-cum-Logistic Consultant, District Coordinator, Data Entry Operator
	November 2020	JCH, Ialong	Medicine Specialist, Medical Officer, Ayurvedic Physician, Nursing Superintendent, Staff Nurses, Pharmacists, Laboratory Technician, Data Entry Operator, and Women with diabetes seeking treatment from the hospital.
	December 2020-January 2021	Nartiang PHC and its six HWCs	Nartiang PHC: Senior Medical and Health Officer In charge, Medical Officer, Ayurvedic Physician, Staff Nurses, Laboratory Technicians, Pharmacists, and Women with Diabetes seeking care from the PHC and HWCs. HWCs: MLHPs, ANMs, and ASHAs
Phase 2	May to August 2021	Nartiang PHC and its Six HWCs and 15 Villages under the HWCs	Nartiang PHC: Medical Officer, Ayurvedic Physician, Staff Nurses, Laboratory Technicians, Pharmacists HWCs: MLHPs, ANMs, and ASHAs Village Headmen and Women with Diabetes Private Hospitals in Jowai (Medicine Specialists and Staff Nurses Private Clinic in Ummulong, Traditional Tribal Healers

Phase 3	June to July 2022	Ummulong CHC and its six HWCs and 5 Villages under the HWCs Private Hospitals in Shillong	Ummulong CHC: Medical Officer, Ayurvedic Physician, Staff Nurses HWCs: MLHPs, ANMs, and ASHAs Women with diabetes, Traditional Tribal Healers Private Hospitals in Shillong (Medicine Specialists, Obstetrician and gynecologists, Diabetes educators, Dietitian, Ayushman Mitra)
Additional Fieldwork	August 2022	Directorate of Health Services (DHS), Shillong District Program Management Unit, MHIS State Nodal Agency, Megha Health Insurance Scheme	State Nodal Officer, NCD program, State Program Officer, State Program Coordinator, State Finance-cum-Logistic Consultant. District Program Manager, MHIS, Nodal Officer, MHIS, JCH, Ialong, Ayushman Mitra State Manager, Claims Officer, and Medical Officer
		In-depth interviews with representatives from the Civil Society Organization and International Development Organization Visits to various University libraries in Shillong as part of the literature review process.	

The rationale behind conducting fieldwork in phases is because of the fact that the present study is exploratory in nature. The phased approach has been adopted by other social science researchers as well (Dutta, 2022). The purpose of conducting the pilot fieldwork is to familiarize oneself with the study settings and to build network. Moreover, pilot phase is necessary because literature relevant to the study are limited. Further, learnings from the pilot phase helps in modification of the data collection tools, which are crucial for the major phases of fieldwork.

4.3.2.1 Health Facility Level:

Apart from participant observation, semi-structured interviews, at the health facilities was also undertaken. Data was collected through informal conversations based on daily interactions with the staff such as doctors, nurses, and laboratory technicians from all the health facilities. Questions related to health record keeping and reporting were also asked. Given their increased work burden during COVID-19, conversing with them as they worked was much more convenient. Hence, they were more willing to talk while working than disturbing them by asking for a separate interview. The semi-structured interview guide was developed separately for different categories of healthcare professionals. The list of semi-structured interview guides for health care providers was enclosed as Annexure 3. At the health facilities, women with diabetes were also identified with the help of healthcare providers. Telephonic interviews were conducted with them. This was done because there was space constraint at health facilities and it was difficult to maintain physical distance as part of the COVID-19 protocol while taking the interview.

4.3.2.2 Community Level:

For respondents identified from the community and the ten caregivers, interviews were conducted at the respondents' homes while following the COVID-19 protocol of sitting outdoors, wearing masks, and maintaining a physical distance. Before conducting the interviews, I read and explained the consent form to them, and the most common response was: *lada ymtoh iwa pher te hoi bait se* (if it is not a problem, then it is all right). Initially they were apprehensive about the interviews, but I assured them of confidentiality. The in-depth interviews were conducted in the Pnar language and were audio recorded. The recorded interviews were transcribed and later translated into English. Follow-up interviews were conducted through telephonic conversation and subsequent fieldwork. An interview guide developed in English but translated into Pnar language

was used while conducting the interviews. Interviews with primary caregivers were also conducted to understand their challenges. The interviews lasted 45-60 minutes. The semi-structured interview guide is enclosed as Annexure 4 for women respondents and caregivers as Annexure 5.

To understand more about the lives of the people in villages during the COVID-19 pandemic, Five Focus Group Discussions (FGDs) were also conducted during fieldwork between June- August 2022 at the HWCs with men and women, mainly in the age group of 30 years and above. FGD guide for the same was enclosed as Annexure 6. During this period, COVID-19 restrictions were lifted as the number of COVID-19 cases had reduced drastically in the State and the district. Analysis of local media such as “*U Nongsain Hima*” “*Rupang*,” “*Wyrta*” on how the COVID-19 pandemic and COVID-19 vaccine were reported during the period between May-June 2021 was also conducted. In-depth interviews with representatives of the Civil Society Organization (CSO) and International Development organization (IDO) were also undertaken to gain their perspectives. The semi-structured interview guide is enclosed in Annexures 7 and 8.

4.3.2.3 Entering the Field: Access to Healthcare Settings, Villages and Respondents:

Access, time, learning the language, participating and observing, note taking, diaries, and memoranda are crucial for collecting data during ethnographic fieldwork (Reilly, 2005). Gaining access to public institutions was considered a herculean task (Abrams, 1988). It is time-consuming and challenging, but participant access is crucial for ethnographic research (Roitenberg, 2022). Ethnography in hospital settings is usually considered unwelcome as the hospital authority fears the hospital’s image will be “tarnished” on publication as they perceive the ethnographic reports as “unfair” or too “critical” (Inhorn, 2004:2096). However, ethnography in healthcare settings has been conducted widely (Nightingale et al., 2014; Ruddock, 2017; Roitenberg, 2022; Palinkas et al., 2022). Most ethnographic accounts documented that access to their study setting is due to their contacts with the “gatekeepers” (Van Maanen, 2011; Ruddock, 2017; Roitenberg, 2022). Gatekeepers, as considered by Roitenberg, (2021), have the power to grant access to the less powerful individuals and consist of many levels and hierarchies.

For the present study, getting access to health facilities was a major task and there were number of gatekeepers. To begin with I sought the permission by submitting an official letter about my doctoral research to gain access to public health facilities to the District Medical and Health

Officer (DM&HO) and then the JCH, Ialong Medical Superintendent for fieldwork. For a visit to the SHCs/HWCs, permission was granted by the Senior Medical and Health Officer of Nartiang PHC. To gain access to the State NCD cell, I sought the permission of the Mission Director, National Health Mission, Meghalaya.

After various rounds of iterations with concerned government officials, permission for the study was granted by the DM&HO on 5th October 2021. The permission letter of the study was also sent to the different health facilities selected for the study on the same date.

The Mission Director granted the permission to collect data from officials of the State NCD cell, State Nodal Agency, Megha Health Insurance Scheme, DM&HO's office, and all public health facilities in West Jaintia Hills District. During the second phase of fieldwork in 2021, due to COVID-19 pandemic, there were restrictions on visiting the villages. However, for the study, I requested the help of the Senior Medical and Health Officer In charge of Nartiang PHC to gain access to the villages under this PHC. In this regard, a letter from the Senior Medical and Health Officer In charge of Nartiang PHC to the village headmen requesting permission to conduct fieldwork in their village was written. The permission letter is enclosed as Annexure 9, where I explained the purpose of the study. The letter was written in Khasi language. Before accessing the community, I first met the village headmen and handed over the letter for permission to them. All village headmen permitted me to undertake fieldwork in their respective villages. In the third phase in 2022, fieldwork was carried out with the ASHAs and MLHPs as part of their routine house-to-house visit activity.

4.3.2.4 Self-Reflexivity:

As discussed earlier, visit and entry into the villages was made through the village headmen during the COVID-19 pandemic. Being a part of the community, I am studying and understanding; I shared similar social and cultural practices with the people with whom I interacted and discussed. Like them, I also speak the same language, which is Pnar. In the villages, when community members and women in particular knew that I belonged to Ummulong village, they said *pra I hi hanpaya* which means we are the same. People in the villages where fieldwork was undertaken knew Ummulong village quite well. They said, “for us, Ummulong is a town.” It is central to their economic activities given its location in the National Highway Number Six, whose North end is

in Assam and South end is in Mizoram. They often visited Ummulong village for many purposes, such as buying essential commodities and selling agricultural produce. They also came to seek treatment, as many private clinics are available in Ummulong village. In most of the villages visited, private clinics are almost absent. As people in the villages identify me as one of them, my presence was not strange. Therefore, I could easily build a rapport with them. Further, frontline health workers introduced me to them as “nurse who is undergoing further study.” They welcomed me wholeheartedly because I asked them questions about their health status which no one had done before with them.

Concerning my identity, the intersection of my age, educational and economic status, alone does not determine the way I interacted with women having limited education, who are elderly, and from low-income group. Other factors such as my family background and place of residence (which is in rural), that shaped my personality and made it easier for me to interact with women. Throughout the study and even in later stages of my career, I will always identify myself with them. But the only differences are that, I am privileged to get the chance to pursue higher education and this privilege is crucial not only for me but for them as well. It depends on the way we approached the people- whether we identify ourselves with them or hold on to our identity that is being acquired gradually. Having a nursing qualification made access to the healthcare settings much easier- as the researcher is also known to the district health officials and even to the healthcare providers especially at the public health facilities. It indeed proved to be a vantage point for the researcher. Similarly, at the community, the researcher being a Pnar, a woman and at the same time seen as one of the healthcare providers, it was much easier to gain the trust of the community members. The detail about my entry to the study villages is enclosed as Annexure 10.

4.3.3 Study Settings:

Given the outbreak of the COVID-19 pandemic, the West Jaintia Hills District was selected conveniently as I belong to this district. Moreover, the district has been under-researched, especially with respect to health of the population. There are several studies on understanding the social science perspective of diabetes in different states of India, but in the northeast in general and Meghalaya in particular such studies are limited and almost absent.

West Jaintia Hills District has three Community Rural and Development Blocks (C&RD)- Amlarem, Laskein, and Thadlaskein. As per the 2011 census of India, the total population of Amlarem, Laskein, and Thadlaskein blocks was 43, 552; 89,965, and 1,36,835, respectively. Out of the three blocks, Thadlaskein having the largest population, was selected for the study. The block was also selected because it has one National Quality Assurance Standard (NQAS)³⁶ certified PHC- known as Nartiang PHC. Ummulong CHC and its HWCs in the block were also selected for the study.³⁷ Other important health offices for the study are located within this block. These include the District Medical & Health Officer's (DM&HO) office, the two private hospitals, Dr. Norman Tunnel Hospital and Woodland Hospital, and the Jowai Civil Hospital (JCH), Ialong, which is the District Hospital. The DM&HO's office is in Jowai town, which is the District Headquarters. Similarly, Dr. Norman Tunnel Hospital, established by the Welsh Mission during colonial times, is in Jowai town. Woodland Hospital, a private hospital inaugurated in September 2020, is located in Sabahmuswang village, 15 minutes from Jowai town.

4.3.3.1 Selection of Health Facilities for the Study:

Fieldwork was carried out at different levels of public health facilities and also in private health facilities.

1. Public Health Facilities:

West Jaintia Hills District has three Community Health Centres, 12 Primary Health Centres, 46 Sub centres, 2 Urban Health centres, and one dispensary.³⁸ In the West Jaintia Hills

³⁶ The NQAS was developed for public health facilities to maintain specific requirements and global best practices. There are eight areas of concern in NQAS: service provision, patient rights, inputs, support services, clinical care, infection control, quality management, and outcome. The purpose of these standards is for providers to assess the quality of their facility and accordingly improve it to meet the pre-defined standards, thereby getting the certification (Available at <https://qps.nhsrindia.org/national-quality-assurance-standards> Accessed on 12th June 2020).

³⁷ As per the information shared by the District Health Official, Ummulong CHC was initially inaugurated as a PHC on 18th September 1986, catering to six sub-centres. On the 3rd of December 2001, Ummulong PHC was upgraded to "Ummulong Hospital" as per the foundation stone laid in Ummulong CHC [its current official name]. All the CHCs in the district has their catchment area, and they did not function as standalone CHCs. In these catchment areas, sub-centers were established and made to report to the concerned CHC. These CHCs do not function as First Referral Unit (FRU) due to the absence of specialists. If the CHC has to function as a standalone facility, then new PHCs need to be established to cater to those sub-centres covered by these CHCs, which is financially impossible. For instance, if an Ummulong CHC has to function as an FRU, a new PHC needs to be established to remove the CHC's role, catering to these sub-centres.

³⁸Information collected during fieldwork from the District Health Official.

district, the MHIS-PMJAY was implemented on 1st February 2019, and about 64.1 percent of households have been enrolled in the scheme.³⁹ The public health facilities visited for fieldwork include JCH, Ialong (District Hospital), Ummulong CHC, Nartiang PHC, and their HWCs (Table 3.6).

Table 4.7 HWCs visited under Nartiang PHC and Ummulong CHC

Public Health Facilities	Health Wellness Centres (HWCs)
Nartiang PHC	• Nongjingi HWC, • Mynkrem HWC, • Thadbamon HWC, • Rakabah HWC, • Mynsgad HWC and • Nonglatem HWC
Ummulong CHC	• Wahiajer HWC, • Moodymmai HWC, • Tyrchang HWC, • Bamkamar HWC, • Sophoh HWC and • Nongkhroh HWC

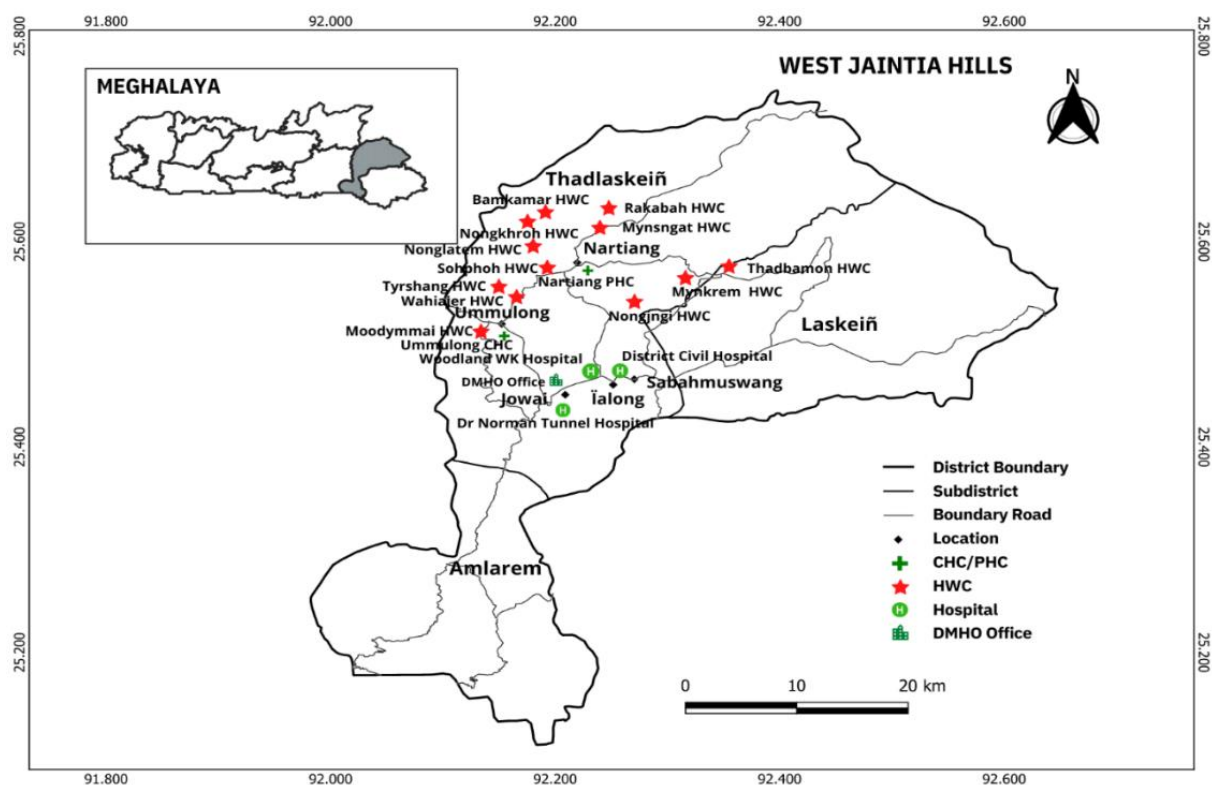
Source: Compiled based on fieldwork

2. Private Health Facilities:

Since private health facilities form a significant source of healthcare service provision, visits to major private hospitals within and outside the district were also made. These facilities were also accessed by women living with diabetes in the study villages. The private hospitals visited include those in Jowai and Shillong. In Jowai, the private hospital visited includes – Dr. Norman Tunnel Hospital and Woodland Hospital. In Shillong, the popular hospitals among the respondents were - Woodland Hospital, Bethany Hospital, Nazareth Hospital, Supercare Hospital, and Dr. H.G. Robert Hospital. Field visits were also made to these hospitals, except one, as the Medical Superintendent did not grant permission for the study. In addition, visits were made to private allopathic clinics of doctors and traditional tribal healers. Figure 3.4 shows the map of public and private health facilities visited for fieldwork.

³⁹ Information collected during fieldwork from the District Health Official.

Figure 4.3 Map showing the location of health facilities visited for fieldwork in West Jaintia Hills



Source: Prepared using qGIS software

4.3.3.2 Selection of Healthcare Officials and Healthcare Providers:

Healthcare providers interviewed were selected using purposive sampling, a widely used qualitative research technique. Purposive sampling is a technique in which individuals with rich information about a topic of interest are identified as respondents (Palinkas et al., 2015). Table 3.7 below summarizes the gender-wise distribution of different categories of healthcare service providers interviewed at public and private health facilities.

Table 4.8 Gender-wise distribution of health officials and healthcare providers interviewed at public and private health facilities

Sl. No.	Category of healthcare providers	Men		Women		Total	
		N	%	N	%	N	%
1.	Government health officials (Includes officers and program managers at the state and district levels)	11	44	5	7.46	16	17.39
2.	Specialists and Medical Officers	8	32	4	5.97	12	13.04
3.	Mid-Level Health Care Providers (MLHPs)	1	4	9	13.43	10	10.86
4.	Dieticians	0	0	5	7.46	5	5.43
5.	Staff Nurses	0	0	7	10.44	7	7.6
6.	ANMs	0	0	14	20.89	14	15.21
7.	Paramedical Staff (Laboratory Technicians and Pharmacists)	1	4	4	5.97	5	5.43
8.	Traditional Tribal Healers and Informal Providers	4	16	4	5.97	8	8.69
9.	ASHAs	0	0	15	22.38	15	16.3
	Total	25	100	67	100	92	100

Source: Compiled from fieldnotes on health facilities visited in West Jaintia District and State Office

I interviewed about 92 health officials and healthcare providers across different levels and types of health institutions. In addition, one representative from the Civil Society Organizations (CSOs) and one from International Development Organization (IDOs) working in the area of health were also interviewed. Women with diabetes constituted one of the most important respondents for the study. Their process of identification is discussed as follows.

4.3.3.3 Identification of Women Living with Diabetes:

Using purposive sampling, women respondents were selected from the District Hospital, Primary Health Centre (PHC), and Health and Wellness Centres (HWCs). Given that the study was conducted during the first and second wave of the COVID-19 pandemic, only a few people living with diabetes had accessed these facilities. There was fear among people as many were not visiting the facilities. Therefore, for additional respondents, frontline health workers, especially Mid-Level Healthcare Providers (MLHPs), were approached and requested for the list of people living with diabetes in villages covered by these health facilities. Only those women living with diabetes and which was also confirmed through their medical records were included. Seventy-one

women participated in the present study (Table 4.8). Out of the 71 women, nine of them do not live in the study villages but were identified from the district hospital. Respondents identified at the facility level will help understand the interaction that happens at different levels of the study settings. As the unit of analysis is women, and I needed to understand the social determinants of diabetes, so I need to collect the information of the women who attended the district hospital. Ideally, people from the villages are supposed to follow the referral chain, but due to the many barriers which exist within the environment they live; therefore, they have to move outside. This is important as it is a part of tracking people with diabetes and their sources of treatment.

I also interviewed about ten primary caregivers of elderly women who have difficulties communicating with me clearly due to hearing difficulties or were unable to recall their illness history. All of the primary caregivers were women. In addition, group discussions with other community members were also undertaken to understand the general perception of NCDs, COVID-19, and vaccines for COVID-19.

Table 4.9 Respondents-Women living with diabetes and caregivers

Sl. No.	Facilities where Women Respondents were Identified	Women
1	From the community through HWCs/SCs and with the help of Community Health Workers	58
2	Primary Health Centre	3
3	NCD Clinic, District Hospital	6
4	Ayurvedic Clinic, District Hospital	2
5	Inpatient ward, District Hospital	2
Total Women Respondents		71
1	Caregivers of Diabetes Patients (family members, friends, etc.)	10
Total Caregiver's		81

Source: Data compiled from fieldwork

Besides health facilities, fieldwork was also undertaken in 20 villages across Thadlaskein block in West Jaintia Hills District, Meghalaya. It became clear from the field findings that the Pnar tribe predominantly inhabits this district. The list of the villages visited is enclosed as Annexure 2. For data collection in the villages of Meghalaya, obtaining permission from the village headmen becomes extremely important. This makes the data collection process a little easier, and people were willing to share information without hesitation. The background characteristics of the village headmen interviewed are shown in Table 4.9 below.

Table 4.10 Background characteristics of village headmen interviewed from select villages

Sl. No.	Village	Age	Sex	Religion	Education
1	V1	58	M	Indigenous tribal religion blend with Hinduism	Class X
2	V2	26	M	Indigenous tribal religion	12 passed
3	V3	36	M	Indigenous tribal religion	Matric passed
4	V4	33	M	Christian (Roman Catholic)	Class IV
5	V5	43	M	Christian (Roman Catholic)	12 passed

Source: Data compiled from fieldwork

Women living with diabetes in villages covered by HWCs under Nartiang PHC and Ummulong CHC were selected as respondents for the present study. Villages in Meghalaya are widely scattered and located in difficult geographical terrain, making accessibility to health services extremely challenging (Nayak & Thomas, 2007). Typically, a village in Meghalaya constitutes a cluster of houses built on “slopes of hills and hillocks” (Roy, 1994:10). As Meghalaya comes under Schedule Sixth of India’s Constitution, Autonomous District Councils are an important institution of governance. Apart from this there are also traditional system of governance which co-exists along with modern political institutions. Thus, the villages of Meghalaya have Village Durbars. They perform the same functions as the Panchayats (Thomas, 2004). The village headmen head the Village Durbars; as the name suggests, all the village heads are men. They are known as ‘*rangbah chnong*’ in the Pnar language, meaning ‘*rangbah*’ means someone who is an elder, and ‘*chnong*’ means village or place where one lives (Oosterhoff et al., 2015). Village headmen are elected through adult suffrage once in three years. The presence of the *Doloi* or Traditional Chief, is required during the voting day to avoid misunderstanding.⁴⁰

Table 4.10 below briefly describes a few villages visited to understand the variation in their demographic structure. All the 20 villages visited are in different stages or levels of development. For instance, of the 20 villages, Ummulong is the most urbanized or is undergoing transition. Due to its strategic location on the National Highway Six, it has much easier access to the district headquarters in Jowai located 13 kms away. Further, travel to Shillong, which is 51kms away from Ummulong is also easier. Local vehicles ply throughout the day. The village has more than ten schools of which four are up to secondary level. It also has one college. Adjacent to Ummulong,

⁴⁰ Information collected through in-depth interviews with one of the village headmen during fieldwork.

is Wahiajer village, where one of the largest weekly markets, known as *Iawpynsin* is being held. Ummulong village has three banks and two Automated Teller Machines (ATMs) (Muksor, 2020). There are also several wholesale groceries stores and pharmacies. There are more than ten private clinics of different systems of medicine, such as Allopathic, Homeopathic, and Ayurvedic. Due to these facilities, most people in the other 19 villages come regularly to access these services. Nartiang village is another village undergoing a transition, as evidenced by the increase in houses, shops, schools, and private clinics. However, in contrast these facilities are almost absent in the remote villages such as Ionglwit, Lumtrep, Takhniang, and the other 15 villages.

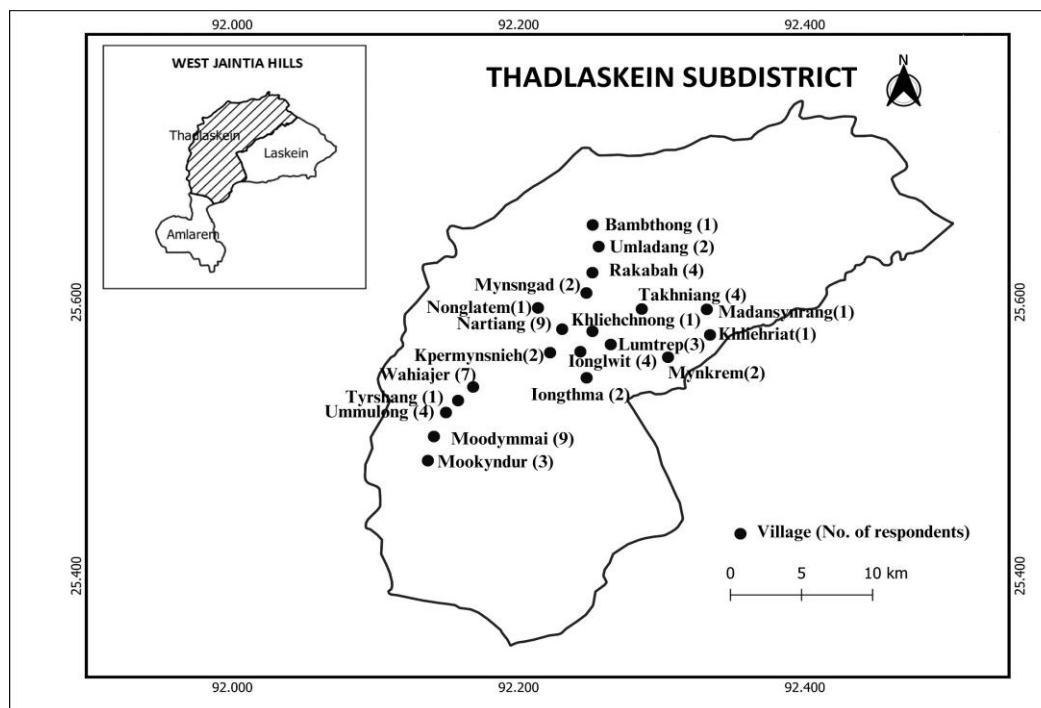
Table 4.11 Demographic structure of select villages representing other 15 villages

(Census 2011)	Ummulong	Nartiang	Mynsngad	Ionglwit	Lumtrep	Takhniang
Total House Hold	514	544	142	265	64	58
Total population	3220	3106	916	2039	651	355
Male	1565	1463	433	1015	331	186
Female	1655	1643	483	1024	320	169
Literacy rate	77.54	58.59%	67.13	43.73	47.88	32.95
Male	74.86	56.56%	61.31	38.38	42.28	28.57
Female	80.01	60.42%	72.25	49.09	53.41	37.40
Total workers	1083	1304	250	644	298	169
Male	670	672	168	398	149	87
Female	413	632	82	246	149	82
Main worker (Employment or Earning more than 6 Months)	915	1110	146	485	227	19
Marginal worker (providing livelihood for less than six months)	168	194	104	159	71	150

Source: District Census Handbook, 2011

Figure 4.4 below shows the number of women respondents with diabetes I interviewed in each village visited. The map clearly shows that more populated villages have more people with diabetes. It may also be mentioned that these villages, especially Nartiang, Wahiajer, and Moodymmmai, are undergoing a transition in terms of an increase in the number of shops and a change in food habits and transportation. Similar is the case with Ummulong, but only four women with diabetes were interviewed as Ummulong was the last village visited, and by this stage, required information from the field has already been collected.

Figure 4.4 Map showing the number of respondents in each of the 20 villages visited in Thadlaskein block, West Jaintia Hills District



Source: Prepared using qGIS software

4.3.4 Timeline for the Study:

Fieldwork for the study was carried out between October 2020 to August 2022 and divided into three phases. Before the three phases of major fieldwork, a pilot study was conducted from 13th April to 31st May 2020. The first phase was conducted in public health facilities between October 2020 and January 2021. The second phase, between May and August 2021, was conducted across fifteen villages. The third phase was conducted between June and July 2022 in private health facilities and the five villages. However, additional fieldwork was again conducted in August 2022 at the State Health Directorate.

I faced some challenges during the first phase of fieldwork, which began in October 2020. Although, during this time, the COVID-19 pandemic lockdown has been gradually lifted, healthcare providers at the health facilities were busy with COVID-19 screening tests, and only a few patients visited the public health facilities. Therefore, I decided to take in-depth interviews with women with diabetes in their homes while strictly following the COVID-19 protocol. In the

second phase in 2021, which is largely community-based, I encountered a few challenges due to restrictions imposed by the district administration, given the second wave of the pandemic. Initially, I could begin fieldwork on the 10th of May 2021, but on the 22nd of May 2021, the District Administration imposed a complete lockdown. Since vehicles were not allowed to ply on the road during this time, therefore, I could not visit the field and instead reviewed literature which included books and research articles. Further, transcription of recorded interviews was also undertaken during this period. I resumed fieldwork on the 28th of June 2021 after the District Administration permitted the local vehicle to ply on the road and after consulting the Senior Medical and Health Officer in charge of the Nartiang PHC. The village visit was made after the headmen granted permission to access the community. There were no more barriers to fieldwork in the third and additional phase as the COVID-19 pandemic lockdown was completely lifted.

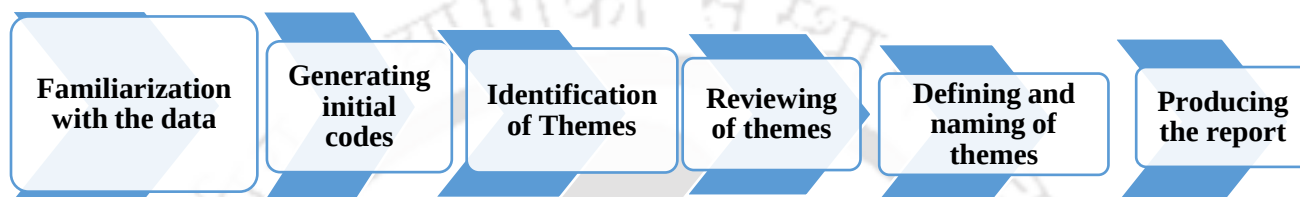
4.3.5 Data Analysis:

Participant Observations contributed immensely to the data collection process through the field notes, which were also analyzed to identify themes and develop codes. The training modules of the ANMs and ASHAs were also reviewed to understand the gaps in the program's implementation process.

Interview scripts of health officials and healthcare providers written directly after the interview were used for thematic analysis. The audio-recorded interviews of women with diabetes were transcribed verbatim in Pnar language and translated into English. The transcripts of the seventy-one women were read and discussed. The transcripts were reviewed, and gaps were identified for further fieldwork. The interview transcripts of each woman were imported into computer-assisted qualitative data analysis software (CAQDAS) or NVivo version 12 software (Dhakal, 2022). Each transcript was read and coded, the first step of qualitative data analysis (ibid)). After all the transcripts had been coded, the code book was generated from the NVivo software. The code book was then exported to Microsoft Office Word, where similar codes from the transcripts were grouped into different categories. The code book was read repeatedly to ensure consistency. The categories or sub-themes were then organized into overarching themes. The overarching themes were identified and presented as findings in the analysis chapters in the present study.

Thematic analysis was carried out in line with the six-step process identified by Kiger and Varpio (2020), as shown in Figure 4.5. These six steps include – “familiarization with the data, generation of initial codes, identification of themes, reviewing of themes, defining and naming themes, and producing the report” (Kiger & Varpio, 2020: 4-5).

Figure 4.5 Data analysis process



Source: Adapted from the work of Kiger and Varpio (2020)

The study was conducted using multiple methods of data collection. Findings from participant observations and in-depth interviews were triangulated with field notes to ensure the credibility of the research. This is further supplemented with secondary data sources such as government documents, guidelines, and reports.

4.3.6 Ethical Consideration:

Fieldwork for the study was carried out per the guidelines for conducting research during the pandemic. According to a Guidance Note by United Nations (UN) Women, it is during times such as a COVID-19 pandemic that research is most important, especially when it comes to long-term illnesses like diabetes. The document provided guidelines on how a researcher should conduct the research effectively. As stated in the guidance note, narrative inquiry can also be adopted as method of data collection during pandemic, while considering the importance of maintaining social distance. Among others, the two guidelines they referred to include- Ethical standards for research during public health emergencies: Distilling existing guidance to support COVID-19 Research and

Development by WHO and The Best Laid Plans...Qualitative Research Design During COVID-19, Published on March 2020 by Ravitch, Sharon M.⁴¹

Adherence to protocols as issued by the District Administration was strictly followed, including wearing a mask, maintaining physical distancing, and frequently using hand sanitizer. Before conducting the interview, women were explained the purpose of the study and their consent was taken verbally. This is because in most cases, and women could not read the written consent form. For health officials depending on their convenience both verbal and written consent was obtained before conducting the interviews. A copy of the consent form is enclosed as Annexures 11 and 12 for women respondents and healthcare professionals, respectively. Names of respondents and health facilities have been changed wherever necessary to maintain their confidentiality. Ethical clearance for the study was also obtained from the Institute Human Ethics Committee (IHEC) of Indian Institute of Technology Guwahati.

Permission for the study was sought from the Mission Director of the National Health Mission, Meghalaya on the condition that anonymity of women is maintained, which is why frontline workers were able to share the details of women with diabetes. In the present study, as medical interventions are not conducted to confirm the diagnosis of women, therefore we have to collect the information from frontline healthcare providers who maintained a line list of people medically diagnosed with diabetes. The challenge in conducting a community-based study, particularly in remote villages is the fact that information about their illness history is not available to women. Therefore, accessing proper information about the respondents from frontline healthcare providers was necessary as they are the crucial source of health-related information in the community. A snowball sampling was also adopted to identify women living with diabetes in the study villages. Further, as there is not much stigma involved for this disease in comparison to other diseases like HIV/TB, therefore it is easier for people to share their diagnosis of diabetes. Moreover, in the present study, women were assured that the

⁴¹Available at <https://africa.unwomen.org/sites/default/files/Field%20Office%20Africa/Attachments/Publications/2020/GUIDANCE%20NOTE%20FOR%20CONDUCTING%20QUALITATIVE%20RESEARCH%20DURING%20COVID-19.pdf> Accessed on 5th September 2020].

confidentiality of information shared would be maintained and their identity would be protected.

As diabetes is a chronic disease that needs regular follow-up, it is imperative for healthcare providers to line list them. This way, resources needed in terms of making drugs and diagnostics available at their HWCs can be estimated. Similarly for the researcher to verify if women have been medically diagnosed, it is important to consult the healthcare providers as in most cases women have lost their medical records due to various reasons, such as misplacing them or forgetting the place they have kept them. Further, it was not so easy to get access to this data from healthcare workers- initially, they were hesitant. However, given the fact that the researcher has promised that the identity of the respondent will not be revealed and that the said information will be used only for academic purposes- the frontline workers agreed to share the information. Given the poor health-seeking behaviour of people in the community, the health workers were also looking forward to understanding from the researcher who is an insider of the community why people do not come forward to seek services or what are the challenges faced by people. Thus, they shared the information after they were given full confidence that we would not reveal the identity of the respondents. Thirdly, both the health workers and the women respondents wanted to share with the researchers their concerns and experiences which to a large extent in the context of West Jaintia was not studied and explored.

4.4 Limitations of the Study:

One of the major challenges that I witnessed in conducting this study was the outbreak of COVID-19 pandemic in 2020 which overlapped with the data collection phase of the study. The pandemic had significant implications for the actual execution of the present study. Thus, one of the study's major limitations was that I had to adapt and revise the methodology. Given that I belonged to this district and had also worked as a nurse with the public health system, it was envisioned that a thick description with long stay at the villages to undertake everyday observations of the people's life, work, and interaction with health systems would be undertaken. In the initial years of doctoral thesis, I attempted to include male respondents with diabetes as well. However, while in the field during the first wave of the pandemic and trying to identify the respondents of the study, the actual turnout happened to be all women. This is because, during the

identification process of respondents, the list of names shared by healthcare service providers had mostly women. When enquired if men do not suffer from diabetes, health workers and officials responded that “health-seeking behaviour of men is very poor in Meghalaya.” The health information systems related to diabetes also show that the number of women who attended health facilities and got diagnosed with diabetes was many times higher than that of men. Therefore, I could not provide much insight from men's perspectives and experiences. Given the low number of men suffering from diabetes and their reluctance to share details with me, it was decided to focus only on women living with diabetes in the study. I adopted different research approaches to give a comprehensive and detailed picture of women living with diabetes in remote and hard-to-reach villages of Meghalaya.

Similarly, restrictions on travel during the pandemic, mobility, and people-to-people interactions are schematically contrary to the pursuits of qualitative research and a field-study such as this. There were also fears and rumors around COVID-19, which had adversely affected the execution of the present study. It restricted the overall time which could have been invested in field observations. As the study is qualitative in nature, findings might not be generalizable for the entire state. Despite these limitations, the present study adds to the gaps in the existing literature on general health and diabetes in most under-research areas of Meghalaya in northeast India.

The other limitation of the study is in terms of the application of the frameworks and approaches adapted across all data chapters except in the last chapter which is Chapter Eight. This is because the study being exploratory in nature, most of the findings have been described in Chapter Five, Six and Seven, except in the last data chapter where structural analysis of findings has been conducted.

4.5 Summary:

To summarize, the chapter discusses the larger context in which the study has been conducted by describing the State, District, and Block Profile as well as the Health Services in the State. Further, the chapter describes the study's settings, selection process of the study population the fieldwork timeline, and the data collection methods used across different levels of the study setting. The chapter explains how the information was gathered and analyzed to achieve the aim of the study. The next chapter discusses the key findings from the field by explaining the socio-

economic and demographic characteristics of the women living with diabetes in the study area and their beliefs and perceptions about diabetes.



Chapter Five

Diabetes in a Matrilineal Society: Experiences of Pnar Women

Introduction:

Based on the findings of the study, the chapter is structured as follows: Section 5.1 provides an overview of the socio-demographic characteristics of women interviewed. Section 5.2 discusses a lay explanations of diabetes in the community. Section 5.3 explains the knowledge and perceptions about diabetes by Pnar women. Section 5.4 focuses on the cultural beliefs and practices related to diabetes and its management. Section 5.5 discusses the barriers to self-management of diabetes among Pnar women, and Section 5.6 summarizes the chapter.

5.1 Socio-demographic Characteristics of Pnar Women Living with Diabetes:

Most women interviewed in the study (n=71) belong to the Pnar tribe except one whose parents had migrated from Punjab. She was born and has lived in the district for the last four decades. The Pnar tribe is a dominant community in West Jaintia Hills District and they are similar to the Khasis. Table 5.1 shows the socio-demographic and economic status of the women respondents.

Table 5.1 Socio-economic characteristics of Women

	Women (n=71)	
	Frequency	Percentage
Age (in years)		
1. <30 years	1	1.41
2. 30-40	5	7.04
3. 41-50	12	16.90
4. 51-60	28	39.44
5. 61-70	18	25.35
6. 71-80	5	7.04
7. >80	2	2.82
Marital Status		
1. Unmarried	1	1.14
2. Married	38	53.52
3. Widow	27	38.03
4. Separated/Abandoned	5	7.04
Educational Qualification		
1. Illiterate/No Schooling	39	54.93
2. Upto Class VII	20	28.17
3. Class VIII-X	8	11.27

4. Class XI-Graduation	4	5.63
Occupation		
1. Attended domestic duties only	8	11.27
2. Self-employed agriculture (farmer)	14	19.72
3. Self-employed non-agriculture (shopkeepers, small traders, drivers, small business)	10	14.08
4. Casual laborer in agriculture (agricultural laborer)	9	12.68
5. Casual laborer in non-agriculture (daily wage laborer)	1	1.41
6 Regular wage and salary (professional, technical, administrative, govt. jobs)	8	11.27
7. Not able to work due to illness/old age/dependent	17	23.94
8. Retired/ pensioners	4	5.63
Religion		
1. Christian	59	83.10
2. Indigenous religion	5	7.04
3. Indigenous religion blends with Hinduism	6	8.45
4. Others	1	1.41
Average annual income		
1. Not reported any income	25	35.21
2. Below 12,000	1	1.41
3.12,000- 84,000	15	21.13
4. 84,001- 1,00,000	12	16.90
5. 1,00,001- 3,00,000	15	21.13
6. Above 3,00,000	3	4.23
Socio-economic groups		
1. Above Poverty Line	27	38.03
2. Below Poverty Line	44	61.97
Number of Children		
1. No Children	1	1.41
2. 1-5	19	26.76
3. 6-10	47	66.20
4. More than 10	4	5.63
Years diagnosed with diabetes		
1. Less than one year	4	5.63
2. 1-10 years	52	73.24
3. 11-20 years	5	7.04
4. 21-30 years	2	2.82
5. more than 30 years	1	1.41
6. Cannot recall	7	9.86
Family history of diabetes		
1. Yes	8	11.27
2. No	27	38.03
3. Don't know	36	50.70

Source: Data compiled from fieldnotes

Majority (n=28) of women were in the age group of 51-60 years. Most of them were currently married (n=38). Widowed women constitute 38.03%. Concerning religion, majority (n=59) of women reported that they follow Christianity. About 8.45% of respondents who resides in Nartiang village reported practicing *Niamtre* blend with Hinduism religion. Around 45 percent of women respondents in the present study were either abandoned by their husbands or widowed. In the present study, more than half (n=39) of the women interviewed reported never attending school. Almost 60 percent (n=48) of the respondents worked in the informal sector. Table 5.1 also shows the kind of occupation that women involved in the informal sector. About 35.21 percent of elderly women reported no income source; they depend financially on their children. Approximately 61.97 percent of the women belonged to the Below Poverty Line (BPL)⁴² category. About 66.20 percent (n=47) have 6-10 children indicating bigger family size. Most (n=52) women reported that they had been diagnosed with diabetes between one and ten years. Seven (9.86 percent) women said they could not recall the year they were diagnosed with diabetes. Only one woman has been living with diabetes for the last 30 years. About 38.89 percent (n=35) of the women reported no family history of diabetes, and most (n=36) do not know if their parents or relatives had diabetes.

All women in the present study reported never being diagnosed with gestational diabetes mellitus or diabetes during pregnancy. The mean age at which Pnar women got diagnosed with diabetes or onset of diabetes among Pnar women is 50.29 years. The next section attempts to explore and discuss the lay understanding of diabetes amongst the Pnar women from the study area.

5.2 Lay Explanations about Diabetes in the Community:

Among the Pnar community, diabetes is known as *kjut chini*, while *chini* means sugar, *kjut* encompasses different meanings – such as pain, illness, sickness, and diseases.⁴³ Explanation of

⁴² Below Poverty Line Households were identified based on the availability of the Antyodaya card provided to the poorest households. BPL is based on the poverty estimation methodology calculated by the Government of India based on indicators such as land holdings, type of house availability of clothing, food security, etc. (GoI,2009:15).

⁴³ It is important to note that Kleinman (1988) explained the distinctions between illness and disease in his work on “*The Illness Narratives: Suffering, Healing, and the Human Condition*.” According to Kleinman (1988:24), illness refers to the innate “human experience of symptoms and suffering.” The illness experience involves categorizing and explaining the forms of distress caused by the physiological processes in such a way that people across social groups easily understand.

diabetes using local terms is common in low-and-middle-income countries (Widayanti et al., 2020). People with diabetes link their beliefs about its cause with their narratives to understand the reason for getting the disease (ibid). Further, based on their experiences, people with diabetes “constructed illness concepts into their personal narratives” (Widayanti et al., 2020:9). In the present study, diabetes is understood differently by women in the community, as discussed below.

While diabetes was known to most women who had lived with it for many years, among elderly women, diabetes is considered a “new disease.” There was also a retrospection about the possibility of diabetes in the community for a long time. Still, according to women, it was unknown as they were not tested for it. This retrospection might have been due to the questions posed during the interview regarding the family history of diabetes among women. Women’s narratives from the field are discussed in detail as follows.

5.2.1 Diabetes is a “New Disease” Caused due to Nutrition Transition:

For elderly women such as Lang, aged 65, widow, retired Primary School teacher in a government school in her village, and her friend, Wan, aged 78, diabetes is a “new disease.” Both reside in Nartiang⁴⁴ village, which is undergoing rapid socioeconomic and nutrition transition. Lang shared:

We do not know where this illness comes from. In the olden days, we do not remember that we need to seek medicine. If we have a cough, we seek *dawai kynbat*⁴⁵ only that, there is no other thing. We do not know about the cause of sugar disease. During our times, we do not even know its name...it was not there earlier. Those days, around ten years ago, we do not get to eat like how we are eating now. Now almost all foods and vegetables are grown using fertilizers. Earlier, they did not spray fertilizer on anything that was cultivated. My friend and I were discussing if these illnesses are due to fertilizers because they are also spraying fertilizers everywhere on vegetables, rice and fruits, etc. So, we thought it is because of that, but still, we are unsure. Because in the olden days, there was no such thing...only soil and cow dung, and it is done...vegetables still grow, but it was not how it is now. Without fertilizers, nothing will grow...

Concerning nutrition transition, Lang shared:

In those olden days, we knew only beans, maize, yam leaves, and mustard leaves as vegetables, others we did not know them. When we were small, we did not know about this

⁴⁴ Nartiang, located in West Jaintia Hills, about 65 km from Shillong and 24 km from Jowai, is the summer headquarters of the Jaintia Kings, who brought their Hindu Brahmin with them and whose progeny are still there. There are clusters of monoliths in Nartiang that are the tallest in the world (Griffin et al, 1995).

⁴⁵ It is a belief that cough is mainly caused due to *kynbat* or harm inflicted by people who have *kynbat* at home.

tomato or potato except yam, yam leaves, and red sweet potato (consume as a tea snack). The other potato cooked as vegetables we did not even know it. We mostly eat wild vegetables and mushrooms depending on the season they grow...such as *la tiang tiang*, *la tang sah* and *iarain* (green leafy vegetables from the forest). These children now do not know about these olden vegetables anymore. None of my children and those of your age group know about these kinds of vegetables. *Ingkhulang la tara* (green leafy vegetables from the forest), they do not know about all of these when they go to the field, but if only we have the strength to go, we would still know them. However, these vegetables do not grow anymore. They have all disappeared. As we used to eat them, so we know those olden vegetables. These kinds of vegetables modern people do not eat them. Those vegetables grow naturally in the environment and are not man-made. We do not need to give fertilizers to pumpkins or yam leaves. We hardly ate potatoes...we only ate those...now all the foods are new...that could be the reason for this disease.

She continued:

Now when I cook *la langam* (a green leafy vegetable available in the forest), my grandchildren will not eat it. I used to eat it alone. My grandchildren only eat potatoes...they said the vegetables I cooked are smelly...because they grow in the wild. Earlier, you see, we never use oil also. We only made boiled food...we do not cook using oil. Now they are making food with lots of oil. We used to eat dry fish for the entire week, but now they do not eat it. We used to eat fresh fish from river; their meat is tastier than pork. We also used to eat deer and bear meat for one week. Their father used to go and hunt. Now my grandchildren are only eating Maggi, only Maggi, and everywhere smells of Maggi. Earlier, there was no Maggi, no cold drinks, we do not know we eat out of foolishness or wisdom...now the new foods are creating many new diseases....

They also shared that now people have shifted to eating fruits from locally grown to those imported from outside the state, which both the elderly women considered unhealthy. Wan, aged 78 years, a friend of Lang and was sitting with her at the time of the interview, shared:

Earlier, our elders used to go to the market once a week. There was no vehicle and no shops like how it is now. If they do not buy for a week, then we will not have enough food to eat. But now they are keeping it right in front of our eyes, we do not even need to go to weekly markets (referring to the increase in the number of groceries stores in their village). It is all because of these new foods that are causing all the diseases. If we eat like how we used to eat in the olden days, then we will not have these many illnesses. Now, most foods are only filled with air. For us, if only the shops were open, children and grandchildren would buy junk food daily. Earlier, we do not even know about biscuits...we do not eat biscuits. During our times, we only eat rice and vegetables, we could not even afford to eat dry fish regularly.

Thus, we see from the detailed narrative of Lang and Wan, who considered diabetes to be one of the new diseases in the villages were not directly aware of the cause of diabetes as a disease. However, they can highlight the change in dietary patterns that have occurred over the last few decades, the increased consumption of oily and fried foods, the way shops are promoting unhealthy

foods, and the change in preference to consume old vegetables, which were popular and widely available naturally in the community. The concept of “newer” diseases among the tribal populations has also been elicited in the study by Liang et al. (2022) in three case studies conducted amongst tribal communities in Assam, Chhattisgarh, and Kerala. People with whom they interacted also mentioned that the changes in food habits and lifestyle are the main cause of new illnesses. They also shared that changing lifestyles, food habits, pollution, and exposure to the outside world led to new illnesses.

However, with limited knowledge about diabetes, women in the community were apprehensive about diabetes being hereditary. They also started questioning the diagnostic tests based on their experiences with the symptoms.

5.2.2 “Ignorance of Sugar Test by Doctors”:

This explanation is mainly the assumption that “sugar must have been there already, but the doctor did not test our grandparents or us during those olden days.” For instance, Rymbai, aged 38 years, primary caregiver of Risa, aged 80, and living with diabetes, said: “Maybe this sugar illness is already there in my mother, but we do not know until the doctor said that our mother has sugar illness, as we never go and do the sugar test.” Then Risa said: “by the time (Dr.) Magdalene (an allopathic doctor in a private clinic) told me that eating biscuits, cake, and sugary products is not good. I have already eaten all of them, now I am tired and have started hating them.”

Another narrative about the presence of sugar in the body that was not diagnosed was shared by Nini, aged 42, shopkeeper, when she was asked about a family history of diabetes. As she narrated:

My mother used to have BP, and it was always high. It was in 2009 that her BP increased, and she became very serious. But it is only now that I started thinking about it because that time, I did not have the sugar yet. Now that I have a sugar illness, I can reflect upon it and think about my mother. I started thinking that had I known my poor mother would not have died. It never occurred to us to get her sugar tested, although we used to go once a week to get her BP checked at a private clinic. We were only worried about her BP. The doctors never tested her sugar when we took her to NEIGRIHMS or Edwin Hospital in Jowai. They never test her sugar. The doctor should have known that they also needed to test her sugar. Otherwise, how would we know? They only tested her BP; my mother also must have had sugar. Our mother passed away 12 years ago (in 2010).

Other women shared a similar narrative or even their primary caregivers, such as Ruth’s daughter, Pari, aged 24, who said: “What if our grandmother also has it had they tested her, but

they did not do the test. She passed away, in August this year (2022).” Ruth aged 65, is a widow who live with diabetes for nine years. The other explanation developed among women depending on their experiences is the “existence of sugar in the body” before the diagnosis.

5.2.3 Delayed Diagnosis: “Sugar must have been there in the Body”:

Rimonmi, aged 65, widow and financially dependent on her children, shared that her craving for meat, such as the fatty portion of pork before she was diagnosed with diabetes, could be an indication that “diabetes is already there in her body.” She was unfortunate also to have a vision problem worsened by the eye surgery. According to her, she always checked her sugar, and it was normal until before the operation on her right eye in 2021 when it was discovered that she has diabetes. As she narrated:

I never used to eat pork, but for more than one and half years (since 2020), I started eating pork, especially the fatty portion, it was very tasty, and I do not like the lean portion of pork. My friends with whom I used to buy meat used to tell me, “From the way you look, it does not seem like you like to eat lots of fats. *Ioo rakhoh wei sti wei raw I man bru*” (you look thin, skinny, and look dehydrated). Only now did I realize sugar must have been in me since then. It was because of sugar that made me crave pork always, I did not even want to eat chicken, but only pork with lots of fats. Sometimes the woman who used to sell pork tells me- take that fat for you, I also took it and made a curry out of it, and after that, I became like this. Regarding food, even now, I still want to take fats and always want to have pork. Nothing is more precious to me than pork. It seems it is that illness that makes me crave for it still. I always want to eat the food the doctor told me not to. The food they advised me to eat I do not like them. I also used to drink tea with lots of sugar throughout my life.

5.2.4 “Increase in BP lead to an Increase in Sugar”:

Other lay explanations about diabetes are similar to the biomedical explanation regarding the comorbidity of hypertension and diabetes. This explanation might have also emerged based on the information shared by women’s physicians. Cynthia, aged 40, a mother who engaged in household activity, shared:

The last time my BP was checked, the doctor told me it was normal. However, sometimes my BP shoots up suddenly, making it difficult for me. But sometimes my BP decreases. It used to fluctuate all the time. Before the lockdown in 2020, I used to seek treatment from Dr. Tony (Medicine Specialist in a public hospital in Shillong), and he told me that if my BP is not stable, I would get sugar disease. As the doctor said, my sugar increased when my BP stopped decreasing. But how could it be like that just because my BP decreases, then my sugar increases? I cannot even imagine it. They used to say that when BP increases, then the

sugar will also increase right. It was because my BP decreased so much, which is why sugar increased, and then again, my BP increased. Then someday they both will increase suddenly.

5.2.5 “Diabetes Do Not Occur Among Younger and Thinner People”:

Women in the younger age group and those underweight perceived that they are not at risk of diabetes. Even their family members perceived the same. According to them, diabetes occurs only in old age, mainly a disease of rich people. In the present study, about ten women were diagnosed with diabetes when they were below the age of 40 years. The belief that diabetes occurs at a younger age made women and their family members doubtful regarding the diagnosis of diabetes. For instance, Sawanka, aged 27, studied up to graduation, and was a primary school teacher in a private school, who was diagnosed with diabetes in 2022, shared:

The moment after I was diagnosed with diabetes (her RBS as of 14/05/2022 was 265mg/dl), I was in awe. I could not believe it was due to sugar. Then I was having tension, but the doctor told me not to have any tension or overthink so much as I would get better soon. I can never imagine how I got sugar at my age. Only after we got the sugar test result did I learn I have sugar disease and never thought I would get it. I cannot imagine it. My family, like my *Beirad* (maternal grandmother), asked me, “How did you get sugar when you are very young? I think it is better to seek treatment from another doctor.” My grandmother said, what if it is not sugar? It is hard to believe. You go and do the test somewhere else.

In addition, Sawanka is neither obese nor overweight. This shows that people in the study villages were aware that one of the risk factors for diabetes is being overweight or obese. However, this awareness is being generated only through discussions among themselves in the community. Thus, the dominant understanding in the study villages is that diabetes can only occur among individuals who are obese or overweight. Therefore, it was difficult for them to believe that even when Sawanka was not so obese, she was diagnosed with diabetes.

Women who are thin and underweight also question the fact that they are being diagnosed with diabetes. Darilin, aged 60, and financially dependent on her children and had been struggling with gastritis and hypertension for more than 22 years was recently (2022) diagnosed with diabetes. She shared:

So, I am like this, with only bones and skin. How come I have sugar? Usually, it is only those who are overweight and healthy, right? I even asked the doctor why a skinny person like me got sugar.

The above discussion provides a brief understanding of how diabetes is understood in the community in general and the lay explanations of the history of the disease in the community. However, knowledge of women regarding risk factors of diabetes, its signs and symptoms, and complications is crucial for effective public health interventions. Hence, the next section discusses the knowledge and perceptions about diabetes from the study villages.

5.3 Knowledge and Perceptions Related to Diabetes:

5.3.1 Knowledge and Perceptions about the Cause or Risk Factors of Diabetes:

Numerous studies have shown poor awareness of diabetes in India, especially in rural areas (Lau et al., 2009; Singh et al., 2012; Deepa et al., 2014). It is documented that individuals with better education are more health conscious, and the knowledge received through education would facilitate understanding of the health information received (Suwannaphant et al., 2017). Further, studies have found that individuals with better educational status were able to explain the risk factors of diabetes (Okram, 2016). Most women with diabetes (n=39) in the present study did not receive formal schooling, and only four studied beyond higher secondary up to graduation, the highest educational level attained by women in the present study. When asked about their perceived cause of diabetes, most women said: “How will we know? You are the one who should tell us instead.” Nonetheless, they tried to explain based on their experiences and world views of diabetes.

While the majority (n=50) of women in the present study did not know the risk factors of diabetes until they were further probed, few of them (n=5) perceived that they had gotten diabetes due to their “bad luck” or due to “supernatural power.” Diabetes is also believed to be mainly an inherited disease by women (n=8), and few (n=8) also believed that diabetes is caused due to “fear and shock” or “sadness and tension.” With their experiences of living with diabetes, they also link the increase in blood sugar due to overconsumption of meat such as beef and pork.

5.3.1.1 Diabetes is Caused due to Supernatural Power:

Marda, aged 52, ancillary staff at a PHC, shared that her diabetes is due to God's will. She said:

When I was alone, I used to think, why am I the only one suffering from diabetes.... then I said maybe it's God's will...

Similarly, Mimi, aged 57, widow, and farmer, expressed her sadness and disappointment, given that she is the only one with diabetes among her entire clan. She said:

I am the only one with a sugar illness in our house, although many belong to the same clan. In our clan, no one is like this. The elders are also not getting this kind of illness. Only I have this illness because of my "bad luck." I have asked and investigated all who belong to the Tyngkra clan in case they have sugar, but no one has this illness.

Risa also acknowledges that diabetes is common in her village Wahiajer, said:

I do not know the cause, but I think God spreads it. I do not know it. The doctors told me it is a sugar illness, so I do not know whether my blood sugar increased or decreased.

She also shared that there is no family history of diabetes, but she is doubtful as she said, "During those days, they did not do the sugar test."

5.3.1.2 Fear and Shock as the Cause of Diabetes:

However, few women (n=8) attributed the cause of diabetes to fear of loss or shock due to the death of near and dear ones and when they became anxious due to some fights or disorder in the neighborhood. For instance, Darilin, aged 60, dependent on family, attributed the cause of diabetes to fear and shock. As she narrated:

Even before I was diagnosed with diabetes, I used to take sugar only in the mouth of the spoon (a very little bit). I never eat any junk food as well. I do not know why did my sugar increase. I do not know the reason why I get this sugar disease. Maybe because sometimes when I am in shock, I feel like something is covering me, which makes me feel suffocated. As women who get pregnant and deliver, once we reach the age of 40-50, we will feel so many changes in our bodies. I think my sugar increased because of fear and shock at even small incidents like arguments and fights in the family. I will then start having the burning sensation *ur ur khlup khlup* (expressive words used to explain the feeling of suffocation), sweat profusely, then I will become unconscious. I think it is because of that reason that I have this sugar. Earlier, when my children were small, I never felt like this. However, whenever there is any incident in which people are fighting, speaking slang, or drunk with alcohol, I will think about it and cannot sleep. I will be scared to death. I am scared because I think, what if they fight as they are full of alcohol and many other thoughts?

5.3.1.3 Family History of Diabetes- "Sugar is in the Blood":

About eight women shared that they had gotten diabetes because it is inherited from their family members, either from the maternal or paternal side. Mary, aged 58, a teacher in a government primary school, shared:

I do not know the cause of diabetes, but doctors told me that our family has a history of diabetes, and that's it. My mother also has a sugar illness, my sister also, and my mother got a stroke from sugar and BP. My mother's sister also suffers from sugar; my maternal aunt's daughter also has sugar illness. So, my family said it is because sugar is in the blood, something like that. The doctor told me that our family has a history of sugar, so for that reason, I have to take care. Now I learned that this sugar illness passes on right. My sister died when she was 61 years old. She was already retired then but suffered a lot because her sugar was very severe....

Another woman mentioned earlier, Cynthia, shared:

I think I had gotten diabetes from my *Niaruit* (paternal aunt), which means from my father's side. All of them have sugar and high cholesterol level. They are all like that. But from my mother's side, it is not there. My *Niaruit* are more fat and taller than I am. They are from Nongpoh (Ri Bhoi district, Meghalaya).

Bella, aged 71, a widow, shared that all her family members, both from the maternal and paternal sides, have diabetes, and she is now scared that her daughter, too, will get diabetes. As she narrated:

All of my family members also have a sugar illness. My grandmother, grandfather, and all in my family, even my siblings and cousins living in Delhi, have sugar. My mother also has sugar, and she died. All of us have sugar, even my uncles. I am praying, oh Lord Jesus, I have only one daughter. What if she has already gotten it from me, but for now, she is healthy? She always complained of dizziness, so I told her that even I always used to experience dizziness during those old days. I thought about what had happened to me, but it was only when I visited the doctor that it was found that it was due to sugar. This sugar is in the blood, I told my daughter to go get her check-up done as she is just like me, always complaining about headaches, and I said you do not remember I always used to complain of headache before I was diagnosed with sugar illness. Once it is there in *Beipun* (grandmother), the other generations will inherit it too.

However, other women who did not have a family history of diabetes questioned why they or their children were diagnosed with diabetes. For instance, Moreen, aged 62, a retired government employee in the sericulture department, shared:

I do not understand it *dong* (meaning a kid, which she used to address me during the interview), I do not know how did I get this sugar disease when they also said that this sugar is something which can be inherited from our parents, but my father and mother do not have sugar, we knew it after we did the test. But then I have it, and even my daughter. If we say that it is hereditary, then it is quite possible. But I cannot explain it *dong*.

5.3.1.4 Tension or Work Pressure as the Cause of Diabetes:

Further, most women attribute the cause of diabetes or an increase in their blood sugar level to stress or tension. For instance, Daphi, aged 55, a teacher in a private primary school and a single mother, shared:

I think it was because my stress was very high when I took care of my mother. My mother was like a baby, she was bedridden, and she used to urinate seventeen to eighteen times a day, and I had to change her diaper. It was stressful, and that is why I got this sugar. I am thinking like that. Who will be able to carry their mother for seven to eight years, but I have to carry her always, even during my pregnancy period. I think it was for eight years and four months that I cared for her like babies are taken care of. When she wants the sun, I have to carry her. When she wants to take a bath, I have to carry her. I think the years before she died, my sugar started because every night for eight years, I have been sleeping for just four hours. If her death could have been delayed, I would have died by now as I was not getting the chance to take care of myself. Now that my poor mother had died so I could care for myself. My children were also very small in the year my mother died...It is all because of my tension.

The other perceptions about the cause of diabetes in study villages were consumption of too much sugar, given its local name, *kjut chini*, (sugar illness) and consumption of meat.

5.3.1.5 Diabetes is Exacerbated due to Overconsumption of Red Meat:

In a nine-year prospective cohort study in China on red meat, poultry, and fish consumption and the risk of diabetes, Du et al. (2020) found that the risk of developing diabetes increases manifold with increased consumption of red meat. The inhabitants of Meghalaya are known to strongly prefer meat consumption (Govindasamy et al., 2018). Fish products, chicken, pork, beef, and mutton are the main non-vegetarian consumed by people in Meghalaya, including the Pnar tribe (ibid). This culture of meat consumption might have influenced their beliefs about the cause of diabetes. Most women attributed the cause of diabetes to overconsumption of beef and pork. Lucy, aged 63, dependent on family, also shared that the reason for her getting diabetes could be because it is “God-made” and also because she used to eat lots of pork. She said:

I do not know what I ate when I got this sugar, but I did not eat so much. I think it is because God only made it. It could also be because I overate pork earlier than I should. I always want

pork and even potato, but I never overeat other foods. However, I had stopped eating potatoes, but still, when we prepare curry potato, I will take the soup, not the potato.⁴⁶

Similarly, Nini perceived that beef could increase her blood sugar. She said:

It was because Dr. Robert told me not to restrict my diet so much. That is the reason I am eating everything but in smaller quantities. But as my sugar kept on increasing so, I stopped eating beef. Sugar will be very strong with beef, so we no longer buy beef. We only eat pork but not every day. We buy pork only once or twice a week besides fish and chicken.

Wulcy, aged 53, does not receive a formal education, works as a daily wage laborer was diagnosed with diabetes in 2019. She shared that when she eats beef, it aggravates her blood sugar level. She said:

Whenever I eat beef, my sugar becomes much stronger. It will affect my heart and then go to my head. Then I would want to sleep and not want to open my eyes, and even my skin will shrink and dry. Even my lips will become dry, and at that time, if I get my sugar tested, it will definitely be high. I can understand when my sugar increases, as I will not be able to open my eyes, it will be like this (half opening her eyes), and my vision will be blurred. For me, it is always like that.

Women's perception of the cause of diabetes is thus attributed to multiple factors depending on their worldviews and experiences of living with diabetes. The next sub-section, therefore, explains how this perception of increased blood sugar develops based on women's experiences with symptoms of diabetes.

5.3.2 Knowledge and Experiences about Symptoms of Diabetes:

5.3.2.1 Knowledge about the Symptoms of Diabetes:

Knowledge about the signs and symptoms of diabetes is important for early detection and diagnosis of diabetes. As argued by Prof. Kleinman (1988), a medical anthropologist, symptom experience is a crucial determinant in seeking treatment. Almost all women have limited knowledge about the symptoms of diabetes, and the three conventional symptoms (polyuria, polydipsia, and polyphagia) of diabetes were perceived by them as normal. When women experience frequent hunger, they consider it a "sign of good appetite." In case of frequent thirst, they still considered it normal, and for them, it is obvious to pass urine frequently as they drank

⁴⁶ Potato is largely grown by people in villages and hence do not have to purchase it. Therefore, it is much more affordable compared to other vegetables.

too much water. This finding is irrespective of the women's socio-economic status. For instance, Moreen shared:

Before I was diagnosed with diabetes, I often felt very hungry, and I used to eat now and then. I used to eat three plates at a time when I ate rice. But then, I do not know yet that I have sugar. I used to drink lots of water too. Even when I go to Church, I always carry water with me. Even during the sermon, I used to have the urge to urinate and cannot control it, so I have to go. From the time I experienced these symptoms up to the time I went to seek treatment; it has been one year already because I did not know that these are the symptoms of diabetes. I think now people are aware that these could be the symptoms of diabetes, and even when they have a small wound that does not heal, they will suspect that it could be diabetes. However, even when we get cut with a knife and if the wound does not heal for months, we will still not think about sugar.

Thus, education does not necessarily impact the knowledge about diseases. In this case, Moreen, although she had studied up to Matriculation, yet, was not aware of the common symptoms of diabetes, and this has delayed her from seeking treatment.

Some women confused the other symptoms of high blood sugar, such as dizziness, with gastritis. Although, at the same time, women ignored the classic symptoms of diabetes. For instance, Wulcy shared how she was diagnosed with diabetes when her RBS was 535 mg/dl. As she narrated:

I used to pass urine throughout the night, but as I was drinking lots of water, how would I know that it was a symptom of diabetes? For me, I thought as I was drinking water too much, so that is the reason I pass urine frequently. I used to feel hungry very frequently as well, but I thought it could be because my appetite is good as I am still young, so I eat whenever I feel hungry. I was such a foodie, and even while I was doing *kynrih kho* (a traditional practice of separating the rice from the ungrounded one), I used to keep a big mug filled with water, like a cow everywhere I went I used to carry lots of water. Every time I eat, it used to go to my head, and I used to think that it was due to acid, and even the doctors I had visited used to give me only acid medicine. It was only in 2019 that Dr. Dauni explained to me and learned that the symptoms of diabetes are, however, like this.

Almost all the women were diagnosed with diabetes accidentally as they could not identify the classic symptoms of diabetes initially. It is only when their symptoms become serious, such as blurred vision and the constant tingling sensation in their hands and feet, that they visit health facilities.

5.3.2.2 Women's Experiences with Symptoms of Diabetes and Knowledge about Hypoglycemia: "Sugar is Scary":

Most women were not aware of the symptoms of diabetes until they were diagnosed accidentally. The main symptoms the women shared include – feeling dizzy, tingling sensations, body aches, blurring vision, frequent thirst, frequent urination, increased hunger, and especially the craving to eat sweet food. Few women consider diabetes a frightful disease; they immediately need the medicine whenever they experience the symptoms. Linda, aged 53, a farmer, “could not afford to go to school” and was diagnosed with diabetes in 2019; the symptoms were different, she shared:

This sugar illness will always make you sick and weak, and you will not feel like talking. Whenever I do not get sugar medicine, it became serious.

She also shared her experiences with symptoms when she was first diagnosed with diabetes:

It all began like this, one day (in 2019) when I returned home from the river after washing clothes. While I was sitting, I was shivering. My thigh, this side, was shivering, then I was thinking, what is happening to me that I am shivering? So, my husband and I went to (Dr.) Dauni (private clinic).⁴⁷ When I reached Dauni, he asked me- *kamon sang wa nang pho u lai kat kat dini tlot kat kat dini kyrbeh pho ong u ia nga!* (How can you even walk here when you are extremely weak and shivering so much, he told me this)? He examined and did the test where he pricked my finger and then told me it was sugar.

The ASHA of one village, Dilla, aged 56, while interacting with women, said: “You must take this sugar medicine continuously as this sugar disease is scary!”

Wulcy shared that she seeks diabetes treatment only when she experiences symptoms. She said:

Initially, I used to go for follow-up once a month, but sometimes I feel tired of going to Shillong as it is very far (located more than 60 km from her village, Wahiajer). I stopped taking sugar medicine for two months because I no longer feel the symptoms. I last visited Dr. Anthony in April 2022, now is already July 2022. I requested that the doctor give me lots of medicine so I do not have to visit him frequently.

According to Wulcy she only needs to seek treatment when she experiences symptoms of diabetes and avoid going to Shillong frequently. She asked her doctor to give her lots of sugar medicine. In

⁴⁷ Dr. Dauni is an Ayurvedic doctor practicing in Ummulong, a village located 20km from Rakabah village.

this case, she had missed the importance of regular monitoring of blood glucose which she shared that she used to check only when she visited the doctor.

Women diagnosed with diabetes in the past two to three years shared that the experiences with symptoms of diabetes are confusing and that it is only when they reach the doctor that they learn whether their blood sugar is either high or low. Nonetheless, when they experience symptoms that they cannot tolerate anymore, they do take some action. Take the case of Biang, aged 49, a trader selling vegetables who shared an instance of her confusing experiences with symptoms of diabetes. She was diagnosed with diabetes in 2019 at the District Hospital. She said:

One day I feel like my sugar is increasing. I was scared of what will happen to me. I had a tingling sensation, my eyes were aching, and my vision became blurred. But I do not know when my sugar decreased also, I became like that. I do not know whether my sugar increased or decreased. Only when I visited the doctor would I know whether it was high or low. When my sugar decreases, my body will feel light, I will not feel heavy like it is now as it is very high now. I think it is like that.

Risa, aged 80, a widow, financially dependent on her children, diagnosed with diabetes in 2020, does not understand when her sugar drops. She said:

My sugar decreased once. It dropped to 55 (mg/dl). But even when it dropped, I did not understand at all. When we visited (Dr.) Dauni, to seek treatment, he checked my sugar and found it had gone to 55. Then he told my children to take me immediately to some shop and have food. But I visited him not because I was feeling weak. I visited him because my legs were heavy right from my waist below it was very heavy.

My interview with women, reveal that most do not know about hypoglycemia and its symptoms. For instance, Cynthia, who was diagnosed with diabetes in 2022, shared that the healthcare providers did not explain the symptoms of hypoglycemia. She said: “No, they did not explain the condition when sugar decreases.” This is not the case for a few women who belong to better social groups and have professional support from family members. For instance, Moreen was explained about hypoglycemia and what to do when she experiences it by her second son, Dr. John, an allopathic doctor. As she narrated:

When my sugar decreases, I will feel sleepy and not want to open my eyes. I will feel very heavy right from my head, then I will shiver, and I will not even feel like opening my eyes, and I cannot even walk as I am shivering. It used to be like that. I will feel very scared. Whenever I experiences these symptoms, I understood that my sugar had decreased, and I would do what John advised me to do. He told me to take half spoon of sugar, and when I did that, I felt relieved.

5.3.3 Knowledge about Complications of Diabetes:

Most women reported that they do not know the complications of diabetes. Majority of the women considered diabetes to be a short-term illness. Although, this is a dominant understanding, some women (n=30) who had observed their friends, family, and relatives suffering from complications of diabetes and had lived with diabetes for years considered diabetes to be a serious disease. For instance, Moreen, a retired government employee, shared a story of her friend who suffered and died due to chronic kidney diseases. She said her friend did not take proper care of herself when she was diagnosed with diabetes and did not follow the doctors' advice on dietary restrictions. Despite being fortunate to belong to good socioeconomic status, Moreen also has a son who is a doctor. She shared:

Regular check-up is very important, but it is my foolishness only that I did not go. Since 2018-19, I kept procrastinating, and then lockdown came, but I let it be. Even now, it is because my son, an MBBS⁴⁸ doctor, has scolded me, and I was also thinking, what if it is affecting my kidney? As I stopped going to the doctor, I knew it would affect my eyes.

Ruth, aged 65, a widow, learned that diabetes is a serious disease because she observed her neighbor who had diabetes for over 19 years. She shared:

Nobody informed me about the complications of diabetes. I am taking care of myself because I am scared when I see those people who get sugar. I saw it in Rimika, my friend from our village. I used to observe that sometimes her body would swell. Sometimes she became very thin, then turned dark as her skin became black. That is how I got scared of diabetes. Because of this fear, I am trying very hard to seek medicine regularly. Then I started thinking- ohh, this sugar illness is like this, so I became scared and very sincere in taking medicine. The moment the doctor told me that I have sugar illness, I started avoiding all the food they told me to avoid. Then I started walking on the grass with dew every morning and ran from here to there. Before waking up, I used to exercise regularly in my bed. I knew about this exercise when I observed it in while taking care of my husband in the hospital.

The lack of knowledge about the symptoms of diabetes and its complications has led to delayed diagnosis and treatment among Pnar women. This is discussed through the narrative of Treki, aged 53.

⁴⁸ MBBS- Bachelor of Medicine and Surgery/Allopathic doctor

5.3.4 Delayed Diagnosis due to Low Awareness about Symptoms of Diabetes:

Women seek care only after experiencing the symptoms for many weeks, and the reason for the reluctance to seek care is undoubtedly concerns about the consequent expenditure, time lost, and poor understanding of the disease. Treki, aged 53, studied till matriculation and works at the Jaintia Hills Autonomous District Council (JHADC) as a Lower Division clerk and was diagnosed with diabetes in 2009. She is a single mother, as her husband abandoned her, and she has two daughters studying in higher secondary school. She was diagnosed with diabetes only when she became unconscious and was taken to a private hospital in Shillong, where she was admitted directly to the Intensive Care Unit (ICU). She narrated her experiences before she was diagnosed with diabetes as follows:

I was unaware of that sugar disease until it became serious when I learned about it. Initially (in 2nd July 2009), I fell at *Iawmusiang* (market in Jowai). I fell *kduk* (sound when one falls down). After I got up from there, I started becoming sick, I was limping for two weeks. At the time when I fell down, there were people selling *kwai* (betel nut) and *pathi* (betel leaf) around, and they gave me Vicks to apply. With the help of my friend, I reached home, and after that, I went to seek treatment from Nongjingi village (traditional healer), and after two weeks, I could go to my office. From that time, my leg started biting, piercing here and everywhere then my body started becoming hot, I was also having a fever. Then I went to Jowai to seek treatment, but the doctors there did not tell me that it was due to sugar illness. After that, I went to Kong Nancy (a Nurse working at a PHC in a village where she was living at that time), who advised me to test for malaria, but it was not. Then I went to Dr. Samila and many other doctors, I do not remember their names anymore, but they did not advise me for any test. On 16th July 2009, I became unconscious. All I could hear was my family discussing about taking me to Edwin Hospital (in Jowai), but I said no, I do not want to go there. I wanted to go to Healing Hospital in Shillong. I could remember only up to that. My family members told me I became unconscious when we reached Healing Hospital, and they took me to the ICU. When I became conscious, the doctor told me it was due to sugar illness. I could not see the Sun or the moon inside that ICU, so I asked them where you have taken me. My sister said that I was hospitalized for one month at Healing Hospital. I think had we delayed going there, I would have died.

The case of Treki shows that her limited knowledge about diabetes prevented her from seeking diabetes treatment early. While seeking care for their symptoms, like in the case of Treki, women first resort to multiple therapies to find relief, thereby incurring costs at every source without any cure. When women visit the hospital or the professional sector, their illness has already become complicated. This thus led to the need for advanced medical treatment and, thereby huge treatment costs.

As discussed earlier, knowledge about the symptoms of diabetes is very limited among women. As a consequence, women's belief about them getting diabetes is almost not there. Most of the diagnosis of diabetes is made accidentally when women visit the health facility after experiencing severe symptoms of other illness. In response to their experiences with diabetes, women have constructed different meanings for it. Depending on their lay knowledge and lay explanation about diabetes in what Kleinman (1988) called "the popular sector," which is the discussion between family, friends, and relatives, women have resorted to different means to manage diabetes. The severity of illnesses is first identified and coped with in the family, which is the popular sector. This brings us to the next section on cultural beliefs and practices related to diabetes and its management.

5. 4 Cultural Beliefs and Practices Related to Diabetes and its Management:

Among the Pnars, there are numerous beliefs regarding illnesses in general. These traditional beliefs are deeply rooted in the community. The members of the community shared this information in focus group discussions during fieldwork: These includes:

1) Taro- In this case, the manifestation of the illness is in the form of an irrational talk by the person who gets possessed by the *taro*, which usually appears as a black cat. The person will become mentally unstable and will roam around. When asked by her relative to whom she belongs, the person who gets possessed will tell the name of the owner of the *taro*, and through this, they will know the person who has the *taro*. In severe cases, it will eventually lead to the person's death if the *taro* does not leave him or her by returning to the owner. It is a belief that the person gets possessed because the person who owns the *taro* hates him or her.

2) Kynbat- While in the Khasi language, *Kynbat* means herbs, in the Pnar language, the meaning of *kynbat* is different. In the Pnar language, it means some black magic where a person through his or her touch or food given to him or her, especially in the form of *kwai* (betel nut and betel leaf/smokeless tobacco). People in the community believe that *kynbat* will then turn into tuberculosis or cancer, and the treatment is through an herbal medicine known as *dawai kynbat*, mainly treated by traditional healers. The belief in *kynbat* in the community has been very strong for the past decades, and it persists even today. For instance, Trichia, aged 62, shared: "My father

passed away because he got *kynbat* from people. They purposely gave it to him, after which he always has shortness of breath and chest tightness.”

3) *Thung*- Another form of infliction is *thung*, in which the person who owns the *thung* inflicts the other person he or she likes in the form of a boil anywhere on the body. The remedy for the same belief by the community is through going to the owner’s house, where the relative of the person who gets the boil will request the owner to take it back if it belongs to them. In case the owner denies it, the boil will become severe.

4) *Ah snuih thlen*- This is another form that means cutting the hair or any parts of clothes, and the person will become sick, commonly manifesting as body swelling. However, one of the traditional healers informed me that this is more common among the Khasis.

5) *Ske khmat*- It means a person who can inflict others (evil eye) just by their look. People in the community believe that if a person has a *ske* watch, the other people eat or praise them for their look, and they will fall sick, usually upset stomach, and the remedy for this is believed to be through applying lime in the stomach.

The above-mentioned types of black magic and beliefs about the origins of diseases have been passed on from generation to generation. If the household does not want it anymore, they can throw it, and someone who wants to become rich can pick it up if they want to be rich. Black magic is believed to come from gold, money, or valuable items. However, in the case of diabetes, such belief is absent as diabetes was known to people in villages only in the last 30-35 years.

Cultural beliefs and practices that determine the behaviors related to self-management of diabetes vary across cultures of different countries. Cultural beliefs and practices can either be beneficial or detrimental to the self-management of diabetes. For instance, “misconceptions” about diabetes, its risk factors, and management shaped by culture can act as barriers to the effective management of diabetes (Sari et al., 2022). Understanding these cultural beliefs and practices related to diabetes is therefore crucial, especially in the context of the indigenous population, where the prevalence of diabetes is increasing, especially among women (IDF Diabetes Atlas, 2021). Arthur Kleinman (1988), a medical anthropologist, argues that most care for illnesses is delivered not by professional practitioners but by family. The treatments used for the self or the family include a change in diet, massage and rest, self-medications, use of medical devices, emotional

support, and religious practices. Findings in the present study shows that there are numerous cultural beliefs and practices related to diabetes. Some of these are harmful practices that can affect the outcome of diabetes and are discussed as follows:

5.4.1 Partial Understandings related to Diet:

As part of dietary management, most women mentioned avoiding taking all vegetables grown underground, such as potatoes, carrots, radishes, and beetroot. While they can restrict themselves from taking all these vegetables completely, switching from rice to *atta* is hard. Most women also believe that eating bitter herbs and vegetables reduces blood sugar. These bitter herbs and vegetables are grown locally, such as *karela* (bitter gourd), *sohpdok kthang* (small green and bitter tomato), and other herbs grown naturally in the wild known as *iarem* (green and bitter leafy vegetables). Women attributed this belief about diet to the advice they received from friends, families, and relatives. They even reported that it is their doctor who gave them the advice not to eat all the foods that are grown underground.

Women have limited knowledge about the dietary management of diabetes. There is a misconception in the community that when one is sick and has diabetes, they should take “Horlicks” without sugar. When a person is sick, their appetite will be low, and in such cases, people in the community take Horlicks to prevent weaknesses. For instance, Ioobiang, aged 57, who was diagnosed with diabetes in 2021 and is also suffering from anemia, shared:

I cannot eat properly; I am just forcing it. As the doctor told me I was anemic, I used to drink milk along with Horlicks. I have completed drinking about 50 bottles of Horlicks. I used to drink like that always. I do not know whether it is good or bad, but I used to take it without sugar. When one is sick, people in the village are advised to buy Horlicks; when someone has sugar, they will say, have Horlicks.

5.4.2 “Walking Barefoot on Pebbles and Grasses is Good for Health”:

One of the myths in the community is that people suffering from diabetes should walk barefoot on *kutchra* roads full of pebbles while exercising. Almost all women shared that they used to go for a morning walk and do exercise every morning barefoot. The belief is that walking on pebbles or grasses with early morning dew will help them in relieving their symptoms of diabetes. Women shared that their doctors advised them to walk barefoot as it would help them relieve their

symptoms of diabetes. Women like Bella, aged 71, who had lived with diabetes for 15 years, shared:

I used to take a walk every morning after I have put on the rice in the rice cooker for our lunch. I used to walk barefoot. The doctor from *dkhar* (Silchar⁴⁹) taught me. He said when I go to *pnar* (Jaintia Hills), as there will be dew on grasses early morning so I should walk on them. Before walking, I used to pick up all the broken pieces of glass bottles one by one to avoid getting injured. I cannot wear slippers as people said those plastic slippers are not good for those who have BP, and the leather slipper is also not good for us. They said that these plastic slippers increase BP. Earlier, this place used to be a place where people sat and drank alcohol, so there were lots of broken pieces of glass bottles. So, I have to be very careful while taking a walk.

Bella lived in an isolated area away from other people's houses and far from the main road. As the place is isolated and near the forest, most men from the village use the place to drink alcohol after purchasing from the stores.

Wulcy, also narrated similar practices of walking barefoot. She shared:

I used to go for a walk barefoot. The doctor only told me to walk barefoot and not to wear slippers while walking in the pebbles and sand. I feel so good, so comfortable whenever I step on pebbles barefoot. If I wear slippers, my feet will become warmer, and I will feel burnt.

5.4.3 “Diabetes is an Episodic or Short-Term Illness”:

Given their low level of education and lack of health literacy, most women were unaware that diabetes is a long-term illness. They considered it a short-term disease, and the moment they stopped experiencing the symptoms, they said they stopped taking treatment and did not go for follow-up. Julie, aged 68, did not receive any formal education during a visit to her house, asked me: *wan phi neibhah ka chini, nga da khuid ko nga* (your visit is related to sugar, right, I do not have it anymore, it is clean now). She shared that her doctor told her that her sugar is “clean now.” The interpretation given by Julie (68) is that her doctor told her that her sugar has decreased, so according to her, it is “clean,” and it is not in her body anymore.

Around 13 women, especially those newly diagnosed with diabetes, perceived diabetes to be a short-term or episodic illness. Women believe that when they do not experience symptoms

⁴⁹ Silchar which is the head quarter of Cachar District, Assam has a sizeable population of the Khasi and Jaintia tribe and historically, they were the original settlers of the region (Buam, 2014).

anymore, it means that sugar is not there. However, when they experience symptoms, it means that sugar has appeared again. Therefore, they only go for follow-up when these episodes of symptoms arise. Lang, aged 65, a widow who had retired from government primary school as a teacher, shared:

I only go for follow-up when I experience the symptoms such as blurring of vision, the feeling of *ngung ngung ngeng ngeng* (dizziness), and when I feel *ngun ngun* (heaviness). Sometimes, sugar is there, BP is there, and sometimes not.

Other women who have had the experience of living with diabetes for many years and whose doctors had explained to them do know the long-term nature of diabetes. They were, however, explained about the long-term nature of diabetes only after their doctors learned that they had discontinued taking treatment for diabetes. Women with professionally qualified children as doctors or nurses also know that diabetes requires long-term management. For instance, Moreen is well-informed about diabetes, including its complications, as her son is an allopathic doctor. She said, “Yes, we must live with it once we get it. Those who get complications are the ones who cannot follow the advice and take care of themselves.”

5.4.4 “Prolonged Use of Oral Hypoglycemic Drugs Can Affect the Kidney”:

There were many fears and misunderstandings related to anti-diabetic medicine in the community. These fears and misconceptions among women were due to their observations about their family members who suffered from kidney failure and blurred vision. For them, complications of diabetes are considered to be the side effects of oral hypoglycemic drugs. For instance, Amy, aged 44, a primary school teacher, shared:

I stopped taking allopathic medicine in 2020. I fear it will spoil my kidney like it did for my mother. My mother has also suffered from diabetes since 2018, but her kidney is now damaged due to the medicines. So, since 2019, she has had to undergo dialysis every alternate day. Now, I am taking Ayurvedic medicine, which I purchased based on the advice of my friends who sells these medicines (Ayurvedic).

Similarly, Mary, aged 58, a primary school teacher, shared:

As I was scared to take allopathic medicine longer, I shifted to an Ayurvedic doctor. I told her I feared taking allopathic medicine, so I requested she treats me with ayurvedic medicine. I have heard people say that this allopathic medicine will affect the kidney if we take it for long...

5.4.5 “Diabetes Can be Cured through Herbal Medicine”:

Women reported that they used numerous home remedies available locally as a means to decrease their blood glucose. These home remedies include passion fruit leaf juices, gooseberry, neem leaves, squash, *sama* (locally available dal-like fruit), bitter gourd, and *bhindi* or lady's finger. The source of their knowledge about these home remedies' effectiveness is unclear. The typical response was *wa ong ki bru*, or people told us. People in Meghalaya have used indigenous wild plants as food and medicine for centuries (Agrahar-Murugkar & Subbulakshmi, 2006; Umdor et al., 2016). Like any other tribal community, they are closely associated with nature. Numerous studies have been conducted on their knowledge and utilization of medicinal plants for many illnesses, including locally available herbs to control blood sugar (Dhungana et al., 2018; Sajem & Gosai, 2006). Women's belief that diabetes can be cured could affect self-management of diabetes as it is a chronic disease that requires continuous long-term management. Few women believe that diabetes can be cured through herbal medication. For instance, Linda shared:

People in our village shared that in Umroi (Ri Bhoi district, Meghalaya), someone provides herbal sugar treatment. That sugar medicine is very good. You know there is someone who gets cured after taking the herbal treatment, my friend's husband who lives in this village only he is cured now. My paternal aunt also told me to go there so that I would get cured.

The above findings correspond to the cross-sectional study conducted by Patil et al. (2017b) in Pondicherry. In their study, these “misconceptions” were attributed to the lack of knowledge and awareness about diabetes among the people (Patil et al., 2017b). In a recent ethnographic study among Javanese diabetic patients by Sari et al. (2022) to explore their cultural beliefs and practices, similar findings were also reported. For instance, beliefs that “insulin causes organ damage,” “diabetes can be completely cured,” and “walking barefoot is good for the body” (Sari et al., 2022: 5-6). Misconceptions are often shaped in people's minds by culture and act as a hindrance in the effective management of any diseases (Patil et al., 2013). Therefore, healthcare service providers must also know what people think about diabetes. These misconceptions often act as a barrier to the self-management of diabetes (ibid) and prevent people from seeking medical care.

5.4.2 Cultural Beliefs and Practices Related Treatment of Diabetes:

5.4.2.1 Dependence on Home Remedies for Controlling Blood Glucose Levels:

In the present study, women resort to numerous home or herbal remedies such as *neem* leaves, gooseberry, passion fruit leaves, squash, bitter gourd, wild vegetables, and fruits known locally as *iarem*, *sama* (dal like and very salty fruit). The information about the types of home remedies for blood sugar spread through word of mouth. Utilization of these home or herbal remedies depends on their seasonal availability. For example, gooseberry is available only during the winter season. Most women (n=23) have tried at least one remedy to control their blood sugar. Some found it helpful and continued, whereas others did not. Thus, their experiences vary. For instance, Cynthia shared:

Sometimes, when I feel dizzy, I pluck that *neem* leaves at the back of our house, cook it with water, and then drink the juice. I found it helpful, especially whenever I feel very dizzy and do not know if it is due to BP or sugar. I used to drink half a glass in the morning, half a glass in day time, and half again at night- after which I feel light. My friend who sells vegetables at Ummulong told me to drink *sama*. Then I told her it was enough that I did not want to do foolish things. You never know, *sama* could be harmful to me, so I did not take it. But with neem, there is some change and not like before.

Moreen who was diagnosed with diabetes in 2018, shared that she also uses some home remedies besides allopathic medicine. According to her:

I used to mix *sama* with water, cook, and drink it. *Sama* is sold in the market for snacking, but people found it helpful for diabetes. That was how it turned into medicine, as people felt it relieved their symptoms. If it is not because of the gastric, I would have taken it, as it can decrease my blood sugar, as per my past experiences. I knew about *sama* through *khana patein* (word of mouth). My cousin and sister from Jowai told me that *sama* is good for sugar. Some people also told me about *neem pata* (neem leaves), but I did not try that.

Lari, aged 62, diagnosed with diabetes in 2014, shared:

I used to eat *samyrlain* (gooseberry) because some people told me it would help reduce BP and sugar. I used to eat it in winter as it is mostly available in winter. My BP and sugar became normal when I eat *samyrlain*. Some people told me to eat *sama*, but when I eat it, my acidity increases, so I am scared of eating *sama*.

Biang, aged 49, was diagnosed with diabetes in 2019. However, finds *sama* to be helpful, as she narrated:

One night when my sugar was high, I felt tingling in my arms. I took the *sama* ground it, and mixed it with water. After drinking it, I feel better. It is only when the symptoms appear that I am taking it. When it is not there, then I will not take it. I am using *sama* and *sohbrob* (passion fruit) as well. It was the *bru khloo* (*bru* means people and *khloo* means jungle) who explained to me to eat *sohbrob* also. *Bru khloo* are the people living in the jungle (she refers to her friends who live in remote villages).

My study shows that women utilize different kinds of home remedies in the form of wild herbs and locally available fruits to control their blood sugar. The narratives shared by women showed a mix of experiences in using *sama* to control their blood sugar. Some found it is causing acidity, while others found it useful in relieving their symptoms. Similarly, Jasna et al. (2022), in their study to explore the different herbs used for curing diabetes by the people in villages of Kerala, found guava leaf, fenugreek, neem, gooseberry, curry leaves, ladies' finger, passion fruit leaves, turmeric, spinach, and ginger, were the common herbs reported to be used by the people. Kumar et al. (2014), in their work on "Some herbal drugs used for the treatment of diabetes" in India, argue that if herbal drugs are consumed without proper identification of the plant or consuming the wrong part of the plant can lead to poisoning. According to them, not all herbal drugs are safe; some could cause allergies or even be poisonous. Further, they also argue that no drug can cure diabetes completely (Kumar et al., 2014).

5.4.2.2 Forced Dependence on Alternative Therapy to Control Blood Sugar during COVID-19 Pandemic Lockdown:

Women who live in remotest villages and belong to poor socioeconomic households could not visit health facilities during the lockdown. Therefore, they must resort to home remedies to relieve the symptoms and control their blood sugar. For instance, Phas, aged 46, daily wage labourer, drank passion fruit⁵⁰ leaf juices to control her blood sugar for one month (May 2021) when the district imposed a lockdown. She used to work as a laborer in the coal mine site of Ladrymbai town but came back to her village due to the lockdown. Her village is located approximately 23 km from the nearest PHC. She was advised to take passion fruit leave juices to

⁵⁰ Passion fruit, known as *soh brob* among the Pnar community, is round in shape. It is hard on the outside, and the center is filled with seeds and juice, which is the edible part of the fruit.

control her sugar by Manda, the ASHA, who is also Phas's sister and was present during the interview. The ASHA said:

During my visit to the Children's Hospital, the owner informed me about it. He showed me the fruit on his mobile. As I told him I am working as an ASHA, he explained how to prepare the juice and its effectiveness in controlling blood sugar. So, it was I who advised her to take it.

During the interview, the ASHA expressed her concern and asked me: "Don't you have free drugs to give her, as medicine is too expensive?" The huge transportation charges and medicine costs posed challenges for Phas in the self-management of diabetes. Therefore, she has to resort to passion fruit leaf juice for one month.

5.4.2.3 Utilization of Complementary and Alternative Medicine (CAM) Due to Increased Marketing in the Community:

Medicines or treatment alternatives other than Western biomedicine are considered Complementary and Alternative Medicine (CAM) (Chacko, 2003). Study villages located adjacent to National Highway Six are well-connected. Therefore, this made it more accessible for the CAM company's agent to visit people's houses and advertise their products, unlike in remote villages. People were counseled and convinced to buy their products at their homes. In most cases, women were convinced to buy these products. For instance, Lari shared how the agent communicated to her about the benefits of their medicines. She was diagnosed with diabetes in 2014. She narrated:

I used to buy and drink that company's medicine as they came to our house to sell it. I have this one (Triphala Juice)⁵¹ which is helping me a lot. It cost around (INR) 500/- (USD 6.03). My acidity also reduced When I started taking this. Whenever they came, I used to say no, but still, they will try to convince me by saying things like "It is good for you as you are fat, let us explain its benefits to you, like that so many things they used to say." So, I did not even understand how they could always convince me, so I bought their medicine.

Lily, the ASHA of Wahiajer village, shared:

If we listen to them (the company agent selling the complementary medicine), we will only spend our money buying their medicines. Many of them used to come to our village; they told us it is Ayurvedic medicine, but I used to ignore them. They cleverly explained the medicine. They would say, "These medicines are good for health. What if you have sugar,

⁵¹ An Ayurvedic drink is claimed to reduce weight, increase immunity, be effective in hyperacidity, and act as anti-inflammatory agents.

BP, and fats in your liver”? Like that, they tried to convince us to believe them. I think those medicines are mostly made of fruits such as grapes, pomegranates, etc.

Due to this marketing of CAM, people in the community were convinced to purchase these products and take them alongside other allopathic medicines for diabetes. For instance, Rimoni, aged 65, who had undergone surgery for both her eyes, also purchased medicine from the Magnum company’s agent. She shared:

Besides the allopathic sugar medicine that (Dr.) Mark (an allopathic doctor) gave me, I also bought these medicines from the Magnum company. They came to our house to sell these medicines for my eyes and sugar. The medicine cost (INR) 1,100/- (USD 13.26) each, and I have taken four bottles. I am taking half of the allopathic medicine and half of the company medicine daily. I used to take the one from Dr. Mark in the morning, whereas the one from the company I take in the morning and at night.

5.4.2.4 Complementary and Alternative Medicine (CAM) are considered as “Sugar Medicine”:

There was also a misunderstanding related to these supplement drinks sold by the company’s agent. For Lanalang, aged 68, a widow, these supplement drinks are perceived as antidiabetic medicine. She showed me the Ayurveda Energy Health Drink, a juice-like drink produced by My Relief Company, and according to her, it is sugar medicine. She narrated:

My brother, who also has a sugar disease, used to take this medicine. My family members then advised me to take it, too, as my symptoms were similar to my brother’s. I had already taken it even before I was diagnosed with diabetes. My family advised me to try drinking it. They said what if my illness is because of sugar. Since this medicine *iatoh* (matches) with me as it relieves the symptoms, they are right that it might be due to sugar. They advised me to mix two spoons in one glass of warm water.

Besides home remedies and herbal medications, women reported using nutritional supplements manufactured by companies such as Magnum and My Relief Ayurveda. This is due to the excessive marketing of these products in a few villages well-connected to towns. Western biomedicine has been considered the most efficacious in treating diseases globally. In addition, treatment beyond the standard biomedical practices, known as CAM, has been used widely. While alternative medicine refers to those practices adopted instead of standard biomedicine, complementary treatments are considered supplemental (Chacko, 2003). The utilization of CAM by different population groups can be understood by examining the complex interactions of

culture, geographic settings, and health experiences (Chacko, 2003:1088). As noted in the present study, women living in villages adjacent to towns were convinced to purchase these products by the company's agents who can easily access them. The fact that diabetes is a chronic disease, women were apprehensive about taking allopathic medicine for long duration. This is the reason, they see CAM as an alternative, as these agents claimed that CAM do not have any side effect.

Across the globe, people suffering from diabetes have adopted numerous treatment therapies based on anecdotal evidence, folklore, and a new belief system (Chacko, 2003). For instance, in a study conducted by Chacko E in the context of Kerala found that people with diabetes used "herbal treatment, meditation, reflexology, cellular nutrition, subconscious healing, pearl therapy, and astrotherapy" as healing practices (Chacko, 2003:1088). Cultural heritage, natural environment, and the material conditions in which patients live also influence their therapy choices. Patients' "knowledge of traditional/folk medicine constitutes an important source of cultural capital" (Chacko, 2003:1088). In recent years, natural medicine has been opted for by many people for the treatment of diabetes due to its fewer side effects (Jasna et al., 2022). Few women in the present study consider these supplementary treatments "sugar medicine." These misunderstandings need to be clarified by the healthcare service providers working closely with the community for effective management of diabetes.

5.4.2.5 Use of Nail Polish and Other Herbal Remedies for Treating a Wound:

Most women were aware that when they have diabetes, they need to protect themselves from getting wounded. However, when it comes to wound care, women adopt different practices based on their beliefs about its cure. One such practice is the application of nail polish to wounds. For instance, Lucy, aged 63, shared:

Once, I went to trap fish in the river, and a piece of glass cut my feet. My daughter told me to take *tek* (a nail polish) and apply it to the wound. When I applied the nail polish, I got a burning sensation. After two days, the size of the wound decreased. I applied *tek*, a black one I had purchased, and after applying, the wound just disappeared.

While it was fortunate for Lucy to recover from her wound by applying nail polish, this is not the case for Queency, aged 50, dependent, who was also under insulin. Applying nail polish worsened the condition of her wound, and she suffered from diabetic foot. Her daughter, Catherine, aged 24, narrated:

It was in November 2020, but I cannot recall the date that a sharp object pricked her while she was going for a morning walk, and she informed us about it. I told her to apply nail polish on the scratch, so she applied and felt better. However, a few days later, the scratch led to pain and swelling in her left limb. The wound gradually increased, and to cure the wound, she started taking medicine from an informal provider living in a village next to ours. But it was not helping her. The size of the wound kept increasing, and she was having much pain due to the swelling.

It was observed that the wound in her left foot had also extended to her leg, her skin was peeled off, and the muscle also became visible. Lay method of wound treatment can thus be harmful to women, especially when they are unaware of the complications it could lead to.

5.4.3 Influence of Culture on Dietary Management:

5.4.3.1 Women Meeting and Eating Together at Workplaces:

The society in Meghalaya follows a matrilineal culture, and women are actively engaged in economic activities outside the home. Women who work as small traders shared that in the market, they used to eat with their friends and share their packed lunches. Thus, when they are with friends, it is difficult for them to resist the food items they should avoid eating. The other challenge of being in the market as part of their occupation is difficulty following the dietary regimen of eating small and frequent meals. At times, they even missed their food timings. For instance, Ristina, aged 67, another small trader shared:

In the market, I have friends with whom I used to have lunch, so I would ask them to give me one or two pieces of potato. We used to share whatever we cooked and packed as lunch at the market. It was always like that. We used to taste each other's food. That is how I got to eat the food and meat the doctor told me not to eat. Thus, my sugar increased and became high. At home, I used to have lunch around 9 am, but when we were busy in the market, we used to eat even around 12 or 1 pm. There would often be customers buying vegetables, and I would be busy. There is no proper time at all. When I am at home only, I could follow the proper timing for food.

5.4.3.2 Culture of Rice Eating:

About ten women were advised to switch from rice to round flat bread made of wheat flour, or *atta* perceived it difficult to follow and practice. According to them, *atta* will not satisfy their hunger, and their “acidity will increase” if they eat *atta*. The cultural practice of eating rice thrice a day by the Pnar community is a barrier to following the doctor's dietary advice. Nini shared:

Since we are *bru iongrim* (olden people), we cannot stop eating rice. At night, I eat rice only. When I stopped eating rice for one week, like the doctor said, it started to *khloh* (poking) me here (pointing towards her chest) because of that sugar. It is biting me here in the chest. The way it bites my chest is difficult to tolerate. It is always biting here. That is why I started eating *ja sngi* (a common practice by the Pnar community where we usually have tea with rice at around 1 pm).

For Lari, *atta* will worsen her gastritis. She shared:

I cannot eat *atta* because my acidity will increase. But when my sugar is very high, I have no choice but to eat *atta*. I always used to eat three *atta* and then have some rice during lunch and dinner. If I do not eat rice along with *atta*, then my acid will increase.

In villages, gastritis is usually known as acid. It is a dominant belief that eating *atta* instead of rice increases acidity for some women.

5.4.3.3 Influence of Religion on Coping with Diabetes:

The majority of the population in Meghalaya practice Christianity. Few of them, however, remain in the indigenous tribal religion, which also largely believes in God as the creator. Women who understand the chronic nature of diabetes have no other choice but to cope with the illness while at the same time having faith that God will provide them cure. After recovering from a serious illness, they shared that it is due to “God’s grace” that healed them. For instance, Nini, a Christian, who got infected with COVID-19 during the second wave shared:

I was admitted to an isolation hospital, but the doctors and I forgot I had diabetes. When I became critical, I realized I have diabetes and informed the doctors. By the time I informed the doctors, my RBS was 600! I was then put under insulin treatment, and the nurse monitored my RBS regularly. Nonetheless, due to my goodness in helping and praying for other patients as I pity them, God helped me recover from my illness and prevented me from complications of diabetes and death. I do not even pay attention to my illness. From that, only God feel pity for me. On the day I was discharged from the hospital, my sugar reduced to 300. But I still feel that I will recover, meaning I trust God. Only God can heal me.

Similarly, other women, such as Mary who is also a Christian, also believe that her diabetes will get cured one day. She said “My diabetes will disappear because it was so high earlier. Now it has decreased. I believe that the blood of Jesus Christ will completely heal me. It will go away completely...”

Ioobiang, aged 57, shared that she is not scared of the complications of diabetes as she has already committed herself to God. She said:

For now, I am not afraid anymore. Whatever happens to me, I committed it to the hands of the one above. I am not feeling scared or nervous anymore, I am taking sugar medicine and other medicines as well, but it depends on the will of the one above. As long as I can work, I will work, but if I cannot, then what will I do, listen, I am not scared anymore.

People living with diabetes are more likely to be in stress, given the long-term nature of the disease. To cope with stress, women in the present study reported that they submit themselves to God and pray for healing. They believed that only God could heal them, which gave them the courage to live with diabetes. Findings from other studies support this finding on religiosity and spirituality. Religiosity and spirituality act as coping mechanisms among people living with diabetes, as it has been found that people with high religiosity have better glycemic control than those with low religiosity (Sari et al., 2022:7). However, Van Houtum (2005) argues that religion can dictate a lifestyle or habits that harm an individual's health or complicate existing illnesses.

5.5 Barriers to Self-Management of Diabetes:

Several social and cultural factors influence the self-management of diabetes. These include social stratifiers such as occupational status, level of education, income level, social class, gender, and race/ethnicity. Moreover, studies have shown that individuals with socioeconomic stability have better diabetes outcomes than financially weak individuals (Arutselvi, 2018b). Thus, self-management of diabetes varies across individuals belonging to different social groups. Women in the present study shared many barriers related to self-management of diabetes. These include those related to diet, exercise, and medication.

5.5.1 Occupation as a Barrier to Self-Management of Diabetes:

About ten women in the present study worked as small traders and spent most of their time in the market away from home. Due to the matrilineal culture where women take an active part in the productive economy, they spend most of their time in the market, and this influenced their self-management of diabetes. Thus, when they are with friends in the market, it is difficult for them to resist the food items they are restricted from eating, as discussed in the previous section. Women used to share the market space and socialize with each other at the same time, having tea together multiple times a day and eating mostly traditional snacks, which are rice based and sold in the market.

Although women in the present study knew they needed to care for and protect themselves from getting wounded, they shared that it was difficult to take preventive measures. According to them, this is because of the kinds of occupation they are involved in, largely farming. For instance, Kmen, aged 67, a widow and farmer cultivating broom, shared:

We cannot protect ourselves as much as we are farmers, so we have to keep using spades, and even when we have to uproot or harvest the broom, it is used to cut also. We are cultivating broom; without it, we cannot get food. No, I do not like using gloves, it is uncomfortable, but it is so difficult when it cuts.

Other women, such as Wani, aged 49, a small trader selling vegetables, used some precautions to avoid getting injured while peeling the betel nut skin. She shared:

Whenever I am peeling betel nut skin, I used to tie my fingers with cloth here, but I hardly get wounded. I am trying to avoid being wounded, and whenever I get pricked, I used to get so scared.

5.5.2 Food Habits of Pnar Women as a Barrier to Self-Management of Diabetes:

The natural environment of Meghalaya, having rich flora and fauna, automatically influences the life of the people, especially in terms of their unique food habits. Rice, meat, potatoes, and other vegetables and fruits grown locally are the staple food of the people in Meghalaya. However, using their indigenous knowledge, the Khasi and the Jaintia tribe also made different types of rice-based food items and are locally called by different names based on the methods they are prepared (Umdor et al., 2016). These traditional snacks are prepared from rice and contain rich calories and carbohydrates but less fat, fiber, and protein. Increased consumption of rice and other carbohydrates rich food is usually attributed to a higher risk of diabetes (Mohan et al., 2010).

Similarly, as discussed in the section on cultural practices, switching to *atta* was reported to be difficult for most women as they had complaints of “acidity” when they ate *atta* which also will not satisfy them. *Atta* makes them feel extremely hungry always and only feel full when they eat rice. The other advice, according to women, their doctor gave them is to shift to white rice as red rice is considered too nutritious. In the study villages, people usually eat red rice locally grown in their agricultural fields. The rice is considered very nutritious, and when cooked, the rice becomes very sticky, unlike white rice. The doctors consider red rice too nutritious for the patients.

Hence white rice is commonly advised by the doctor. However, women shared that they only consume white rice when they consider themselves serious or when their blood sugar level is very high. When their symptoms disappear, they start eating red rice again, especially when it is grown in their field. Manda, aged 60, shopkeeper selling pork in the village market, said:

This red rice has a lot of fats (high in nutrient content), and if I eat it, it will raise my sugar level. So, when my sugar is high, I purchase and eat white rice, but now that my sugar is slowly decreasing, I can eat red rice...

At the grocery store, varieties of white rice are sold. These are mainly imported from outside the state. Similarly, white rice is distributed to the people at the ration shop. The white rice available from both sources is known to the people locally as *kho dkhar*.⁵² The three types of rice women mentioned in the present study were red, brown, and white rice. From the study, it was reported that red rice is nutritious. Therefore, it must be substituted with white or brown rice. However, findings show that white rice has a high glycemic index, but brown rice is recommended for people with diabetes. Numerous large-scale, population-based prospective cohort studies conducted worldwide have found that increased consumption of white rice is associated with an increased risk of diabetes, especially among women (Nanri et al., 2010; Hu et al., 2012; Ren et al., 2021). However, in a population-based cohort study conducted in Spain, Soriguer et al. (2013) found that people who consumed white rice were less likely to develop diabetes after six years of follow-up. They compared their findings with those conducted in Western and Asian countries, where it was found that white rice consumption increases the risk of diabetes to justify the contrast in the results. Soriguer et al. (2013) argue that these findings could be partly explained by the high Glycemic Index (GI) value of white rice consumed in Asian countries. The GI values of white rice range from 40-100, and the variation are due to inherent botanical differences of rice across countries and its preparation methods. The method used to classify dietary carbohydrates based on their effect on blood glucose levels is known as the glycaemic index (GI). The risk of diabetes decreases with consuming foods with low GI values (Osman et al., 2017; Indrasari, 2022). One of the ways to cope with diabetes is by

⁵² *Kho* is a pnar word, meaning rice, whereas *Dkhar* is a word used to indicate the mainland- meaning it is rice that comes from mainland India to the state. The word *Dkhar* is also used for a person from the mainland. However, it also has a historical significance and is one of the clans' names in the state. In the present study, too, there are women with the clan's name *Dkhar*.

consuming low-GI rice (Indrasari, 2022). In the experimental study conducted by Osman et al. (2017:275) in Malaysia to estimate the glycemic index of rice-based mixed meals, they found that consumption of rice along with fat and protein reduced the glycemic response compared to rice alone. Adding proteins, fats, and vegetables to white rice reduces the glycemic response by almost 50 percent (ibid). The traditional varieties of rice are composed of approximately 75 percent carbohydrates and 25 percent moisture, protein, fat, fiber, and ash (Muttagi & Ravindra, 2020). Ahuja et al. (2008) argue that ancient literature of Asian countries such as Thailand, Myanmar, China, Malaysia, Indonesia, and India, known for growing rice, has attributed medicinal properties to rice. According to them, “in early oriental writings, whole brown rice was mentioned as the perfect food” (Ahuja et al., 2008:94). Colored rice, both red and black, has anthocyanin or colored pigment and flavonoids associated with antioxidant properties (ibid:102). Red and black rice also contains a rich amount of iron, zinc, and minerals and are therefore considered nutritious. For instance, In Sri Lanka, parboiled⁵³ red rice has a lower glycemic index than white rice and has been recommended for people with diabetes.

Not all rice has a high glycemic index. Some indigenous rice varieties also help prevent and control diabetes, such as the Thuyamalli rice, Khichili Samba rice, Kattu Yanam rice, and many others from Tamil Nadu (Dharshini et al., 2021). However, studies on the glycemic index of *Kho so* or the local red rice in Meghalaya are absent. Therefore, it is difficult to conclude whether it is good or bad for diabetes. Ahuja et al. (2008) also argue that although rice contains a rich amount of complex carbohydrates and has been categorized along with bread and potato as high glycemic index food, wide traditional rice varieties have a low glycemic index.

Although women shared that their doctors advised them to shift to white rice as red rice is highly nutritious, literature shows it is highly polished (Nanri et al., 2010; Hu et al., 2012; Ren et al., 2021). The highly polished white rice commonly consumed in India has an extremely high GI value of approximately 75-80 (Mohan et al., 2010). Mohan et al. (2010) argues that to address the epidemic of diabetes in India, there is a need to introduce foods with low GI value and high fibre into the market. They also recommended replacing refined grains such as polished rice with brown or minimally polished rice. Identifying low-GI food products in the

⁵³ A rice that has been boiled along with the husk before the milling process.

market is challenging as most food items in India today have a high GI. The authors also encourage increased protein and dietary fibre consumption, low fat and lower glycaemic carbohydrate, and increased fruit and vegetable consumption. Awareness about the ill effects of high GI diets must also be disseminated to the community. These measures need to be taken into consideration while implementing the NPCDCS program.

5.5.3 Betel Nut Consumption as an Inhibiting Factor in Controlling Blood Sugar:

People in Meghalaya also regularly consume smokeless tobacco in the form of *kwai* (betel and betel leaf applied with lime), a part of the culture to socialize with others. According to the Global Adult Tobacco Survey-2 (2016-17), the percentage of men and women who smoked and used smokeless tobacco was 59.8 percent and 34.2 percent, respectively, in Meghalaya (WHO, 2017). In the epidemiologic study conducted by Tseng in Taiwan in 2010 using a national sample database, he found an association between betel nut chewing and the newly diagnosed case of diabetes. Therefore, the author concludes that the habit of tobacco chewing is diabetogenic. In the present study, almost all women chew tobacco except a few. These women who did not chew tobacco belong to the Church denomination, such as the Church of God prohibiting betel nut chewing. However, women from Presbyterian Church and Catholic Church were not prohibited from consumption of betel nuts. For instance, Bial, aged 53, farmer, who belonged to the Presbyterian denomination and was diagnosed with diabetes in 2017, shared:

In one day, I used to chew around ten betel nuts. When I stayed at home, I used to chew tobacco continuously. I can avoid foods that the doctor told me to avoid, but not tobacco, even if they told me to. It is very hard; I cannot stop chewing betel nuts. If I do not chew betel nuts, I will feel sleepy the whole day, my throat will also be dry, and I will not feel good.

Betel nut, betel leaf, and lime are food items that the *Pnar* community purchase once a week during the weekly market. The expenditure on food includes the expenditure on these items as well. When asked about the amount spent per week on tobacco, Bial said- it is around INR. 500/- (USD 6.03) or more per week just for betel nut, betel leaf, and lime. She used to incur around INR. 1,000/- (USD 12.05) per week, along with food. The culture of chewing betel nut among the *Pnar* community is so deeply rooted that women even sacrifice their money to purchase betel nut, betel leaf, and lime every week instead of basic food items.

5.5.4 Barriers to Regular Exercise:

Women mentioned numerous barriers to exercise. These comprise musculoskeletal problems, illnesses that make them weak and feel dizzy, time constraints due to working hours, household responsibilities, and weather conditions, especially during the rainy season. People with multiple chronic conditions, such as back and joint pain, asthma, congestive heart failure, chronic obstructive pulmonary disease, and fatigue, often experience barriers to self-management (Mogre et al., 2019:2306). This is due to the simultaneous demands of co-morbidities requiring extensive care. Women are overburdened with domestic and economic responsibilities; therefore, they cannot exercise regularly due to time constraints. Women, therefore, consider household activity as an exercise to reduce their blood glucose. For instance, Manda, aged 56, did not receive formal education and worked as a shopkeeper selling pork at the market located 1.5-2kms from her house, shared:

As per the doctor's advice, I am supposed to wake up in the morning and go for a walk. However, since morning I have been busy with domestic chores. I carry water from the well near my house early in the morning. I fill water from the well into the pots and keep it in my house, and it is not as if I sit when I am awake. I keep doing work. Moreover, after working, I feel good. This is like exercise only. I carry around two to three aluminum pots of water for cooking, and I am already tired by the time I plan to exercise. However, if you wake up and sit ideal, then it is dangerous.

The other barriers women mentioned include other illnesses/morbidities such as migraine, knee joint pain, and fractures that restricted and prevented them from undertaking regular exercise. For instance, Lari, a farmer but now financially dependent on her children, shared:

When I feel light in the morning, I used to go for a morning walk, I used to walk in the grass always here and there. But now that my illness has become serious, I have become very weak that I don't want to go for a walk. Otherwise, I used to go regularly.

For Cynthia, it is due to a sudden feeling of dizziness, and she also shared that it could be because she used to also suffer from hypothyroidism. As she narrated:

Dr. Lari at Civil Hospital (District Hospital), Jowai, told me to walk for one hour in the morning, one hour in the daytime, and one hour in the evening. This past one-two days, I did not go otherwise, I used to go. I did not go because I feel dizzy suddenly, especially in the morning when my head feels very dizzy right in my brain, I cannot go. Even while walking, I used to feel sleepy. I don't know why I feel like that. The last time they tested me for thyroid, they told me it had increased but now, not anymore.

For Ristina, aged 67, a widow, her daily household chores prevent her from going far for a morning walk and doing exercises. As she narrated:

I cannot go far for morning walks as I have to cook and pack food for my children, who go to the field daily early morning. So, I am doing the exercise here at home only, and at the same time, I am cooking. Before they returned from the field, I started cooking again, as we have to cook using firewood, so it takes much time to cook food.

Another elderly woman, Teresa, aged 62, got injured in her left foot because of an accident narrated:

I met with an accident when I was young, during 1981-82, and since then, I cannot walk without slipper especially my left foot. Even stepping in the sand will be very painful, as if I will die. I never walk without slippers, as here (pointing to the sole of her left foot) there is no more bone. The flesh became very soft that I could not walk without slippers anymore. I mostly take the support of my right foot. I did go for a morning walk, but when I go, my legs are paining, and I feel the more I walk, the more my joints are paining. This is why I stopped going for a walk and exercising, as I thought I would only go to get pain. Sometimes, I did try to wake up by 4 am and take a short distance walk.

The occupation of their husband also determines the self-management of diabetes in terms of women's ability to wake up early morning and do some physical activity. Nini shared that although her doctor had advised her to do regular exercise as she had to sleep late at night waiting for her husband, who is working as a mechanic in a workshop, to come from work, it is difficult for her to wake up early morning and do exercise. As she narrated:

Dr. Margaret encourages me to exercise regularly, but I cannot wake up early as I have to sleep late at night. I used to wait for their father as he was working late in the *karkhana* (workshop for repairing vehicles), and in the *karkhana* they had irregular timings sometimes. He used to come from work at 9, and sometimes, he came at 10 pm. If he comes around 9/10, then by the time we sleep, it will be 11/12, always like we used to sleep. Why it reached 11 pm is because when he comes, he will take a bath, have dinner and then sleep. So, my sleep is not proper, and even my diet, I eat everything I cannot control, but I do not eat much.

5.5.5 Presence of Comorbidities and Multimorbidity as a Barrier to Self-Management of Diabetes:

Table 5.2 shows that 23 women with diabetes were also diagnosed with hypertension. The diagnosis of hypertension was made along with diabetes, before or after women had been diagnosed with diabetes. About 17 women reported that along with hypertension and diabetes, they also suffer from other morbidities such as gastritis, joint pain, and musculoskeletal disorder.

Table 5.2 Presence of comorbidity and multimorbidity among Women

Presence of comorbidities	N=71	
	N	%
1. Hypertension only	23	32.39
2. Hypertension and other illnesses (gastritis, fractured hips, joint pain, fractured hands)	17	23.94
3. Gastrointestinal problem	2	2.82
4. Musculoskeletal problem	1	1.41
5. Blurring vision and hearing problems	3	4.23
6. Others (ovarian cyst, urinary tract infection, anemia, hypotension, liver disease, heart disease, asthma, chronic kidney disease)	11	15.49
7. None	14	19.72
Total	71	100.00

Source: Field data compiled based on fieldnotes

These morbidities not only act as barriers to conducting regular exercise among women, as discussed earlier but also to following the dietary advice given by the doctors. For instance, Chiang, diagnosed with diabetes in 2017, shared her difficulties following the dietary advice as she also suffers from Hypertension, Diabetes, and Gastritis. Chiang, aged 55, works as a daily wage laborer, shared:

If I eat vegetable soup, my BP will get stronger. If I eat sweet, my sugar will be strong, I have only to eat bitter food. I told my children this. For me, it is only bitter things. Even getting a job also is very *kthang* (literally means bitter, she meant extremely difficult to get jobs). I tried to avoid eating meat, oil, and fatty food but avoided social gatherings, but I have to go to my close friend's place whom I love. I used to request them to cook boiled fish for me, but I feel almost all the food I was advised not to eat...but still, I am trying to avoid them...

She was advised not to eat lots of fruits, not to eat rice, banana, cucumber, tomato, pumpkin, potato, and anything that grows underground. She said she has been eating only fish for four years now. However, she said that it is difficult for her to comply with the advice given as she thinks that almost all kinds of food are forbidden for her to eat. She is not allowed to eat anything made out of rice- the traditional snack of the Khasi and Jaintia people in Meghalaya. She expressed the problem she encountered in adhering to dietary advice given to her as she constantly mentioned the three health problems she is suffering from- Hypertension, Diabetes, and Gastritis. She continues:

I am only eating boiled food. It is bland. I want to have chili sometimes. I have BP, Sugar, and Gastric is also high. Some doctors told me they did not understand what to tell me to

avoid. If I avoid this, I will get that I don't understand it...I have to understand it myself. As illnesses are of many types... it is difficult for me to understand. I stopped attending functions such as Christening a baby or Sacrifice (a practice specific to those who belong to the indigenous religion of the district) ...it is very hard for me...I cannot eat sour things, sweet things, only bitter things I can eat...how will I live.

Multimorbidity prevents women from choosing the diet of their choice. Without dietary advice or counselling, it is difficult for them to choose the diet appropriate for their health and, at the same time, affordable.

5.5.6 Barrier to Follow-Up and Adherence to Antidiabetic Medicine:

People with diabetes need to follow strict diet plans, medications, regular monitoring of blood glucose, and regular interactions with healthcare providers (Verma et al., 2021a, Verma et al., 2021b, Grabowski, 2021). With the outbreak of COVID-19, the vulnerabilities of people with comorbidity, such as diabetes, have increased manifolds. Due to the subsequent lockdown imposed, they face numerous challenges in accessing healthcare facilities (Muksor & Parmar, 2022).

Since the study was conducted during both waves of the COVID-19 pandemic lockdown, i.e., in 2020 and 2021, the lockdown in both waves restricted people living with diabetes from visiting hospitals for follow-up. Nevertheless, this is not the case for all women as those with good socio-economic status and who have a vehicle at home could access the health facility after getting permission from the village headmen. Table 5.3 shows the different means through which women access antidiabetic medicine. Less than 50 percent of women (n=41) reported that they could take antidiabetic medicine during the COVID-19 pandemic lockdown. They shared that their doctor had already given them enough medicine during the lockdown period. Almost 43 percent (n=38) of women did not take an antidiabetic medicine for two months or more. The reason they shared was “difficulty in getting a vehicle to go for follow-up,” “did not feel the need to take medicine as I did not experience symptoms anymore,” and so on.

Table 5. 3 Access to antidiabetic medicine during the COVID-19 pandemic lockdown

Sources of Antidiabetic Medicine	Women (n=71)	
	n	%
Antidiabetic medicine was available from the last follow-up	32	45.07
Antidiabetic medicine purchased from Pharmacies	10	14.08
Stopped taking antidiabetic medicine and no dietary restriction	11	15.49
Blood sugar control only through diet and exercise	18	25.35
Total	71	100.00

Source: Field data compiled from fieldnotes

Self-monitoring of blood sugar can be done at home, provided a glucometer and other consumables are available. Only a few women (n=4) could afford to buy a glucometer. These women belonged to a better socioeconomic group. For instance, Emma, aged 66, retired government bank employee, too has a glucometer at home. She has two daughters who are nurses, and even when they are not at home, their other sister used to check Emma's RBS regularly to adjust the dose of oral antidiabetic medicine. The glucometer was purchased by her daughter, a nurse who also taught their elder sister, a teacher, how to monitor the RBS of Emma regularly. Another woman, Mary, aged 58, studied up to Class X and worked as a school teacher. She used to check her RBS regularly as her children had bought the glucometer for her. She shared:

I cannot go to Shillong for a check-up because of the corona. If I go there, I have to quarantine myself, and regarding medicine, now I have the experience of taking them myself. The doctor told me that if my RBS is 200 or 300, I have to take it twice a day, but if it is below 140, I have to take it once daily. Now, I am taking it once a day. I became my doctor, and once my sugar goes up, I will know it as there will be a change in my body. I feel uncomfortable, I feel exhausted, and it reaches my head just like it is burning, and when I go for testing, it will always increase to 200 or more than 200, and when it is not there, I feel fresh.

The ability to purchase a glucometer and the educational background of women and the social capital in terms of having professionally qualified relatives and children enables those belonging to higher-income social groups to properly and regularly self-manage their diabetes despite the lockdown.

However, this was not possible for most women from poor socioeconomic households, and they faced severe difficulties in ensuring regular blood sugar checking as seeking diabetes care was highly costly. For instance, Syntiew, aged 55, widow and a daily wage laborer, finds it challenging to purchase medicine from a private pharmacy, let alone a glucometer. Another elderly widow, Rimonmi, aged 65, suffered eye complications due to diabetes and is financially dependent on her children, who are working as daily wage laborers, shared she was “forced” to buy the glucometer during the second wave of the COVID-19 lockdown. She said:

The nurse from our village, whom we consulted during the lockdown, told me that I needed to buy a glucometer. She said my sugar keeps fluctuating, so I must check it regularly. She also said that rather than my children taking me to her house daily to check my blood sugar, I need to *shahiap* (make a financial sacrifice) and buy the machine. She helped me get the glucometer, which cost (INR) 3 000/- (USD 36.16), which is very costly.

Previous studies showed a mixed response when it comes to blood-glucose monitoring. For instance, Ghosh et al. (2020) reported that in most patients, there is a significant decrease in the frequency of blood glucose monitoring. However, Verma et al. (2021b), in their telephonic survey conducted in Northern India, found that most of their participants who attended the private clinic reported no change in the frequency of monitoring their blood glucose during the lockdown. Similarly, the present study found that the frequency of blood sugar monitoring varies across respondents depending on their ability to access healthcare facilities and purchase a glucometer, which was largely influenced by their socioeconomic status.

Few (n=16) women with secured income sources could afford to follow the advice related to diet, exercise, and medicines and believe in the benefits of self-management of diabetes. They believe that following a strict dietary regimen, regular exercise, and compliance with medication will enable them to control their blood sugar and provide symptomatic relief. Diabetes self-management, such as regular exercise, enables women to live their lives effectively and enable them to perform their daily roles and responsibilities. However, this is not the case with poor women who work as traders and daily wage laborers, who must balance their work at home and work. Thus, the time left to care for themselves is limited as they have to leave home by 7-8 am and then return late at night, around 9-10 pm. The present study thus reveals that matriliney does not keep women in an advantaged position. Instead, she suffers the double burden of responsibility.

Prof. Nongbri (2008:3), the renowned Sociologist from Meghalaya, argues, “The matrilineal principle of kinship has important implications for the role of women within the family and society. By conferring the right of descent on the mother, matrilineality places a heavy responsibility on women to raise their children.”

HocSHChild (2003) argues that working women spent more time on housework and taking care of their children than men. For each week, women worked fifteen hours longer than men. In a year, women worked an extra month of twenty-four-hour days (HocSHChild, 2003:4). This is another time to do a paid job, housework, and childcare. Thus, “women more often juggle three spheres- job, children, and housework- while most men juggle two-job and children” (HocSHChild, 2003:9). This undoubtedly makes women more likely to suffer from ill health than men, and their busy schedule makes them sacrifice their health.

5.6 Summary:

Women’s status in a matrilineal society is considered higher than in a patrilineal society. Their freedom of movement enables them to attend school and engage in economic activity. Women’s access to land resources also enables them to decide their occupation or labor activity (Jeffrey, 2005). However, education and access to financial resources alone do not guarantee health literacy for women, even in a matrilineal society. The context in which the Pnar women grow, age, work, and life, even if it is matrilineal, does not ensure their access to education and job opportunities. The erstwhile Jaintia Hills district is considered backward and underdeveloped in education and health. People living in villages historically lack access to basic facilities such as educational and health institutions, electricity, banks, post office, and even roads which are the only means of transportation, are largely unsurfaced (Nayak & Thomas, 2007).

This is evident from the present study, where most women are deprived of education and basic health information. Information related to diabetes was largely incomplete and spread through word of mouth depending on women’s lived experiences with diabetes. The lay explanation as discussed includes- diabetes is perceived as a new disease by elderly women who have just heard about the disease. For them, the emergence of diabetes is due to the shift from traditional farming practices to extensively using fertilizers and pesticides. While reflecting on their past, they shared the changes they had observed in their children and grandchildren. In their

village, people have stopped the consumption of wild fruits and vegetables, which the tribal population usually depends upon, and shifted to consuming fruits and vegetables imported from outside the state. According to them, this is the main risk factor for diabetes and other newer diseases. Middle-aged women assumed diabetes was in their elderly parents during the olden days. According to them, the doctors' ignorance of the "sugar test" makes them unaware of the health condition of their parents. Based on their experience of living with diabetes, women attributed their craving for pork, bakery products, and sweets before they were diagnosed with diabetes to signs of diabetes. However, according to them, they were not aware of it until when they became sick and had to go to the doctor. They learned that "these must be the signs that diabetes had been in their body for a long time."

The study clearly shows that women, irrespective of their education, have limited or almost no knowledge about the three classic symptoms of diabetes which are increased thirst, hunger, and urination. They are also not aware of the complications of diabetes. However, only a few women know the complications of diabetes, which they learned based on their own experiences and observation of their friends, relatives, or family members. These few women are privileged to have children or relatives who are doctors and nurses. Thus, there is a variation in the study related to awareness about the complications of diabetes across women as they belong to different socio-economic groups having different means of access to information. This knowledge thus helps these groups of women understand the importance of management of diabetes in terms of keeping their blood sugar under control.

Women in the study mentioned various home remedies and wild herbs in controlling their blood sugar. This knowledge based on their experience could be attributed to their active role in agricultural and food production activities. Ene-Obong et al. (2017) argues that women played a crucial role in ensuring food diversity in their households. Thus, this might impact women's knowledge about the types of vegetables and herbs that help control their blood sugar. Besides home remedies and antidiabetic medicine, women who live in villages adjacent to National Highway 6 have also started using CAM to control their blood sugar. Healthcare practices beyond the country's tradition or not a part of mainstream healthcare delivery is referred to as CAM. In the 20th century, it has been observed that there is an increasing trend in the use of CAM in many

Western countries (Albert, 2014). Thus, this culture seems to have spread in a few well-connected villages through the company's agent who manufactured these medicines.

Given the fact that women largely understood diabetes from informal sources, therefore many misconceptions regarding diabetes have been noted. These include the misconception that diabetes is a short-term and episodic illness. Again, this misconception varies across women. Women who have lived with diabetes for a long time are aware of the chronic nature of diabetes, whereas those newly diagnosed with diabetes consider diabetes to be like a fever that can be cured. This misconception could negatively affect the management of diabetes as it might lead to complications when women stop going for follow-ups on the pretext that their diabetes is cured. Other practices that prove to be counterproductive in managing diabetes include- excessive consumption of carbohydrates in the form of rice and traditional rice-based snacks, walking barefoot while undertaking physical activity, and the misconception that taking antidiabetic drugs for a long duration could harm the kidney.

Depending on their occupation and also the perceived severity of diabetes, there is a variation in self-care practices for the management of diabetes across women. Women in the present study are not a homogeneous group. Women with secured sources of income, having highly qualified children as doctors, and working in the formal sector could follow a strict regimen in controlling their blood sugar through diet, exercises, and regular medication and follow-up. Whereas, for women who spend most of their time in the market and other people's houses or stone quarry sites, following the strict dietary regimen of eating small and frequent meals is difficult. They are left with no choice but to forego this advice and continue with medications if they cannot afford to go for a follow-up. The other challenges to regular follow-up include financial difficulties, geographical barriers, and many others, as discussed in Chapter Seven, which is on the utilization of health care services for diabetes by women. However, before understanding the utilization of healthcare services for diabetes, it is important to explore the existing healthcare services for diabetes treatment in the district. Healthcare organizations, as identified in the social determinants of health (SDH) framework by WHO, is an intermediary determinant of health that influence health outcomes (WHO, 2010). This is discussed in detail in the next Chapter.

Chapter Six

Diabetes Care and Management: Availability of Services and Healthcare Providers' Perspectives

Introduction:

The healthcare system which is an intermediary determinant of health, plays an important role in influencing the outcome of diabetes (Brown et al., 2004). According to Kleinman (1980), the healthcare system encompasses not only modern healthcare but also the folk or the traditional sector. The present chapter, therefore, attempts to discuss the plurality of treatment sources and services for diabetes care and management. Understanding the plurality of systems of medicine is necessary, especially their role in addressing the problems of diabetes. This will aid health planners and policymakers to further improve the services provided by these facilities, especially in public health facilities located in rural and tribal areas. The official public health systems constitute India's primary source of health services provision. This formal state-funded public health sector includes Sub Health Centres (SHCs)/Health and Wellness Centres (HWCs), Primary Health Centres (PHCs), Community Health Centres (CHCs), and District hospitals (DHs). In public health facilities, prevention and control of diabetes is carried out through the National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases, and Stroke (NPCDCS) implemented at different levels of public health facilities.

Apart from this, private healthcare providers also play a significant role in delivering healthcare services in Meghalaya. Private clinics are run by qualified individual doctors providing allopathic, Ayurvedic, and tribal medicine. The private health sector, particularly at the secondary level and tertiary level, includes nursing homes and super-specialty corporate hospitals (Baru, 1998). In Meghalaya, they are small compared to other developed states of India. Four big private hospitals in the state have confined themselves in Shillong, the state's capital. Apart from this, Mission Hospitals such as Nazareth Hospital aims to provide "compassionate, affordable, quality, and holistic care"⁵⁴ to the population of the state. In addition, private and public pharmacies

⁵⁴ Available at <https://www.nazarethshillong.in/> Accessed on 20th September 2022

directly dispense medicines for various ailments and constitute an important source of treatment for most people in poor socio-economic communities.

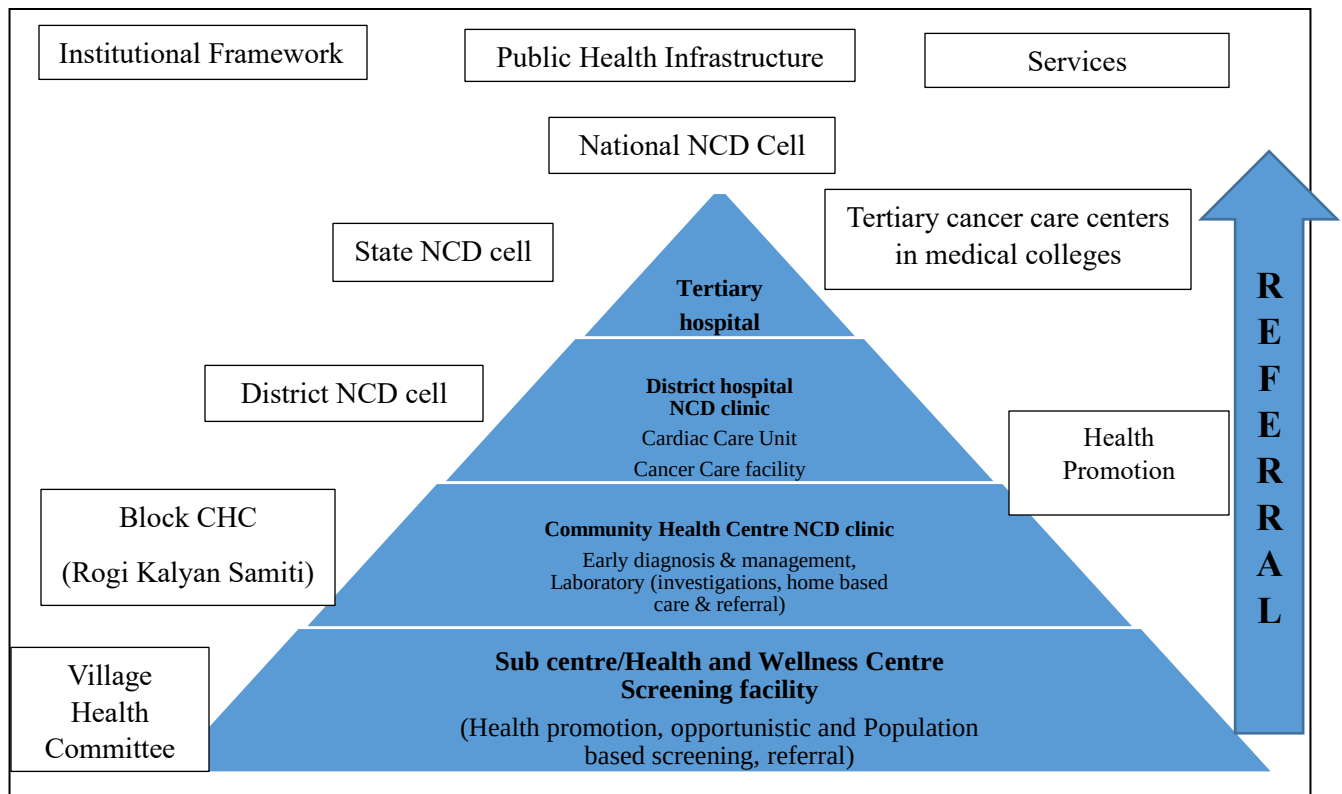
In Meghalaya, there is also a predominance of tribal traditional healers who constitutes an essential segment of care in the informal sector. Further, there are also several folk practitioners and healers, both registered and unregistered. Therefore, in the present chapter, I will describe the different services available in the health facilities that women access for diabetes care and management. Apart from analyzing the NPCDCS program's operational guidelines with respect to its implementation in the state, the chapter is also based on field interviews that I conducted with various health professionals and healthcare providers. Further, the chapter is also based on field notes of participant observation I undertook during fieldwork at the health facilities.

The chapter is divided into four major sections. Section 6.1, which forms the major portion of the chapter, focuses on discussing the provisioning of diabetes care at public health facilities through the implementation of the NPCDCS program. Section 6.2 of the chapter discusses the services for diabetes available at private health facilities, including those in the professional and folk sectors. Section 6.3 of the chapter explains the perspectives of healthcare providers on diabetes and its management, and Section 6.4 provides a summary of the chapter.

6.1 Provisioning of Diabetes Care Services in Public Health Facilities- NPCDCS Program

This section is based on field interviews conducted with healthcare officials, providers, and frontline workers at public health facilities and the analysis of the NPCDCS operational guidelines. The details about their background characteristics are enclosed in Annexure 13. This section aims to broadly describe and understand the key components of the program and the various activities to be undertaken based on the revised operational guidelines of the NPCDCS implemented at various levels of public health facilities. Figure 6.1 depicts the institutional structure of the NPCDCS program.

Figure 6.1 Structure of the NPCDCS program in India



Source: Adapted from the work of Selvaraj et al. (2022:166)

6.1.1 Packages of Services Available at Each Level of Public Health Facilities:

The Operational Guideline of the NPCDCS program was first issued in 2010. In 2013, the Government of India issued a revised guideline that discussed the detailed package of services to be delivered by different public health facilities, as shown in Table 6.1 below.

Table 6.1 Packages of services for NCD at each level of health facility

Health Facility	Packages of services
Sub Centre/HWC	• Health promotion for behaviour change and counselling • Population-based and Opportunistic Screening of Diabetes using glucometer kits and Blood Pressure measurement. • Awareness generation of early warning signals of common cancer • Referral of suspected cases to CHC/ nearby health facility
PHC	• Health promotion for behaviour change and counselling • Opportunistic Screening of Diabetes using glucometer kits and Blood Pressure measurement.

	• Clinical diagnosis and treatment of common cardio vascular diseases (CVDs), including Hypertension and Diabetes • Identification of early warning signals of common cancer • Referral of suspected cases to CHC
CHC/FRU	• Prevention and health promotion, including counselling • Early diagnosis through clinical and laboratory investigations • Management of common CVDs, diabetes, and stroke cases • Lab. investigations and Diagnostics: Blood sugar, Total Cholesterol, Lipid Profile, Blood Urea, X-Ray, Electrocardiography (ECG), Ultrasonography (USG) (To be outsourced, if not available), Opportunistic Screening of common cancers (Oral, Breast, and Cervix) • Referral of complicated cases to District Hospital/higher health care facility
District Hospital	• Diagnosis and management of cases of CVDs, Diabetes, Stroke, and Cancer (outpatient, inpatient, and intensive Care), including emergency services, particularly for Myocardial Infarction & Stroke. • Laboratory investigations and Diagnostics: Blood sugar, Lipid Profile, Kidney Function Test (KFT), X-Ray, ECG, USG, Echocardiogram (ECHO), Computed Tomography (CT) scan, Magnetic Resonance Imaging (MRI), etc. (To be outsourced, if not available) Referral of complicated cases to higher health care facility Health promotion for behaviour change and counselling • Opportunistic Screening of NCDs, including common cancers (Oral, Breast, and Cervix) • Follow-up chemotherapy in cancer cases, rehabilitation, and physiotherapy services

Source: Adapted from the operational guidelines for the National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases, and Stroke (GoI 2013:9)

With the launch HWCs under the Ayushman Bharat program, there has been much emphasis on providing comprehensive health services, including care for chronic illnesses. Thus, at the upgraded HWCs, the services to be provided include health promotion for behaviour change and counselling, screening for diabetes and hypertension, awareness generation, and referral of suspected cases (GoI, 2013:9). This is to be carried out by the ASHAs, ANMs, and MLHPs. The program's main components include activities undertaken concerning health promotion, opportunistic screening, diagnosis and treatment, referral, and capacity building of health staff (ibid). These are discussed thematically based on findings from the field and analysis of the program's operational guidelines.

6.1.2 Awareness and Information, Education and Communication (IEC) Related to Diabetes:

Awareness about the risk factors of chronic illnesses, promoting a healthy lifestyle, and curative services provided under the program have been publicized in Meghalaya through various

communication channels such as radio, television, and print media. Increased intake of healthy foods such as those which have low fat and low sugar content, increased physical activity through sports, exercise, etc., avoidance of tobacco and alcohol consumption, stress management, and warning signs of cancer constitutes the key message for creating community awareness about the risk factors of the NCDs (GoI, 2013:5). Primary prevention of diabetes through promoting healthy lifestyles and risk reduction has been widely recognized as a cost-effective intervention strategy for controlling diabetes (Venkataraman et al., 2009).

Community-level activities in villages related to the prevention of diabetes and health promotion are mandated to be conducted by ASHAs and ANMs. The ASHAs are expected to educate the community through home visits and meetings in collaboration with community-level organizations such as Village Health Sanitation and Nutrition Committee (VHSNC) and Village Health Councils. The ANMs can provide person-to-person, group health education and family counseling as avenues to create awareness about diabetes. They can also use health camps, campaigns, health melas, Village Health and Nutrition Day (VHND), and other channels to create awareness about diabetes in the community.

In all the health facilities visited, starting from Jowai Civil Hospital Ialong, Nartiang PHCs, and all the HWCs, it was observed that information education and communication (IEC) material related to diabetes was inadequate. On asking the ANMs and the MLHPs at the HWCs about the unavailability of the IEC materials, it became clear that they had to collect the materials from the district NCD cell. Their HWCs are located far from the district NCD cell, so they can only collect when they visit the NCD cell for other purposes, such as for attending meetings. The poster explaining NCDs, such as heart disease, diabetes, and its risk factors, was observed only at the Anganwadi Centre, where one HWC conducted the NCD screening. Another poster on NCD was observed at the emergency OPD of the Jowai Civil Hospital Ialong. The poster observed at the AWC, HWC, and the OPD of the Civil Hospital was in English, which might create a barrier to understanding the message, especially for patients who cannot read and understand the English language (Figure 6.2). IEC materials are very important for creating community awareness and promoting good health in the population. However, the absence of these materials is one of the shortcomings concerning the implementation of the program, given the fact that the program has been institutionalized since 2016 in the district.

6.1.2.1 Health Promotion and Awareness Generation by JCH, Ialong:

World Diabetes Day is observed every year on the 14th of November in all the public health facilities in the district. Similarly, JCH Ialong Hospital organized the program in collaboration with the district NCD cell as a part of awareness generation among patients coming to the OPD for check-ups and patient attendants. The theme of World Diabetes Day celebrated on 14th November 2020 in the midst of the COVID-19 pandemic, was titled “The Nurse and Diabetes.” It was observed that during the celebration of the program, the doctors and nurses of the hospital explained the risk factors and prevention of diabetes to around 50 participants of the program in Pnar language. Dr. Kilang, aged 42, health official associated with the program, explained the importance of consuming locally grown vegetables and food prepared at home and not those sold in the market which is high in sugar and fats, such as cold drinks. He also informed the people about the availability of the screening program at HWCs. As part of the World Diabetes Day Observation, screening for hypertension and diabetes was also conducted for individuals 30 years and above free of cost, unlike on other days where Rs. 50/- was charged for Random Blood Sugar (RBS) test. However, despite the announcement made for the screening program, out of the 50 people who attended the program, only 27 showed up at the “NCD clinic” of JCH, Ialong. Of the 27, there were 24 women, and only three were men.

Figure 6.2 A poster on diabetes displayed in one of the HWCs in English language



Source: Image captured at one HWC during the fieldwork carried out in 2022

6.1.3 Screening of Diabetes:

The program mandates that individuals aged 30 years and above must be screened for the five conditions –hypertension, diabetes, oral cancer, breast cancer, and cervical cancer at different levels starting from the HWCs, PHCs, CHCs, and District Hospitals. Screening populations at regular intervals helps in early diagnosis and reducing the complications caused due to NCDs, as suspected cases will be referred to higher-level health facilities. Diabetes is asymptomatic in its early stages; therefore, it can go “undiagnosed for many years” (American Diabetes Association (ADA), 2002: S21). Kumari et al. (2017) argue that screening is a good preventive method, as early detection of diabetes will prevent complications that are difficult to manage.

6.1.3.1 Definitions of Screening:

According to WHO (2003), “screening is the process of identifying those individuals who are at sufficiently high risk of a specific disorder to warrant further investigation or direct action” (WHO, 2003:5). While screening is conducted among asymptomatic individuals who are having the risk of suffering from diabetes, diagnostic tests are conducted for individuals with symptoms or signs of diseases such as increased urination, increased thirst, increased hunger, weight loss, and blurred vision (ADA, 2002). The positive screening test is usually followed by a diagnostic test to confirm the diagnosis. WHO (2003) mentioned three approaches for screening of diabetes; these include screening the entire population also known as population-based screening, opportunistic screening and selective or targeted screening.

- a) **Population-Based Screening** attempts to screen every person in the entire population. Under the program, it is mandated that all individuals in the age group of 30 years and above need to be screened (GoI, 2016).
- b) **Opportunistic Screening** is a screening conducted by health workers when patients visit the health facility to get themselves examined by health care providers for reasons other than those being screened-i.e., non-communicable diseases. The screening is opportunistic because, as the name suggests, patients visiting the health facilities for other illnesses were also screened for common NCDs (Kumari et al., 2017).
- c) **Selective or targeted screening** is conducted among the population subgroups at a higher risk of diabetes. These risks include age, body weight, ethnic origin, etc. (WHO, 2003).

In the study area, it was observed that only two approaches were employed for the screening of

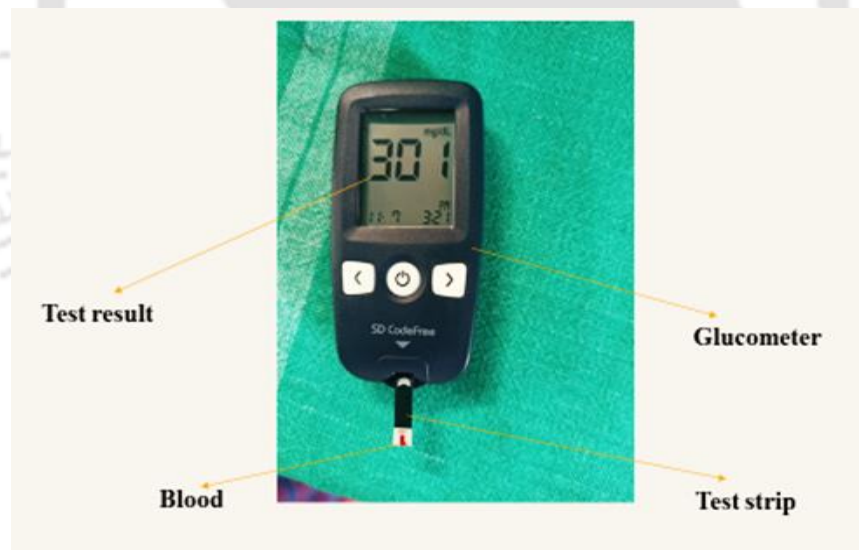
diabetes, i.e., opportunistic and population-based screening.

6.1.3.2 Equipment for Screening of Diabetes:

In the case of diabetes screening, there is a need for a glucometer, which is a medical device used to estimate the concentration of glucose in the blood. A small plastic strip used for inserting at the end of the glucometer, known as glucostrip or test strip, is an important consumable for effectively using a glucometer. The blood sugar cannot be checked without this strip, as a small drop of blood needs to be applied to this strip (Figure 6.3).

In the field, it was reported that the outbreak of the COVID-19 pandemic, the delay in the supply of glucometers and the irregular supply of glucostrip had disrupted the screening process. Although the NPCDCS program was implemented at the HWCs since 2019, they were provided with the glucometer only in October 2020. The population-based screening was only initiated in December 2020; only opportunistic hypertension screening was conducted earlier.

Figure 6.3. Checking of Random Blood Sugar (RBS) using a glucometer



Source: Image captured at one HWC during the fieldwork carried out in 2022

6.1.3.3 Screening at the Village Level: Findings from Six SHCs-HWCs:

In rural and remote areas, the HWCs or the Sub Health Centres, as they were known previously, form the most critical part of delivering health services in the public sector. It is the “first point of contact between the primary health care system community” and forms the basis for implementing national programs (Narlarwar & Saurav, 2018:160). Therefore, the success of any program will largely depend on the functioning of the sub centres (ibid). Before discussing the implementation of the population-based screening program in these HWCs, we will first briefly describe the HWCs visited in Table 6.2. The HWCs/SCs are named based on the village they are located.

a) General Description of the HWCs:

Table 6.2 General information on the HWCs visited

HWCs	Distance from the PHC/CHC (in Kms)	Total Population covered	Human Resources at the HWCs	No. of ASHAs	No. of Villages
Mynsgad HWC	8	5,777	1 MLHP, 1 ANM (R), 1 SW, 1 Chowkidar	7	4
Thadbamon HWC	26	5,368	1 MLHP, 2 ANMs (R&C), 1 Fieldworker, 1 Chowkidar (Security Guard)	8	8
Nonglatem HWC	20	2,911	1 MLHP, 1 ANM (C), 1 Surveillance worker, 1 Chowkidar	5	4
Rakabah HWC	28	4,875	1 MLHP, 1 ANM (R), 1 Surveillance worker, 1 Chowkidar	6	5
Nongjingi HWC	18	6,397	1 MLHP, 1- Surveillance worker, 2- Vaccinators, 1- chowkidar	8	11
Mynkrem HWC	22	2,495	1 MLHP, 1 ANM (C), 1-Vaccinator, 1-chowkidar	3	5
Nartiang Notional SC	0	5,981	2 ANMs (R&C)	3	2
Wahiajer HWC	2	8,282	1 MLHP, 2 ANMs (R&C), 1 Health Assistant, 1 Fieldworker, 1 MPW, 1 Chowkidar	6	6
Tyrchang HWC	4	3,382	1 MLHP, 2 ANMs (R), 1 Chowkidar	3	3
Moodymmai HWC	4	9,337	1 MLHP, 2 ANMs (R&C), 1 Fieldworker, 1 Chowkidar	5	9
Sohphoh HWC	10	3,532	1 MLHP, 1 ANM (R), 1 Chowkidar	8	7
Nongkhroh HWC	18	2, 872	1 MLHP, 1 ANM, 1 Fieldworker, 1 Chowkidar	4	3
Bamkamar HWC	30	2,242	1 MLHP, 1 ANM, 1 Chowkidar	4	4

Source: Data compiled from field notes; *R-Regular; C- Contractual

As per the Indian Public Health Standard (IPHS) guidelines 2022, one HWC is to cater to a population of 5,000 in plain and 3,000 in hilly areas (GoI, 2022). As the present study was conducted in hilly areas of the country therefore one HWC is supposed to cater to a population of 3000. However, eight of the twelve HWCs visited cater to more than the norm, with Moodymmai HWC covering more than thrice the population recommended (Table 6.2). This shows a huge shortage of health infrastructure, and the health workers are overburdened with many roles and responsibilities, which could hamper health service delivery at the community level.

At the notional Sub centre or Sub Centre co-located in village where there is PHC, MLHP is not posted as doctors are available at the PHC.

b) Opportunistic and Population-Based Screening (PBS) at HWCs:

At HWCs, opportunistic screening was started in 2019, and PBS was initiated in October 2020 by only the six HWCs. PBS for NCDs is a newer initiative started in 2017 in selected districts of India. Opportunistic screening at HWCs is one of the packages mandated by the NPCDCS operational guidelines. All individuals 30 years and above who visited the HWCs for other diseases were opportunistically screened for hypertension, diabetes, and oral and breast cancer (GoI, 2013). The ANMs or the MLHPs refer suspected cases to PHC or any nearest health facility. Based on the observation of training module for ASHAs and ANMs' an individual with an RBS of 140mg/dl should be referred to the PHC for further diagnosis and treatment. However, the present study found that in most cases, only individuals with RBS 200mg/dl or more are usually referred for confirmatory diagnosis.

Population-Based Screening (PBS) at HWCs:

The first step in population-based screening of NCDs is population enumeration. Population enumeration, also known as the line listing of individuals in the community, is carried out by the ASHAs before the screening and is supervised by the ANMs. In the HWCs, PBS of diabetes is supposed to be conducted once a week on a day designated by the frontline workers, and around 30 individuals should be screened. To plan for the screening, the ANMs, and the ASHAs were trained according to the modules prepared by the National Health Systems Resource Centre (NHSRC), New Delhi, the technical support group to the National Health Mission (NHM),

Government of India. The status of screening for diabetes which is mandated to be conducted annually, is one of the types of information recorded among others in the individual health record. Findings show that the ASHAs had already conducted population enumeration before the COVID-19 pandemic. The details are manually collected and filled in the family folder by the ASHAs. The information in the family folder includes the socio-economic profiles of the family and individual health records.

This is followed by gathering and filling up information in the Community Based Assessment Checklist (CBAC)⁵⁵ form restricted to individuals aged 30 years and above. For each CBAC form filled, ASHAs are paid INR 10 (USD 0.12) as an incentive. The ASHAs, ANMs, and the MLHPs coordinate to conduct the PBS. ASHAs conducted mobilization of the community before the screening day. As per the operational guidelines on “Prevention, Screening, and Control of Common Non-Communicable Diseases: Hypertension, Diabetes and Common Cancers (Oral, Breast, and Cervix) (Part of Comprehensive Primary Health Care)”– the principles of screening at the community level are- no individual should need to travel more than half an hour to be screened, and screening should be carried out according to standard protocols. Screening of diabetes can also be conducted through outreach services at the village level, such as the Anganwadi Centre or during Village Health and Nutrition Days (VHNDs) apart from the SHC-HWCs. Based on the screening records maintained by HWCs, an attempt was made to understand the different days on which PBS is conducted and the total number of individuals who participated in the screening as well as those who were referred. Table 6.3 below shows the number of people who attended the screening HWC-wise.

⁵⁵ Based on the observation of the CBAC and discussion with ASHA, it was found that the CBAC form include of three components- general information about the individual, risk assessment and early detection. In West Jaintia Hills, the form is translated to Khasi language. In risk assessment part, the ASHAs will have to ask six questions from the individual and accordingly provide scoring to each. She then has to tally the score and based on the total screening will be prioritized. But the ASHAs needs to remember that all individuals aged 30 years need to be screened irrespective of the scoring. As a part of early detection, it is the responsibility of the ASHAs to ask the individual if the person has any symptoms as mentioned in the CBAC form and accordingly refer to him or her to the PHC.

Table 6. 3 Findings from the population-based screening conducted by HWCs

HWCs	Date of the Visit	Total No. of individuals who attended the PBS	No. of individuals referred to PHC
Mynsnagad HWC	14 th December 2020	10 (8-women, 2-men)	None
Thadbamon HWC	17 th December 2020	10 (7- women, 3- men)	2 (both women)
Nonglatem HWC	21 st December 2020	6 (4-women, 2- men)	1 (woman)
Rakabah HWC	22 nd December 2020	9 (7-women, 2-men)	None
Nongjingi HWC	28 th December 2020	17 (16-women, 1-man)	None
Mynkrem HWC	7 th January 2020	None	None
Nartiang notional SC	12 th of January,2021 & 14 th of January,2021	1 st day- 45 (43- women, 2- men) 2 nd day- 34 (30-women, 4-men)	Six on the first day and seven on the second day

Source: Data compiled from field notes

Table 6.3 shows that most individuals who attended the population-based screening were women, and those suspected of diabetes were also mostly women. More women were attending the program because most are confined to domestic work at home or works in farms or nearby shops, and ASHAs can easily communicate the information about the screening to them. When asked for the reason for low attendance among males during the screening program- it became clear that men are usually out for work, and meeting them is challenging for frontline health workers. One of the main occupations of men in the district is driving taxis in the city. Therefore, they have to leave home early morning and come back late at night. Phyrnai, aged 42, an ASHA, shared:

Even during VHND, you will not see any men. Amongst women, it is only those who have young children who attend VHND. Sometimes, the mother sends their young children alone for vaccination as they trust us. The mothers say that they are busy with different work. Even during the home visit, it is difficult to find men at the house as they mostly go out for work.

c) **Benefits of the Screening Program: Experience in the field**

The screening process, if conducted regularly, proves to be beneficial not only in early diagnosis but also in following up on diagnosed cases of diabetes. During the screening program, awareness about the availability of services such as measurement of blood pressure and RBS under the NPCDCS program was also generated. As the screening process is not only being conducted

at the HWCs but also in places that are accessible to the people, such as the Anganwadi Centre,⁵⁶ hence people can easily attend the screening. For instance, patients previously diagnosed with diabetes but stopped going for regular follow-ups showed up during the screening. During the screening process conducted at the Anganwadi Centre of Nartiang village on 12th January 2021, Syntiew, aged 55, a widow and a daily wage laborer diagnosed with diabetes in July 2020, attended the screening program. She said: “I did not go to the PHC anymore as the last time (August 2020) I went, there was no medicine.” When her RBS was checked, it was found to be more than 300mg/dl. The ANM, who conducted the screening along with the ASHAs, referred her immediately to Nartiang PHC per the program’s protocol. The ANM also informed her regarding the availability of antidiabetic medicine at the PHC.

6.1.3.4 Opportunistic screening for diabetes at Nartiang PHC:

PHCs are the first point where qualified medical doctors and patients interact (GoI, 2022). The packages of services mandated at the PHC level for diabetes include health promotion for behavior change and counselling, opportunistic screening, clinical diagnosis, and treatment of diabetes (GoI, 2013:9). At the PHC, not all patients aged 30 years and above got their RBS checked. The decision for screening diabetes at the PHC depends on the clinical decision made by the doctor and also on the availability of glucostrips. Patients with symptoms of diabetes, such as increased hunger, increased thirst, increased urination, blurred vision, and complaint of tingling sensation, were usually advised for an RBS test. According to ADA (2002), testing patients with symptoms is considered diagnostic testing, not screening.

At PHCs, the existing staff provides services related to diabetes as there is no provision for separate staff under the NPCDCS program. The following Human Resources are providing services at the PHC on January 2021 (Table 6.4).

⁵⁶ A Centre where children between the age group of 0-6 years are provided with different food items to meet their nutritional needs. It is an initiative as a part of the Integrated Child Development Services of the Government of India.

Table 6.4 Human Resources (HR) at PHC (2020-2021)

Sl. No.	Designation	In position
1.	Medical Officer-MBBS	2 (1- Regular;1- Adhoc basis)
2.	Dentist	1 (Regular)
3.	Pharmacist	2 (Regular)
4.	Laboratory Technician	2 (1- Officiating; 1- Contractual)
5.	Health Educator	1 (Regular)
6.	Staff Nurse (GNMs)	7 (3-Regular; 4- Contractual)
7.	Lady Health Visitor (LHV)	1 (Regular)
8.	ANMs	4 (2-Regular; 2-Contractual)
9.	Sanitary Inspector	1 (Regular)

Source: Data compiled from field notes

At the PHC, the RBS of people 30 years and above is checked by laboratory technicians depending on the doctor's advice at the PHC. Similarly, confirmatory tests are also conducted by laboratory technicians using a glucometer. A staff nurse assigned to the program enters the patient's socio-demographic details in the NCD register.

6.1.3.5 Opportunistic Screening for Diabetes at JCH, Ialong/District Hospital:

District Hospital is an important component of the public health system, providing secondary-level healthcare services. Promotive, preventive, and curative healthcare services are mandated to be provided at the District Hospital (GoI, 2022). Similarly, for diabetes, services provided at the district hospital include preventive, promotive, and curative care. The program also necessitates setting up new infrastructures, such as the CHCs and district hospital NCD clinic, to provide screening, diagnosis, and treatment. As per the guidelines, the NCD clinic is to be manned by health workers such as doctors, nurses, laboratory technicians, physiotherapists, counselors, and data entry operators (Table 6.5). To a large extent, most of these health workers are recruited on a contractual basis (GoI, 2017).

As mandated by the program, the packages of services related to diabetes in the district hospital are to be provided through the "NCD clinic." The program stated that financial support would be provided to set up the clinic. In October-November 2020, when the fieldwork was conducted in the hospital, the Emergency OPD is being utilized as an "NCD clinic" due to space constraints. The Emergency OPD is known to patients as Room No. 107. The NCD clinic started

functioning in 2016 when the program was implemented in the district and is manned by two staff nurses, one laboratory technician, one physiotherapist, and one Data Entry Operator (Table 6.5). However, it was only until 12 November 2020 that a new doctor for the program was appointed. The post has been vacant since 2016. Diagnosis and treatment of diabetes are therefore made by the two medicine specialists and medical officers in the hospital.

Table 6.5 Human Resources at NCD clinic (2020-2021)

Human Resources	District Hospital			CHC		
	Sanctioned	In Position	Vacant	Sanctioned	In Position	Vacant
General Physician	1	0	1	1	NCD clinic is yet to be established at Ummulong CHC	
GNM	2	2	0	1		
Laboratory Technician	1	1	0	1		
Physiotherapist	1	1	0	0		
Counsellor	1	0	1	1		
Data Entry Operator	1	1	0	1		

Source: Data compiled from field notes

In both Nartiang PHC and JCH, Ialong, screening of all patients aged 30 years and above is not conducted due to constraints of resources such as an irregular supply of glucostrips. Further, patients visiting for other health conditions, such as dental problems or Ear, Nose, and Throat (ENT) problems, do not consider the need for checking their blood pressure or blood sugar. The other reason is that during the time of registration or entry to the hospital, patients were not instructed by the staff at the registration counter regarding the need to go to the “NCD clinic.”

The data analysis for one day to understand the low number of patients who visited the NCD Clinic/Room No. 107 shows that not all patients who are 30 years and above visited the NCD Clinic/Room No. 107 of JCH, Ialong. The patients who got screened are mostly those coming to medicine and surgery OPD. It may be mentioned that both departments are located on the same floor and near the NCD clinic/Room No. 107, thus making it accessible for the patient. Patients who visit the hospital for Ear, Nose and Throat (ENT), dental, or eye-related problems are usually missed in the screening program as they directly visit these OPDs located on another floor of the hospital or in another building of the hospital campus- for example, the ENT OPD is located in a separate building in the hospital campus.

Opportunistic screening is conducted at the hospital daily. The procedure is after the registration process, patients who waited near the doctor's consultation room were called by the NCD nurse to check their blood pressure, height, and weight. As in the case of HWCs and PHCs, she also has to record similar information in the NCD register. The RBS is checked at the laboratory by the laboratory technician. RBS is only checked after history taking, Precious, aged, an "NCD Nurse" for the last three months, said: "if there is no history of diabetes and if it is checked already within 2-4 months, it will not be checked anymore, if there is history and was not checked for many months, we used to check it by ourselves when we have time otherwise, we advise patients to go to the laboratory." The RBS test is charged Rs.50. When asked why the test was charged, Santi, aged 32, laboratory technician who worked for two years seems confused said: "We were told we need to buy reagents and we need money for purchasing and that is why." At JCH, Ialong, screening is done before the doctor's consultation, unlike in the PHC, where it happens just the reverse.

6.1.4 Diagnosis, Treatment, and Follow-up of Diabetes:

6.1.4.1 Diagnosis of Diabetes:

Suspected cases of diabetes identified through the screening at HWCs are referred to Nartiang PHC by the MLHPs for confirmatory testing, diagnosis, and treatment. Fasting Blood Sugar (FBS) and Post Prandial Blood Sugar (PPBS) are the two confirmatory tests conducted at the PHC using a glucometer. At the PHC, diagnosis of diabetes is made by allopathic and Ayurvedic doctors. Patients with RBS of 200mg/dl or more are usually advised to undergo confirmatory tests- Post Prandial Blood Sugar (PPBS) and Fasting Blood Sugar (FBS). Similarly, at JCH, Ialong, patients with symptoms of diabetes and having RBS of 200mg/dl are usually advised for confirmatory tests. Besides the two confirmatory tests-HbA1c or glycated hemoglobin (as the name suggests, it is a fraction of hemoglobin in the RBCs, which has glucose attached to it), is also advised by medicine specialists at JCH, Ialong. According to the medicine specialist, Dr. Yowan, aged 30: "If the HbA1c is more than 6.5, the patient is considered to have diabetes. HbA1c is required to monitor patients' blood sugar after four weeks to three months to understand the self-management of diabetes."

The NPCDCS program mandated that the diagnosis of diabetes be made according to the WHO (1999) criteria, as shown in Table 6.6. In the present study, the capillary blood sugar test or

finger prick using a glucometer is used, and not venous blood hence the reading for post food, /post glucose/post-meal which was > 200 mg/dl cut off as shown in Table 6.6 is revised to >220 mg/dl. Thus, patients with fasting glucose of more than or equal to 126 mg/dl and two-hour post-meal glucose of more than 220 mg/dl are diagnosed with diabetes.

Table 6.6 Criteria for diagnosis of T2DM using venous blood samples according to WHO definition 1999

	Fasting Glucose (mg/dl)	2-hour Post-Glucose Load (mg/dl)
Diabetes Mellitus	≥ 126	≥ 200
Impaired Glucose Tolerance	< 126 and	>140 to <200
Impaired Fasting Glucose	≥ 110 to 126	

Source: WHO criteria for diagnosis of diabetes (1999:6)

Pre-diabetes

The 10th edition of the Diabetes Atlas of the International Diabetes Federation (2021) also mentioned two more conditions:

- 1) Impaired glucose tolerance (IGT)
- 2) Impaired Fasting glucose (IFG)

The two conditions are raised blood glucose levels above the normal range and below the recommended diabetes diagnostic threshold. The condition is termed “prediabetes” or non-diabetic “hyperglycaemia” or “intermediate hyperglycaemia” (IDF, 2019:13-15). It is crucial to recognize the importance of IGT and IFG as these conditions signify the risk of the future development of diabetes and denote the risk of cardiovascular diseases such as heart attacks and strokes (ADA, 2002; WHO, 2016). Detection of IGT and IFG can lead to the prevention of diabetes (IDF, 2019).

However, it was observed from the field that counselling and follow-up mechanisms for patients diagnosed with pre-diabetes are absent at the PHC and JCH, along due to the absence of counsellors and dietitians.

The data analysis provided by the West Jaintia Hill district and the State NCD cell shows that the number of women diagnosed with diabetes at public health facilities is higher among women than men (Tables 6.7 and 6.8).

Table 6.7 No. of men and women newly diagnosed with NCDs during 2019-20 at Public Health facilities (PHCs/CHCs/District Hospital) in West Jaintia Hills, District

No. newly diagnosed with	Men	Women	Total
Diabetes Only	185	307	492
Hypertension Only	686	1182	1868
Hypertension and diabetes	48	46	94
Stroke	39	32	71
Chronic Obstructive Pulmonary Disease	87	31	118
Chronic Kidney Diseases	32	14	46
Other cancers	14	3	17

Source: Data provided by District NCD cell

Table 6.8 No. of men and women newly diagnosed with NCDs during 2020-21 at Public Health facilities in Meghalaya

No. newly diagnosed with	Men	Women	Total
Diabetes Only	930	2106	3036
Hypertension Only	2362	3585	5945
Hypertension and diabetes	308	703	1011
Cardiovascular Diseases	24	21	45
Stroke	101	60	161
Chronic Obstructive Pulmonary Disease	124	42	166
Chronic Kidney Diseases	41	30	71
Oral Cancers	66	23	89
Breast Cancer	0	30	30
Cervical Cancer	0	27	27
Other cancers	196	88	284

Source: Data provided by State NCD cell

The above two tables also show that the number of those diagnosed with complicated NCDs, such as comorbidity of hypertension and diabetes, stroke, and chronic kidney diseases, is higher among men. Similarly, Chronic Obstructive Pulmonary Diseases (COPD) and cancers are higher among men. Preliminary findings from interviews conducted with healthcare providers and officials show poor health-seeking behavior among men in Meghalaya. This finding provides the scope for further research in Men's health.

6.1.4.2 Diabetes Treatment:

Diabetes treatment causes an enormous economic burden on the global healthcare system and economy (WHO, 2016). Further, people suffering from diabetes and their families incur high out-of-pocket expenditures and suffer a loss of wages due to disability associated with diabetes

and premature deaths (ibid). Diabetes, like any other chronic disease, requires long-term treatment. To reduce the out-of-pocket expenditure on the management of diabetes, the NPCDCS program also aims to provide free diagnostic services and anti-diabetic medicines in public health facilities.

At HWCs, the main aim is to provide free anti-diabetic medications closer home for those coming for follow-up. The objective is to reduce travel and medicines expenditures (GoI, 2018b). At the HWCs, anti-diabetic medicines can only be dispensed and not prescribed by the MLHPs to patients diagnosed with diabetes. The doctors at Nartiang PHC make the diagnosis and initiate the treatment. All complicated cases of NCDs coming to Nartiang PHC, including diabetes, are referred to JCH, Ialong.

As discussed earlier, Oral Hypoglycemic Agents (OHAs) or antidiabetic drugs are also provided under the NPCDCS program at Jowai Civil Hospital Ialong. During one month of fieldwork at JCH Ialong, it was observed that there was no interrupted supply of oral antidiabetic drugs. However, Dr. Kilang, a medicine specialist, said there were instances of shortages of anti-diabetic drugs. The OHAs or antidiabetic drugs supplied to the public health facilities under the NPCDCS include- metformin (500mg and 1000mg) and glimepiride (1mg and 2mg).

Dr. Kilang shared that metformin is the first line of drugs commonly prescribed for patients diagnosed with diabetes. However, in the case of uncontrolled diabetes, glimepiride or a combination of metformin, glimepiride, and other OHAs is also prescribed. For advanced diabetes cases, insulin is initiated by the clinicians.⁵⁷ In most of the cases, it has been observed in the study that only patients who got admitted were prescribed insulin. Antidiabetic medicines are usually prescribed for 15 or 30 days, depending on the clinical decision of the doctors and the patient's condition. The prescriptions for the duration of taking the medicines also depend on the availability of antidiabetic medicines at public health facilities.

Diagnosis and treatment of diabetes at JCH, Ialong is made by the Medicine Specialists or MBBS doctors on duty and by an Ayurvedic physician at the Ayurvedic clinic of JCH, Ialong. Although diabetes can be treated in the hospital, in case of complications such as chronic kidney disease, patients are usually referred to higher centers such as NEIGRIHMS and Civil Hospital in

⁵⁷ Information collected from the interview with Medicine Specialists.

Shillong. This is because the hospital still lacks specialists and infrastructure to provide advanced care to patients with complications due to diabetes.

6.1.4.3 Follow-Up Care for Diabetes:

Follow-up of people with diabetes in the community is yet to be carried out by the ASHAs. It was observed that hardly two to three patients attended each HWC per month for follow-up care of diabetes, such as checking their RBS and collecting antidiabetic medicines in case it is available in stock. At the PHC, a register to track patients coming for follow-up of diabetes is maintained. When asked about the follow-up status, Dr. Pynhun, aged, 43, an allopathic doctor said: “The follow-up is very poor. Patients diagnosed with hypertension or diabetes come once or twice and disappear.” This is supported by the findings from the register where patients who were diagnosed with diabetes was recorded. It was observed that they either come back after one year or only when the symptoms get severe. The data analysis from the follow-up register maintained by the doctors showed that, from November 2019 to January 2021, only eight patients visited the facility twice, and five visited thrice for follow-up. Although in the community, the ANMs or the ASHAs are responsible for making follow-up visits to ensure compliance with treatment, there is no mechanism for reminding the patient to come for follow-up from the health system side.

At JCH, Ialong, apart from the NCD register, no electronic health record system tracks patients coming for follow-up. When asked how the doctors know about the past treatment given by them, Dr. Kilang said: “This is verified through the treatment history from the old records that the patient used to bring to OPD or indoor patient department.” Similarly, Dr. Yowan, the medicine specialist, said: “Through the prescription slip, patients usually brought the old prescription slip with them. Services or medicines provided to the patients are recorded in his or her OPD ticket, including diagnosis and prescription.”

In all the public health facilities visited, it was reported by the healthcare providers that there is poor treatment follow-up for diabetes. The health facilities also have no mechanism to track and ensure patients come for follow-ups. Bhojani et al. (2013), in their study on health system challenges in organizing quality diabetes care for the urban poor in Karnataka, South India, also found the same. There is no active reminder for patients to come for follow-up in both public and private healthcare facilities. Chronic diseases like diabetes require long-term treatment; hence,

follow-up is necessary to control blood glucose. Beaglehole et al. (2008), in their work entitled “Improving the prevention and management of chronic disease in low-income and middle-income countries: a priority for primary healthcare,” argue that although the aim of primary healthcare is for the prevention and management of chronic diseases, service delivery is however compromised as the focus is more on acute illnesses. Primary health care design usually involves the follow-up visit plan for patients with chronic diseases.

Lack of knowledge about diabetes also affects the ability to manage the disease (Venkataraman et al., 2009). Poor follow-up at the public health facilities visited could be because patients perceived diabetes as low risk. This is reflected in the lack of attention to maintaining the records. Patients coming for follow-ups hardly bring the past prescription slip, making it difficult for the doctor to track past treatment. The female doctor said patients never carry their old prescription slips when they come to the PHC, so it is difficult to know the past treatment since thousands of patients visit the PHC monthly. Based on the observation, patients hardly come with an old prescription slip. When asked about the old prescription, most patients said: “It is lost,” or “do not remember where I have kept it.” Hence, interventions from the health system’s side, such as patient education and patient reminders, can motivate patients to come for regular follow-ups (Weingarten et al., 2002).

6.1.5 Recording and Reporting of Diabetes Care: Digitization of Health Information:

At the HWCs, all the activities related to screening, referral, and follow-up of NCDs, including diabetes, are mostly recorded in the NCD register by the MLHPs. The information from the NCD register is then collected and updated in the monthly reporting formats required to submit to the PHC. There are numerous NCDs related reporting formats and these include Form 1, which is under the NPCDCS program, where the total number of people screened and attended the HWCs for follow-up are recorded. Besides this format, there is another form known as the HWC format, which is in hard copy, and the soft copy of the form is available on the tablet of the ANMs/MLHPs in the HWC portal. At the SHC-HWCs, apart from the reporting formats, the “NCD Application” installed in the ANMs’ tablet is also used to record information of individuals screened for NCD. The application is linked to the NCD app at Nartiang PHC.

In 2018, Dell developed the NCD Application for the MoHFW, GoI, to digitalize the NCD-related records maintained by the frontline workers, thereby facilitating the process of referral and

treatment (GoI, 2020). The other aim of the application is to ensure continuity of care as a record of each individual will be made available in all the levels of health care facilities. The major data elements of the application include “enrolment, CBAC, screening, examination, diagnosis, treatment, laboratory, drugs, investigations, follow-up, and referral” (GoI, 2020:4). Through this application, the frontline workers will develop electronic health records for each individual, in which his or her health status will be updated regularly.

At the PHC, the nurse assigned to the NPCDCS program is burdened with much clinical work. The data quality is poor, with repeated counting of patients screened or diagnosed in a month. For instance, the indicator in the monthly reporting forms (Form 2 of the NPCDCS), i.e. “total no. of persons attended a clinic for NCD (new and follow up),” does not reflect the exact number of patients. Some patients might attend the PHC twice or thrice and be recorded repeatedly.

The NCD App was not yet fully functioning at Nartiang PHC during fieldwork as no one was operating the Application. The Medical Officer in charge of the PHC shared that entering every detail of a person requiring NCD care is challenging as it is time-consuming. Therefore, at the PHC, there is no staff to update the application. At Jowai Civil Hospital, Ialong, apart from the NCD register and Form 4, the monthly reporting format of the NPCDCS for District Hospitals, there is no electronic health record system to track patients coming for follow-up.

The NCD app needs to be linked with the district health administration, where the program’s health officials can monitor the progress and estimate the burden of NCD (GoI, 2018). Updates from the “NCD App” and HWC portal are being provided to the district in real-time by the HWCs related to their progress. Through the portal, the states and the districts can monitor the operationalization of the HWCs and accordingly track their progress. The status of NCD screening, newly diagnosed cases, and the number of patients under treatment for NCD, wellness sessions organized, and teleconsultation done are some of the primary data elements of the HWC portal (GoI, 2020).

In the present study, although, at the grass-root level, efforts have been made to the digitalized health record, such a system for tracking follow-up is yet to be made fully functional at the PHC and JCH, Ialong. When asked about the absence of the NCD app at the district hospital, Nicky aged 33, a district health official, said, “We did not get instruction yet to implement it at the

district hospital.” Therefore, the doctors are relying on the patients past prescription slip only at present to know the past treatment given by them.

6.1.6 Program Management: Functions of State and District NCD cell:

The NPCDCS program mandates setting up the NCD cell at the National, State, and District levels to implement and supervise the program's activities. NCD cell at each level is necessary to carry out the administrative functions of the NPCDCS program (Figure 6.1). In the present study, a visit was made to both State and District NCD cells. The State NCD cell is located within the building of the Directorate of Health Services, Shillong, and the district NCD cell, West Jaintia Hills district, is located in an old building adjacent to the office of the District Medical and Health Officer.

6.1.6.1 Implementation of the Program in the State and West Jaintia Hills:

The program was initially implemented in 2014-15 in two districts of the state- East Khasi Hills and West Garo Hills district. When asked about the rationale for selecting these districts, the state health official, Tom, aged 31, a state health official, said:

We just joined in 2019, and it is a new program, so the previous officials may want to start it first in these two districts as a pilot and then roll it out to other districts later. The selection of the districts was random.

And as the senior official, Dr. Silva, aged 51, a state health official is also new to the program; she could not provide the rationale for selecting the district when the program was first implemented. In West Jaintia Hills, the program was implemented in 2016-17, and since 2018-19, the program has been implemented in the whole state.

6.1.6.2 Human Resources at the State and NCD Cell:

As per the NPCDCS program's operational guidelines, a State Nodal Officer and District Nodal Officer who is an MBBS by qualification should head the State and District NCD cell, along with assistance from other contractual staff. Table 6.9 below shows the status of human resources at the state and district NCD cells. While at the state NCD cell, all the required posts were filled. The program officer and coordinator posts were vacant at the district NCD cell. All State and district NCD cell officials were recruited contractually, except the State and District Nodal Officer.

Table 6.9 Human Resources at the state and district NCD Cell (2020-2021)

Human Resource	State NCD Cell			District NCD Cell		
	Sanctioned	In Position	Vacant	Sanctioned	In Position	Vacant
Program Officer	1	1	0	1	0	1
Program Coordinator	1	1	0	1	0	1
Finance-cum-Logistic Consultant	1	1	0	1	1	0
Data Entry Operator	1	1	0	1	1	0

Source: Adapted from the operational guidelines for the National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases, and Stroke (GoI, 2013)

6.1.6.3 Functions of the State and District NCD Cell:

Each State and District NCD cell official has different roles and responsibilities. Besides the NPCDCS, officials at the State NCD cell managed two other programs –the National Program for Health Care of Elderly (NPHCE) and the National Program for Palliative Care (NPPC). Similarly, besides the NPCDCS program at the district level, the officials have to manage many other programs.

The State NCD cell is headed by the State Nodal Officer and assisted by other officials- the State Program Officer, State Program Coordinator, and the State Finance-cum-Logistic Consultant. The main function of the State NCD cell is to plan, organize, and monitor NCD-related activities. The state officials are also responsible for designing and developing Information, Education and Communication (IEC) materials for the NPCDCS program. The state official, Tom shared:

We are only the planners- we develop plans for procuring drugs, consumables, and equipment. We also go for regular monitoring visits to the district. We also develop IEC materials, translate them into Khasi and Garo languages, and then distribute them to the district. Concerning awareness, we are only giving IEC materials to the district. The implementers are the district officials only.

At the State level, numerous activities were undertaken to create awareness about NCDs. Tom shared:

We are trying through various platforms such as radio jingles, Doordarshan News (local news channel), and social media platform of the NHM like Facebook and Twitter, creating videos for playing during the health calendar day- like World Diabetes Day. Last year (2021), we developed and translated a booklet on dietary management for NCDs. We have given it to the district as per their requirement. There are the districts that made documentary films, and flip charts, which they distribute to their facilities, such as Ri Bhoi District. Some

of the districts are utilizing the services of the MLHPs as well. They perform a street play, which serves as a means of generating community awareness.

For the financial year 2021-22, the State NCD cell already supplied different IEC materials to all the districts. According to the State NCD cell official, the IEC materials supplied to West Jaintia Hills Districts include- 496 leaflets, 168 posters, and 340 NCD booklets. All of these IEC materials have been translated into Khasi and Garo languages.

In West Jaintia Hills, the district NCD cell functions under the supervision of the District Nodal Officer, an MBBS doctor by qualification, and in charge of eight other programs. She is assisted by several contractual staff such as the District Program Coordinator, Finance-cum-Logistics Consultant, and Data Entry Operator. Their main functions include “preparing the district action plan, maintaining and updating the district database for NCD, conducting training of health workers, maintaining fund flow, submitting financial reports to the state NCD cell, and convergence with NHM activities and other related departments” (GoI, 2013:18). At the district NCD cell, the district Finance-cum-Logistic Consultant has to manage many other programs besides the NPCDCS, given the busy schedule of the District Nodal Officer (DNO), due to the ongoing COVID-19 pandemic. The DNO is also the District Surveillance Officer of the Integrated Disease Surveillance Program (IDSP). When asked about the function of the district NCD cell, Nicky, aged 30, an official said:

It is per the operational guidelines (he was simultaneously reading it from his desktop). I am responsible for doing administrative work, including ensuring a supply of logistics to the public health facilities, processing the incentives of MLHPs, maintaining the accounts, and updating the HWC portal regularly. We also used to go on work tours to supervise and monitor activities in the field, organize training, and other related activities such as observation of the health calendar day.

Concerning monitoring and supervision, he said they regularly visit the field and used the HWC portal maintained at the HWCs to monitor their progress from the district NCD cell. The district NCD cell is also responsible for disseminating the IEC materials related to the prevention of diabetes to public health facilities. When asked about the status of the distribution of the material in the health facilities, Nicky said: “Yes, IEC materials are available in sufficient quantity.” But as mentioned earlier, IEC materials in the form of posters were observed in only a few health facilities and printed in English.

Planning and Organizing Training for Healthcare Providers on NCDs:

Given that most healthcare providers were largely trained in providing maternal and child health services only, there is a huge emphasis on training the human resources in healthcare facilities to provide effective services related to NCDs. Therefore, the other functions of the state NCD cell include organizing training and orientation on the latest program guidelines and applications, such as the NCD App for ANMs, MLHPs, and Medical Officers, as shared by one of its officials.

At the district level, the official shared about 273 ASHAs, 33 ANMs, 9 Staff Nurses, and 9 Medical Officers/trainers, and all the 20 MLHPs in the district have been trained under the NPCDCS program till 2020. The ASHAs were trained for five days on five common NCDs (Hypertension, Diabetes, Cervical cancer, Breast cancer, and Oral cancer) by the district trainers, who are a team of nurses who were promoted and posted as Supervisors or Health educators in the DM&HO's office. Modules were provided to them in the Khasi language. The ANMs were also trained for five days by the District Nodal Officer and provided with a module related to NCDs. Staff Nurses and Medical Officers were trained for three days.

Procurement of Logistics:

Procurement is done through the NHM as the NPCDCS program is under the umbrella of the NHM. As one of the state health officials mentioned earlier, one of their functions is planning to procure logistics such as drugs, equipment, and consumables. This is mainly carried out by the State Finance-cum-Logistic Consultant (FLC). Moreover, there is also a "State Expert Committee" consisting of a Chairman, Secretary, and members, including Nodal Officers of different national health programs, Specialists, and Medical Officers who make the decisions regarding the drugs to procure. Isabella, aged 42, state health official, shared:

All the health facilities in the State were asked to place their requirement in the software known as Drug and Vaccines Distribution and Management System (DVDMS). Accordingly, we placed the requirement before the procurement officer. The DVDMS is a software that links facilities of all districts with the State. After getting the logistics, we then supply it to the districts accordingly. Sometimes, the district makes irrational demands, so we must decide based on what is needed. Imagine one district once asked us for 500 BP instruments. So, like this situation, we try to verify with them before supplying what they demand.

When asked about the challenges in the procurement of drugs and if there is any shortages or report of stock out at the state level, Isabella, said:

No, we never have shortages of drugs, and we used to supply to the health facilities based on the indent they made. The supply was only interrupted during the COVID-19 pandemic. Otherwise, we never faced any shortages in medicines and even glucostrips.

Her argument, however, counters the findings from the public health facilities visited, where it was reported that there is a frequent and irregular supply of consumables and antidiabetic medicines. When the I was re-checking with her on why there were shortages of consumables like glucostrips and medicines like antidiabetic in the field. The state-level official Dr. Silva, said: “We have enough. It depends on the indent made by the districts. If they are not indenting, then, of course, they will face shortages.”

Concerning the frequent stock out of drugs at the HWCs, Dr. Silva said:

It depends on the HWCs staff. If the delays in indenting are from the PHC, they will have a shortage. Sometimes they do not even keep enough buffer stock. Otherwise, the problem with that is the failure of indenting because the staff at the sub-center cannot indent directly from the State. It must be indented at the PHC, their nearest facility. They give to the PHC from the district, and the PHC will give to the HWCs. Maybe the HWCs also exhaust their medicine at that time. We do not know. However, in the future, we will ensure that if they do not have the drugs at the PHC, they should get them from the district store. Otherwise, people have benefitted greatly from the HWCs, except there are few breaks in between.

Thus, it was observed that there was a disconnect or miscommunication between the healthcare providers and healthcare officials.

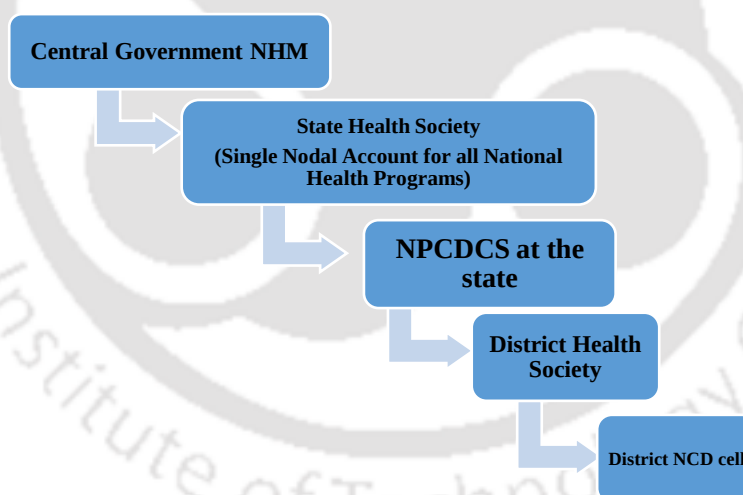
Based on the requisition, the state NCD cell supplied logistics to the district NCD cell. The district NCD cell then supplies them to the health facilities where the program is operational. The supplied equipment includes a glucometer, sphygmomanometer, weighing machines, stadiometer, consumables glucostrips, and lancet. The pharmacist carries out maintenance of the stock for antidiabetic drugs posted at the district NHM warehouse. The frequency of indent for antidiabetic drugs by the health facilities such as PHC, CHC, and the district NCD clinic depends on stock availability. However, the pharmacist reported challenges related to the supply of antidiabetic drugs, and said the drugs were last issued in July 2020. Despite the sophisticated software for indent and supply of drugs, irregular supply is still being reported in the field.

Data related to NCDs at the State and District NCD cell are maintained by Data Entry Operator (DEO). The main roles of the DEO include updating the data submitted by the districts to the State NCD cell and by public health facilities to the district NCD cell through the formats of the NPCDCS. DEOs are essential to maintain the data to understand the epidemiological situation of the State and the district. At the state level, data analysis related to the distribution of NCDs across districts was conducted by the State Epidemiologist/Program Officer. However, at the district level, based on the observation made, the data were not analyzed, given the fact that the DEO is not yet trained. Moreover, during the pandemic, a field visit at the district NCD cell was made, and the DEO was allotted COVID-19 duty.

Process of fund flow for the NPCDCS program:

The Government of India finances the program under the umbrella of NHM. At the state NCD cell, the state FLC is responsible for maintaining the funds for the NPCDCS program. Figure 6.4 shows the process of disbursement of funds from the central to the state and the district level.

Figure 6.4 Process of fund flow for the NPCDCS program



Source: Figure developed based on interviews

According to the information shared by Isabella, the State received the funds for NHM annually in the Single Nodal Account (SNA), which is the account for all the funds of National Health Programs. At the state level, funds are allocated to each district based on the approval made by the state. The district has to submit a monthly program implementation plan to the state, which the state will discuss and approve through the Record of Proceeding (ROP). The funds are then

disbursed to the district quarterly. The funds are broken into four parts based on the PIP prepared by the district. The transfer and flow of funds from the state to the district is through the Payment Financial Management System (PFMS). Since the financial year 2021-22, prepayment advice was introduced to make the transaction cashless. In this case, for each activity that they planned to conduct, the FLC of each district needs to prepare the Pre-Payment Advice (PPA) receipts and submit them to the FLC of the state NCD cell, which will then submit them to the bank where the SNA account was opened. Accordingly, the bank will pay the supplier. The PPA receipts submitted to the bank are like cheque books. This is how the allotment basis works. The district can do this for all the activities approved in their ROP. However, there is a limit set on the system where the district cannot spend more than what has been allotted for them. The official at the state NCD cell maintains the transaction made in the cash book. When asked about the shortages and delay of funds, Isabella said:

We have no shortages of funds at all for the program, nor is there a delay. When we first implemented the district, we received a huge amount of funds, but as the program was new, we did not know how to use it. As a result, we have a huge amount of unspent balance for two years. We were told to use the money. Otherwise, we will not receive any more funds. The unspent balance arises because we could not utilize it due to many challenges- for instance, we planned to make the coronary care unit (CCU- provision under the program) at Civil Hospital Shillong, but there was no space. So, we have to face these administrative challenges as well.

The district health official, Nicky, reported the delay in receiving the funds from the state but not its shortages. He said, “The funds are provided per the approval made in the Record of Proceeding (RoP) after the state submits the PIP.” In 2020, when fieldwork was conducted in the district, the district was not involved in making the PIP. Nicky also said: “Since 2019, the state has made the PIP. Earlier, it used to be by the district.” However, for the financial year 2021-22, the PIPs are again prepared by the district. This is as per the NHM guidelines, where the approach for preparation of PIPs should be “bottom up.” The block and district-level inputs are collated before sending to the state.

6.1.7 Gaps and Challenges in the Implementation of the NPCDCS Program:

At the management level, the district official, Nicky mentioned numerous challenges in implementing the program. These include- “disruption in screening process due to COVID-19 pandemic, the ANMs are overburdened and not familiar with new technology (NCD app), they are

having problems in operating the tablet despite the training, high turn-over of staff, lack of human resources, shortages of NCD medicine, no vehicle to go for a tour.” These gaps and challenges have been identified at each level of the health facilities and discussed thematically as follows.

6.1.7.1 Challenges in Conducting the PBS at the HWCs:

Following were the challenges noted in conducting the PBS at the HWCs:

- a) Although the training of ASHAs and ANMs has been completed since 2019, the population-based screening for NCDs was only started in October 2020. On 4th December 2020, a weekly Friday meeting with the frontline workers of the SHC-HWCs was held in the conference hall of the Nartiang PHC. From the meeting, it became clear that population-based screening of NCDs has not yet started at the SHC-HWCs. The meeting identified numerous reasons for the delay in population-based screening for NCDs. These include- “no proper place,” “no table and chairs,” “just received the glucometer and the glucostrips” and “people are not willing to come.” However, in the meeting, the MLHPs and the ANMs conveyed that population-based screening of NCDs will be initiated. The screening dates were also intimated to the Senior Medical and Health Officer In- charge of the PHC. The ongoing COVID-19 pandemic and the disruptions of essential services have further delayed initiating the population-based screening at the HWCs.
- b) Estimating the number of individuals in the age group of 30 years and above is reported to be a challenge by the ASHAs. This is due to out-migration within the district, making it difficult to give the exact number. Some of the ASHAs, therefore, have not completed filling out the CBAC form. Evelyn, aged 45, an ANM, shared:

Today the ASHA will collect the information in her village, but the next day that person will get married and shift to another village where his information will be collected again. In most cases, as men are usually out for work, it is difficult to know if their information has been collected. Hence, the chance of double counting is also expected while estimating the total population eligible for annual screening for diabetes.

Therefore, awareness about population enumeration under the NPCDCS program needs to be generated so that the people in the community will cooperate with the frontline workers and hence avoid all these complexities.

- c) The Problem of Repeated Screening: In the present study, the PBS of diabetes emphasized that all individuals aged 30 years and above must be screened for diabetes annually in case the test

result is normal. However, opportunistic screening at the PHC leads to multiple screenings of the same person whose test result was normal. Bethel, aged 40, an ANM, said:

We have to screen the people again even if they are screened here (at the PHC) because we also need to fill in the patients' information on our tablet (in the NCD App). This is because earlier patients' records might not be available anymore.

Thus, the importance of records needs to be emphasized to know the screening status of the person, thereby avoiding repeated screening in a year among individuals with normal RBS. With frequent stock out of glucostrip reported already, checking the RBS of the same person multiple times will further lead to the constraint of resources. While one person's RBS is checked multiple times a year, the other who attended the PHC or HWC during the stock out of glucostrip will not get the opportunity to get the RBS tested even when he/she is suspected of diabetes.

- d) Confusion Related to Program Guidelines for Referral of Suspected Diabetes Cases: As per the training module for ASHAs, ANMs, staff nurses, and medical officers, a referral from the screening site to the PHC should be made when RBS is more than 140 mg/dl for further investigation. The names of these individuals suspected of diabetes, when recorded in the NCD Application by the MLHPs/ANMs in the tablet, automatically get reflected in the NCD App at the PHC as referred, even when the patient is not physically referred yet. Practically, only individual with RBS of more than 200mg/dl is usually referred for confirmatory test by doctors. There is, thus, a mismatch between the guidelines and practice. Lall et al. (2019), in their study conducted on "Challenges in primary care for diabetes and hypertension: an observational study of the Kolar district in rural India," found that doctors at public health facilities were unaware of the treatment guidelines. Pudder and Keller (2003:532) argue that poor compliance with guidelines could be because of a "lack of knowledge about the guidelines, the doctor's belief about the guidelines, and the fact that these guidelines are based on relatively new data unknown to the physician." The beliefs and attitudes of the doctors also influence their adherence to the guidelines. According to the doctors interviewed at the JCH, Ialong, and Nartiang PHC: "As we consume rice, our RBS will be high, and even if it is 200 mg/dl, it is normal."

The practical challenge with referring individuals with RBS of 140mg/dl or more to the PHC is travel cost, as there is no provision for travel in the program. Thus, the individual referred will

question the staff on why he or she is being referred. The MLHP of one of the HWCs shared: The common response from patients whenever their report turns negative “It is useless, such a waste of time when nothing happens to us; why did they send us there.” Undoubtedly, one of the program’s objectives is early detection, but these practical challenges also need to be considered.

6.1.7.2 Irregular and Shortages in the Supply of Diagnostic Testing Kits and Medicines:

It was observed in the field that there is an irregular supply of glucostrip, which hampered the screening process for diabetes. For example, in one of the HWCs visited, the frontline workers were apprehensive about getting the supply of glucostrip on time based on their experience of delay in getting the supply. For instance, Ella, aged 25, an MLHP, shared:

Last time, we had indented the glucostrip in November 2020, but we got it after one month in December 2020. We were told it is unavailable at the District NCD cell as it is out of stock.

Given the unavailability and delay in receipt of glucostrip the frontline workers could not check the RBS for all the people visiting the HWC. The health workers thus decided to use the limited glucostrip judiciously and kept it only for checking the RBS of the person who was already diagnosed with diabetes. Hence, this does not allow for identifying new cases of diabetes in the community. Thus, we can observe from the field that the objective of screening all individuals in the age group of 30 years and above gets reduced to only people who come for follow-up at the HWC. Given the inadequacy of glucostrip, some of the HWCs do not announce the screening day for diabetes and only call a few people at a time. However, for the other seven HWCs, it was observed that glucostrips were available in sufficient quantities, and they did not report such a problem.

At the PHC, frequent stock-out of glucostrip, which sometimes lasts for three weeks or more, makes it difficult for patients who come for follow-up. Only one glucometer is functioning at the PHC. The glucometer is available only at the laboratory, which can be used only during the OPD timing, as the laboratory technicians are available only during OPD timing, and the glucometer is kept under their custody. In an emergency, and when patients need admission to the PHC ward, their RBS cannot be checked as the glucometer in the in-patient ward became non-functional for a long time. For instance, when Monlang, aged 42, a daily wage laborer, was admitted to Nartiang

PHC for three days, the nurse could not check her Fasting Blood Sugar until she was discharged, even when she was suspected of diabetes. She shared:

I was told to come again here without food to get my sugar tested, but I could not come at that time to the PHC as it is the harvesting season. Again, I went to Dr. Jenny (a private physician) at Ummulong as I was sick, she also told me that my sugar is high and I needed to come again and get my sugar tested without food...but I could not go because I was busy taking care of my children during that time....”

The previous record showed that her RBS was over 200mg/dl. However, due to the non-availability of glucostrip and glucometer in the in-patient ward, the nurse or doctor at the PHC could not confirm her diagnosis of diabetes. Moreover, the laboratory technicians used to come by 11:00 am to the PHC. Hence it is difficult for the patient to wait on an empty stomach to get the confirmatory test for diabetes done.

During the first phase of fieldwork in 2020, anti-diabetic medicines were unavailable in all the HWCs visited as population-based screening had just begun, and awareness about the availability of such services in the community is yet to be generated. However, anti-diabetic medicines were available during the second fieldwork phase in 2021 at these HWCs. Nonetheless, antidiabetic medicine such as metformin was out of stock at Moodymmai and Rakabah HWC. Frequent stock out of metformin was also reported at Nartiang PHC. Dr. Hannah, aged 29, an allopathic doctor, said: “At the PHC, there is one patient who used to come here to get diabetes treatment but now stopped, as the last time she came, the antidiabetic medicine was over.” The frequent stock out of antidiabetic medicine reported at the PHC is one of the reasons that demotivates the patients to go for a regular check-up at the PHC and also results in poor satisfaction with the service provided by the PHC.

However, officials at the state NCD cell argue that there should not be any disruption in the supply of antidiabetic drugs or consumables for screening as at the state, there is “a sufficient quantity of both.” Dr. Silva shared:

The challenge when it comes to ensuring the availability of NCD drugs is that staff at the periphery do not have the concept of maintaining a buffer stock. Buffer stock should be maintained to address the interrupted supply of NCD drugs. The supply of antidiabetic drugs was disrupted only during the COVID-19 pandemic. It was because of the disruption in the supply chain as the drugs were supplied outside the state at that time. Now we do not get any

more complaints. After the COVID-19 pandemic, the state DHS (MI)⁵⁸ and NHM also provide us the medicines, so we have a surplus of NCD drugs. With regards to diagnostics, there is a plan in 2022 to make all the laboratory tests available in-house, for instance, making the HbA1c available at the PHC.

In the situational analysis of diabetes care in public health facilities in India conducted by Tripathy et al. (2019), in both rural and urban districts of Delhi, Karnataka, and Maharashtra in 2016, it was reported that oral antidiabetic drugs were available in all the facilities they visited. But in their study, not only oral antidiabetic drugs were available in sufficient quantity at the district hospital they visited, but insulin was also available. This is not the case in the present study. Atre (2019), in his work on “the burden of diabetes in India,” argues that for many years, people still faced problems in availing of antidiabetic medicines from public health facilities. As a result, they are compelled to visit private practitioners. The long-term nature of diabetes has also led to high treatment costs, thus creating a huge burden to the patient and his or her family in the form of high out-of-pocket expenditure. Similarly, Birabwa et al. (2019) in their study to assess the quality of care and barriers to service delivery in rural districts of Uganda, found that inadequate supply of test strips and antidiabetic medicine are the most common barriers reported in the effective delivery of services for diabetes care. The fact that medicines and diagnostics are provided free of cost to patients is a matter of appreciation. Nevertheless, frequent stock-out might hamper the utilization of services for diabetes at these public health facilities.

Further, insulin injection, usually prescribed for patients with uncontrolled blood glucose, is not available at the JCH, Ialong, despite being the referral site for the district. Patients have to purchase it on their own from private pharmacies. There were 4-5 pharmacies located just outside the hospital premises. In their study on “Insulin prices, availability and affordability in 13 low-income and middle-income countries,” including India, Ewen et al. (2019) argue that insulin availability is poor because only three companies dominate the market. High price and inadequate funding by the government is linked to its poor availability at public health facilities. Therefore, the problems can only be addressed through national and global actions.

⁵⁸ Directorate of Health Services, Medical Institutions

6.1.7.3 Challenges Related to Human Resources:

Human resource-related challenges have been identified at each level of the health facilities. This could include conflicting roles and responsibilities, poor and inadequate training, and vacant posts.

a) Challenges Faced by ASHAs:

While performing their roles related to NCD, the ASHAs in the villages of West Jaintia Hills District reported that they faced lots of verbal abuse by some community members. Judgments such as “you are trying hard to come to us always and ask questions because you are going to get extra money right” were passed on to them. This demotivates the ASHAs to perform their activities. In one of the study villages, the headman did not permit the ASHA to go for home visits during the second wave of the COVID-19 pandemic. He considered the ASHAs to be the carrier of the COVID-19 infection, which was also reported as one of the reasons for the delay in filling out the village's Community Based Assessment Checklist (CBAC) form. The NPCDCS program recommended measuring waist circumference by the ASHA to assess NCD risk factors. The ASHAs, however, reported this as one of the challenges in filling out the CBAC form as they are not comfortable measuring the waist circumference of men, and some men even asked them questions like- “how can you do this? I think it is uncomfortable for you to do it by touching men’s bodies. Let me do it by myself.”

There is hardly any Multipurpose Worker Male (MPW-M) in the HWCs visited. Efforts were made to know the reason from the state officials for the fewer MPWs (Males) posted at the HWCs. The answer was that there is health worker (males), but the post-sanctioned is less. Ktai, aged 48, a senior Public Health Nurse who trained the ANMs for NCDs, said that although there are some MPWs or Health Assistants (male) in the state, but only the ANMs were called to attend the training for the NPCDCS program.

b) Conflict Roles and Responsibilities Between Healthcare Providers at HWC:

The fact that MLHPs who were newly added health cadre under the Ayushman Bharat in 2018 are also called CHOs creates confusion with the CHOs who were staff nurses appointed by

the State Government⁵⁹ on a regular basis. On asking why the MLHPs are not called CHOs in Meghalaya, a senior official, Dr. Pynhun, said:

It is because of this confusion. In Meghalaya, the CHOs under the HWCs are called MLHPs to avoid the clash in designation with the CHOs of the state government. The CHOs post is equivalent to Public Health Nurse (PHN).

Public Health Nurse is a post available at public health facilities per the Indian Public Health Standards. Although the designation is the same but the responsibilities are different. The main role of CHOs in HWCs is to supervise community-level activities of their concerned SHCs-HWCs; the CHOs under the state government are responsible for monitoring all the SHCs under the PHCs/CHCs, to which he or she is posted. Hence, there is confusion about these two cadres of health workers in the field area. Concerning the designation, Lily, aged 30, an MLHP, shared:

The CHOs feel threatened by our presence- the state seems to have a problem with our designation earlier. They told us that we would be called CHO, later on, MLHP, and now Health and Wellness Nurse.

With the change in designation, the cadre who initially joined the program as CHO are now disappointed, leading to low job satisfaction.

Earlier, before the introduction of the HWC, it was the ANMs who were trained to undertake the NCD screening program at the SC level. However, with the integration of MLHP into the HWC, the role related to NCD has shifted to the MLHPs. Blossom, aged 45, a senior nurse, said: “The MLHPs look into the NCD program, as the ANMs are already busy with many other programs.” In this case, the regular CHO refers to them as MLHPs, whereas those recruited as MLHPs under HWCs want them to be called CHOs. Further, with the introduction of MLHPs, most of the ANMs in the HWCs visited have restricted their roles to only Maternal and Child Health, and the entire responsibilities related to the NCD program has been shifted to MLHPs. However, in one of the HWCs, it was observed that the MLHP was also busy doing vaccination of infants and Tetanus Toxoid injections to pregnant women. Hence, most of the MLHPs working at the HWCs perform multiple roles related to MCH and NCD services. One of the MLHPs’ roles is to conduct NCD screening along with the ANMs. In addition, as part of providing clinical care,

⁵⁹ The Community Health Officers (CHOs) are Staff Nurses who are promoted as CHO. They are recruited on a regular post by the State Government.

the MLHPs need to coordinate with the medical officer or the medicine specialist to manage chronic illnesses after diagnosis of patients is made and they initiate treatment. The coordination can be achieved through the provision of telemedicine or teleconsultation. The MLHPs can also dispense drugs, but it has to be according to the medical officer's standing orders (GoI, 2018b).

The MLHPs seem to lack satisfaction in their job because they are not given full authority to perform their role. Although the advantages of MLHPs have been widely recognized, doctors' associations continue to oppose this initiative (WHO, 2020). This could probably be the reason for not delegating full authority to the MLHPs, given that doctors dominate the health system. Similarly, there seems to be dissatisfaction with the operationalized incentive structure for MLHP. For instance, Eleanor, aged 27, an MLHP said:

We are paid (INR) 25,000/- (USD 300.25) as salary but (INR) 15,000/- (USD 179.98) as performance-based incentives. We receive the incentives only if we perform the 15 indicators. We will not get it if we do not perform these work responsibilities. However, I have known others who just filled out the form for incentive without really performing their roles. But I do not feel this is the right thing to do. So, out of the (INR) 15,000/- (USD 179.98), I used to get only INR 2,000/- 3,000/- (USD 24.11-36.16). One of the officials used to tell me to fill out the form-such as yoga, so I could organize it one day and click photographs of it. However, we do not have anything to do those activities- such as a yoga mat, and the HWC building is still under construction.

Many of the MLHPs consider themselves doing the ANM's job and not theirs, according to the training imparted to them. Constraints of resources, such as shortages of medicine and consumables, and poor infrastructure to do the "wellness session," such as yoga, act as barriers to performing their roles.

The fact that the HWCs are not yet fully operational and awareness about the various services provided for NCDs is not publicized amongst the community could be one of the reasons for its underutilization. Hence, the MLHPs are busy "doing the ANM's job," as Dr. Elizabeth, aged 44, a district health official, opined. Eleanor, the MLHP, further shared:

I am the only one who did whatever the ANM told me to do and did not stick to my job responsibilities; as a result, I cannot do what I am supposed to do. I feel like I am the ANM's assistant. I understand that we should help each other, but I feel I cannot do much to provide all the services required by the HWC. We are not given the authority to practice what we are supposed to.

The recruitment of MLHPs was done before making changes in terms of creating awareness about the range of services that MLHPs are capable of providing at the HWCs. These challenges, if not addressed, can affect the implementation of the program at the HWCs, as job satisfaction is crucial to retain staff in remote and rural areas.

Most MLHPs are young women of reproductive age, but the policies are not friendly toward them. During the six months of maternity leave, her responsibilities will be kept pending as the ANMs do not consider the work of the MLHPs to be hers as well. My study shows that women within healthcare cadres are not a homogenous group, and there is a hierarchy based on their years of experience, age, educational qualification, and professional training.

Thus, we can apply the theory of intersectionality even within this group of women health workers. The ANM is considered “veteran” and powerful as she is regular and has years of experience, whereas the MLHP. However, she is young and well-trained when compared to the ANM. She is considered inferior to the ANM as her work is contractual. These power relations among women in terms of who is the health facility's “boss” also impact the health facilities' functioning at the community level. However, the tag of “Officer” and Team Leader in the CHO designation often makes ANM threaten her seniority position and years of work experience at the HWC as now the senior ANMs have to work to the instructions of the CHO constantly.

These power relations among healthcare providers and even among women in terms of who is the boss also impact the functioning of the health facilities at the community level (George, 2010). When the MLHP is on maternity leave, all the NCD-related services, including those for diabetes, are affected as the ANMs consider the tasks to be of the MLHPs without even considering the need to support the MLHPs or, for that matter, ensuring the continuous delivery of services for NCDs including diabetes. Sen and Ostlin (2010) argue that gender differences between men and women are a well-known fact. However, even among women, there can be important differences based on age, socio-economic status, race or caste, and ethnicity. In this case, women in the most advantageous positions are those as a regular cadre ANMs.

c) Recruitment for Vacant Posts:

The state-level officials shared that an order was released to terminate the recruitment of HR for vacant posts. Tom said:

We are having many problems related to Human Resources, as we cannot fill all the vacant posts anymore. This is as per the order which was released in 2019. All the vacant posts due to staff resignation cannot be filled anymore except for the posts of MLHPs. This is due to financial constraints as no more funds are available for HR. Recruitment of HR has become saturated. The existing HR from NHM will now have to look after other programs. For instance, in Jowai, where the District Program Coordinator (DPC) post is vacant, the District Program Manager is now responsible for performing the DPC roles.

Concerning staff turnover, Dr. Silva shared: “Now no more turnover (except MLHPs), if the staff resign the existing staff have to take over there is so much problem with HR now.” Regarding vacant posts such as that of a dietitian at JCH, Ialong, officials considered it an administrative issue. Dr. Silva said: “That is an administrative issue. We do whatever they told us to do”. Unless these issues are addressed at the state level, it will be difficult to ensure comprehensive care for diabetes at the district level.

d) Poor Training and Absence of Orientation for Regular Staff:

The program is known among the health care providers as the “NCD program,” but they were unaware of its functioning. The health care providers who play a crucial role in the screening of diabetes, such as the laboratory technicians, staff nurses, and the data entry operators, were not yet oriented about the program. This became clear during the interviews conducted with healthcare providers. Similarly, pharmacists and medical specialists were unaware of the NPCDCS program. The lack of orientation became clear when Dollie, aged 28, an ancillary staff said: “Look, I do not know if I am doing the reporting correctly. I did not understand what I am doing.” This could compromise the data quality, which is crucial in translating it to public health action. Inadequate training is also reflected in how information is recorded in the reporting formats, with many discrepancies observed.

A gap between the training and practice was also noted during fieldwork. For instance, the ANMs appear to have detached from the program completely. Instead, the MLHPs performed all the roles related to NCDs. One of the ASHAs at the HWCs asked me: “why do doctors always say that you have to take medicine for diabetes always.” Thus, knowledge about the long-term nature of diabetes seems to be lacking among the ASHAs. This was the case, although the district had trained and provided them with modules in the Khasi language. In one of the HWC visits, all the health workers, ASHAs, ANMs, and MLHPs, were newly recruited in the mid-2020s. They were

yet to receive the training for the NCD Program. Ella the MLHP, shared:

We are not yet trained on how to conduct the screening program. I got my permanent posting only in December 2020. The ANM and the ASHA are also new and not trained. Although we have called people for the screening, we doubt they will come as we are new, so it is difficult to convince the people to come.

Evelyn, an ANM reported the challenges she faced while cross-checking the CBAC forms filled out by the ASHA. After reading the form critically, she found that some individuals she knew were not suffering from hypertension, but the ASHAs marked them as hypertension. When Evelyn called the ASHA and enquired what symptoms the people were suffering and if it was a real case of hypertension, the ASHA said: “That person had complained of headache and feeling dizzy, so I marked them as hypertension case.” Therefore, this implies that the ASHAs might not have fully absorbed the training and skill provided to them. Thus, continuous support is required through monitoring and supervision. However, the Supervisors did not receive training or orientation related to the NCD program, making monitoring and supervision difficult. Blossom, a senior nurse said: “They did not give us any training. How will we know what they are supposed to do, and what do we need to ask from them?”

The other HR-related challenge is training new staff when the MLHPs leave for other jobs. As the MLHPs are recruited on a contractual basis, they are inclined to look for a secured job, which on getting a permanent posting, they will automatically resign. Hence, the state will have to recruit new staff and train them again. Concerning the frequent staff change due to resignation, Dr. Elizabeth said: “When will the work move forward if we end up giving training almost daily?” Nevertheless, for the program to be effective, it is essential to train all staff regularly to ensure that new staff is equipped to deliver diabetes care (Mamo et al., 2007).

6.1.7.4 Health Information System for Diabetes: Too Many Forms, Poor Data Quality:

An information system is crucial for any chronic disease program to track the patients’ registered under these programs. Similarly, the NPCDCS program mandates using an NCD register to record patients’ information. The demographic profile of patients is recorded along with information related to investigations, diagnosis, treatment, and follow-up of visits. Utilizing the information from the NCD register, the number of diabetes cases per month is recorded in the monthly reporting formats by the MLHPs or the ANMs in the SCs/HWCs, the staff nurse in

Nartiang PHC, and Data Entry Operator in JCH, Ialong.

The report from the HWCs is sent to the PHC, and at the PHC, reports from all the HWCs are compiled together. The report from the PHC and the compiled report of HWCs are sent directly to the District NCD cell. At the SHCs/HWCs, frequent change in the reporting formats was observed, and discrepancies in recording information in the forms were also observed. For instance, while the number of people in the treatment column was recorded as ten, no supply is written in the section on medicines. As a result, it is difficult to estimate how many people living with diabetes attended the HWCs for follow-up. Training for filling out the formats was given to the MLHPs only during their induction training. This was imparted to the MLHPs after their appointment but not after changing the formats. This could be because the program officials were busy with the COVID-19 pandemic. Therefore, attention given to the program is limited. Nevertheless, discrepancies in the recorded information indicate the need for skill assessment of the ANMs and the MLHPs to understand the training process's effectiveness and identify gaps. The information collected should not only aid in understanding the burden of chronic diseases such as diabetes and track patients for regular follow-ups at the SHC-HWCs, PHC, and the District Hospital. However, a system of tracking mechanisms is not in place at the District Hospital. The role played by district hospitals in providing diabetes care is indispensable. Still, poor reporting mechanisms and the absence of linkages with the peripheral facilities (PHCs and SHCs-HWCs) prevent patients from receiving appropriate care at the right level (Tripathy et al., 2019).

Therefore, regular monitoring and supervision from the district and state NCD cells are crucial to understanding the effectiveness of the implementation of the program. Nonetheless, in the field, frontline workers reported that officials of the district NCD cell hardly visit them.

6.1.7.5 Disruptions in NCD Service Provision due to the Outbreak of the COVID-19 Pandemic:

The outbreak of COVID-19 has disrupted many essential health services and the functioning of many health programs. One of the main causes of NCD service disruption identified by WHO in the survey conducted between 1st and 25th May 2020 is the closure of population-level screening programs (WHO, 2020b). This was also observed in the case of the present study. It was observed from the field that those activities related to awareness generation regarding the

NPCDCS program was stalled, and the population-based screening for NCDs was delayed. For instance, Lily, an MLHP shared:

We had already planned to inform the people about the HWC, but the outbreak of COVID-19 made everyone busy. The plan was that awareness would be generated in coordination with the Village Headman and other members of the village administration who are also involved in preventing COVID-19 through the Village COVID-19 Management Committee (VCMC).⁶⁰

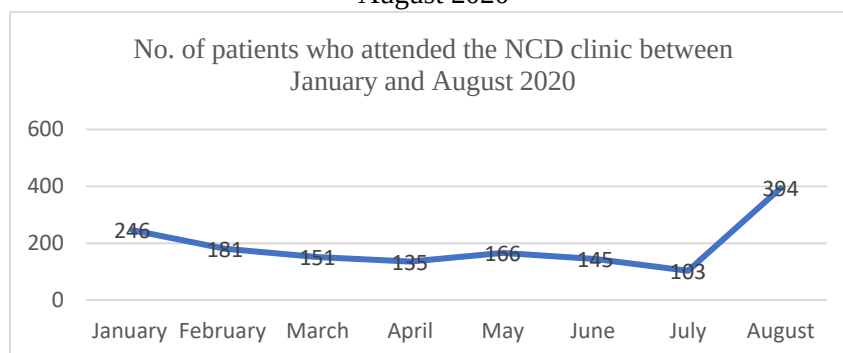
During fieldwork, it was discovered that the community still considers the SHCs-HWCs a “dispensary” that provides services only to pregnant women and children. On asking women who attended the screening if they were aware of the program, the common response was, “We do not know” because now they “never go to the dispensary as we do not have small children anymore.” People’s perception of the SHC-HWCs can be changed only through an awareness program. Otherwise, the objectives of comprehensive primary health care will be elusive.

6.1.7.6 NCD care during the COVID-19 pandemic at JCH, Ialong:

When asked about the barriers to providing NCD, the clinicians said- “there is no barrier from our side. It is from the patient side as they are afraid because they know they belong to a high-risk group; if they come, we treat them”. The analysis of the NPCDCS program monthly reporting format reveals a fall in the number of patients who attended the NCD when the COVID-19 pandemic lockdown was very strict. However, in August 2020, when the unlock 3.0 was taking place, we can see a sudden rise in the number of people who attended the NCD clinic (Figure 6.5). Thus, this shows that COVID-19 impacted the follow-up of people living with NCDs.

⁶⁰ It was observed during the fieldwork that the village administration, through its volunteers, was also working hard to prevent the movement of people from one village to the other during the initial phase of the lockdown. As unlock gradually took place, the village authority, through the Village COVID-19 Management Committee (VCMC), also framed the rules and regulations with emphasis on prevention strategy. For example, shops were advised not to allow too many people crowding at a time, keeping hand sanitizer and duration for the shop to open was fixed. The Village administration coordinated with the health department regarding arrangements of quarantine centre at the community and also ensuring that food is provided to those under quarantine. The VCMC also makes sure that they know who comes in and goes out of the village and accordingly they took decision regarding the need for quarantine.

Figure 6.5 A graph depicting the number of patients who attended the NCD clinic between January and August 2020



Source: Compiled from field notes

According to the officials of the State NCD, the implementation of the NPCDCS program was disrupted during both the wave of COVID-19. Tom shared:

There were disruptions in the supply of drugs, and then we could not do awareness. Even the screening performance had also gone down. However, when COVID-19 cases decreased, the number of people screened again increased. Not only is NCD being affected other programs are also for mother and child. Nonetheless, during COVID-19, we still provide services for NCDs through the Village COVID Management, and we also provide some diagnostic services- they have the Saturation of Peripheral Oxygen (SpO2) machine, the Blood Pressure (BP) apparatus, and the thermometer. For those who are on regular medication, follow-up is made by ASHAs through home visits.

The COVID-19 pandemic has also disrupted the monitoring and supervision activity by officials at both the district and state levels. This was because officials were engaged in continuous surveillance activity related to the COVID-19 pandemic.

6.1.7.7 Low Importance given to the NPCDCS Program:

The program lacks ownership at JCH, Ialong; this could be because of the absence of dedicated leadership. For instance, the medical officer for the NPCDCS program was appointed recently, i.e., in November 2020; the post has been vacant since the program's inception, i.e., 2016. The new doctor appointed just completed her MBBS degree. The staff under the NPCDCS program are appointed on a contractual basis, so there is a higher turnover rate. For instance, the two nurses interviewed were posted two months ago, i.e., August 2020, as the previous nurses had resigned.

The two “NCD nurses” perceived that the program was not taken seriously. They said nobody seems to “care about the program,” and “it is taken very lightly.” For instance, the

responsibility of ensuring the availability of antidiabetic medicines is vested on the Data Entry Operator (DEO), who lacks the technical expertise. The two pharmacists, recruited on a regular basis to dispense antidiabetic drugs to patients, were also unaware of the program. Dollie, aged 28, an ancillary staff also expressed her concern regarding the storage of antidiabetic drugs as the storekeeper of the hospital, who is also a pharmacist recruited on a regular post, does not want to take responsibility for maintaining the stock. Dollie said: “He is willing to take responsibility for drugs related to other programs, but not NCD drugs. He thinks the NCD program is not his responsibility.”

The lack of importance could be because the NPCDCS program was institutionalized recently in 2016, and NCDs, given their long-term treatment, is a new health concern. Earlier, health systems were only meant to provide maternal and child health services for acute illness. Hence, the health workers and the infrastructure are yet to be prepared for chronic illnesses (Venkataraman et al., 2009).

6.2 Services Available for Diabetes at Private Health Facilities:

It is well documented that the majority of the population in India utilizes private health care. This dependence on the private sector has a bearing on the equity in access and utilization of health services and the health status of the people (Verma et al., 2018). The following section attempts to understand the different types of private healthcare facilities providing diabetes care in the study area. The background characteristics of healthcare providers interviewed at private health facilities are enclosed in Annexure 14.

6.2.1 Private Clinics-cum-Pharmacies: Private Practice of Public Sector Doctors

It has been observed that the private-for-profit sector is growing in the state as a whole and the district specifically. This growth is more evident in cities and towns. For instance, in September 2020, Woodland Hospital also established a branch in West Jaintia Hills District. Besides the hospital, there are several private clinics-cum-pharmacy, which has grown over the years. Most doctors who sit in these clinics are government doctors who are retired and working at JCH, Ialong, CHCs, and PHCs of the district. The private practice of government doctors seems to be accepted in the state. For instance, the medical officer at the CHC has a private clinic directly opposite the CHC. A long line of patients was observed every morning from 7 am until 11 am and from 4 pm

to 6 pm. At Ummulong, he is one of the most famous doctors among the people living with diabetes in the villages visited. In Ummulong, for a long period, there were only three to four clinics that existed for a long period. However, in 2021, it was observed that new clinics have started coming up. Now there are more than ten private clinics within a single village. The three private clinics belong to three doctors posted at the CHC. Since 2020, another nurse from Ummulong village has also started providing diabetes treatment. People described that she used a “computer” to do all the tests and provided treatment that included allopathic and ayurvedic medicine. Given that her father is a retired pharmacist from government services, they got the license for setting up the pharmacy. This growth seems unregulated, especially in a village undergoing transition.

The private clinics visited by women in the present study are numerous. All these doctors work at government health facilities. These doctors are residents of their village, so it could be convenient for them to set up a home-based private clinic. They often refer patients visiting the PHCs/CHCs/District Hospital to their private clinics as the medicine they prescribe to patients are unavailable in pharmacies of these public health facilities. They practice at their clinic in the afternoon or the evening.

6.2.2 Private Diagnostic Centres:

The private clinics in the district and Shillong are usually manned by only a doctor and a pharmacist or a helper who will dispense medicine to the patients. Therefore, most of the advanced diagnostic tests for diabetes are referred to private diagnostic centres, similar to the case in public health facilities where patients are referred to private facilities for diagnostic tests. In Jowai town, there has been significant growth in private diagnostic centres in recent decades. Based on the observation and the names mentioned by the respondents, these include- Woodland Diagnostic Center, Passah Diagnostic Centre, and Compassion Laboratory, among others. In Ummulong Town, it was absent until 2022, when a new diagnostic centre was set up. As opined by one pharmacist, Kenny, aged 34, the mushrooming of pharmacies and diagnostic centres in the district is due to the lack of job opportunities for young graduates in Pharmacy and Laboratory technology. They graduate every year from medical and training institutes. Kenny further shared: “A career in health offers better job opportunities. Over the years, the number of young people who aspire to

become pharmacists or laboratory technicians has increased. However, upon graduating, they have nowhere to go but to establish their pharmacies or diagnostic centres.”

6.2.3 Private Hospitals in the State:

Within the district, two private hospitals provide secondary care- Dr. Norman Tunnel Hospital and Woodland Hospital. Dr. Norman Tunnel was established in the colonial period and is a Mission Hospital in Jowai. Woodland Hospital was established in September 2020 by the owner of Woodland Hospital Shillong at Sabahmuswang, about 2-3 km from Jowai town. Besides private clinics, women also reported visiting private hospitals to seek diabetes treatment. Private hospitals, especially those in Shillong, were reported as the second primary source of treatment for diabetes after private clinics. The hospitals visited by women in the study are – Woodland Hospital, Shillong, Bethany Hospital, Nazareth Hospital, Supercare Hospital, and Dr. H.G. Robert Hospital.⁶¹

Findings from field visits to these hospitals showed that the range of services provided for diabetes varies across the hospitals. All the hospitals in Shillong have dietitians to provide dietary counselling to patients with diabetes. However, the private hospitals in Jowai town do not have a dietitian.

a) Role of Dietitians in Providing Care for Diabetes at Private Hospitals:

Following a healthy diet and regular physical exercise can help manage diabetes (Siopis et al., 2020). Although diet is crucial to prevent and manage diabetes, changing one’s dietary regimen is a challenging task. Knowledge about nutrition, skills to prepare food, and access and affordability for healthy foods with low glycaemic index are important (ibid). This is possible with the help of Accredited Practising Dietitians (APDs). Dietitians’ knowledge, skills, and experience are needed to assist and counsel patients regarding appropriate dietary regimens for diabetes. As a consequence, it will lead to good blood sugar control and prevent complications (Siopis et al., 2020). Empirical studies have shown that dietary intervention by dietitians improves the outcome of diabetes by controlling the blood glucose, cholesterol, and triglycerides concentration (Nisak et

⁶¹ Field visits were made to all these hospitals except Woodland Hospital, as the hospital's owner, did not grant permission for the study.

al., 2013; Liu et al., 2015). The roles and responsibilities of the dietitians interviewed include- planning of therapeutic diet and patients' meal cards, preparation of menu with the consultation of the head chef, patients round, evaluation of food before serving, dietary counselling to educate patients regarding the nature of the disease and provide a dietary prescription to patients.

The information gathered from women in the study regarding their dietary management was found to be contradicting the information shared by the dietitians. For instance, while most women reported that they could not eat anything grown underground, the dietitians shared that patients can eat carrots and beetroot as they form an important source of vitamins. The other recommendation given by dietitians for people living with diabetes is to eat small meals at frequent intervals. However, only a few women from the present study reported being aware of this information. Nevertheless, even if people are aware of the advice, it is still difficult to practice due to the nature of the occupation they are involved in; in this case, most women are farmers and small traders. The dietitians also shared that eating a balanced diet is very important to meet the body's nutrients requirement. According to them, everything can be eaten but as per the calorie required by the body. Nevertheless, the amount of rice should be only a quarter of the plate, and half of the plate should be green leafy vegetables. Besides these, snacking between meals is also essential. However, most women in the community find it difficult to follow this dietary advice, even if they are aware. Medical Nutrition Therapy (MNT), which dietitians usually give patients, includes advice to reduce carbohydrate consumption, especially rice, but not to avoid rice altogether. Riana, aged 33, a dietitian at Newlife Hospital Shillong⁶², said:

As part of Medical Nutritional Therapy (MNT), we advised diabetic patients to control their carbohydrate intake, especially not to take rice and potato in excess. We advised them to eat in small portions to maintain a balanced diet having proteins, vitamins, and raw vegetables. Regarding diabetic diet, we have a diabetic exchange list, and based on the calories, we plan how much and what to give patients. We gave the patient the diet chart, a list where patients can choose from varieties of food depending on their ability to afford it. For instance, some patients said they could not eat *atta*, so I suggested they eat white oats instead.

Amar Hospital also has a diabetes educator besides dietitians. Amar Hospital and Healing Hospital in Shillong have a diabetic clinic within their hospital premises. In Amory and Newlife Hospital, there is no diabetes clinic, and the Medicine Specialist at the medicine OPD himself

⁶² In the field narratives, the names of hospitals have been changed to ensure confidentiality

treats patients with diabetes. At Healing Hospital, patients with diabetes are treated at the diabetic clinic. The diabetic clinic opens a week, i.e., Tuesday, Thursday, and Saturday thrice, from 11 am to 1 pm. For all three days, the clinic is attended by three Medicine Specialists. A nurse working at Healing Hospital since 2002 registered patients with diabetes and checked their blood pressure, weight, waist circumference, and blood sugar, both fasting and postprandial, using a glucometer. For patients who are coming for the first time, they were advised to do all the biochemistry tests. The nurse said Fasting and Post Prandial Blood Sugar must be checked every time the patient comes for a follow-up, whether once, twice, or thrice a month. The interval for follow-up is decided by the doctor, depending on the patient's condition. She also shared that as part of the routine investigation to rule out the complications of diabetes, creatinine, and HbA1c, tests need to be conducted once in six months. Similarly, at Amar Hospital, the diabetes educator does the complete patient assessment, including foot assessment at the diabetes clinic after patients are diagnosed with diabetes. This explains the quality of care for diabetes at private hospitals, which is absent at the public health facilities visited.

b) Services to People Living with Diabetes and Infected with COVID-19:

Due to the absence of well-equipped healthcare facilities within the district, women suffering from complications were forced to visit the private hospitals in Shillong, traveling more than 60 km. People living with diabetes were worst affected due to the pandemic and the accompanying lockdown resulting in severe complications. The analysis of the data (Table 6.10) provided by one private hospital in Shillong shows that the number of women with diabetes who were hospitalized had almost doubled in 2021 when compared to the previous years. In contrast, for men, it remains almost constant. This indicates that poor follow-up during the lockdown period could have been a factor for women suffering from the complications of diabetes and hence were hospitalized.

Table 6.10 People from West Jaintia Hills District admitted in a private hospital, Shillong

Years	Admitted due to diabetes along with its complications but not infected with COVID-19		Infected with COVID-19 along with other complications such as chronic kidney disease, stroke, coronary artery disease, and others	
	Women	Men	Women	Men
2021	31	14	11	13
2020	23	14	0	0
2019	17	17	0	0
2018	14	15	0	0

Source: Data shared by a private hospital

The private hospitals in Shillong played a major role in providing healthcare services to women from the West Jaintia Hills district, given the poor availability of advanced medical care in the public hospitals. Besides private hospitals, findings in the present study also show that women accessed the services of traditional and informal providers for the treatment of diabetes. This is discussed in the following subsection.

6.2.4 Services Provided by Traditional Healers:

In remote villages of the district, there are very few qualified medical practitioners. This gap is filled by informal providers, unqualified practitioners, and traditional healers, both men and women, who provide traditional medicine (Albert, 2014). In the study area, tribal medicine is mainly provided by traditional healers. The rural households reported higher use of services offered by traditional healers as they believed it to be cheap, effective, beneficial, and easily accessible. In the West Jaintia Hills district, the practitioners of tribal medicine are known as *Doktor Pnar* (Pnar Doctor).⁶³ They provide treatments, drugs, tablets, and medicinal plants for which they depend on nearby forests. They are very popular and famous in the community. Some have formal education and are registered Khasi Hills Autonomous District Council practitioners (Albert, 2014). Their education ranges from schooling to diploma to graduation. Many tribal medicine practitioners have opened a clinic in an adjacent room of their own house or a clinic in the market area. Their experience ranges from 5-20 years. Some tribal healers are herbalists. Apart

⁶³ The doctors practising modern allopathic medicine are known as *Doctor Phareng* (Foreign Doctor referring to allopathic doctors).

from this, there are ritualistic healers. Tribal healers mainly belong to the Christian community, while ritualistic healers are associated with indigenous religions (ibid). A traditional healer can be from any faith, and they dispense medicines. The ritualistic leaders offer prayers and conduct rituals to discover the cause of the disease. Most healers reported that they have been practicing because of the transfer of knowledge and skills from their ancestors or older family members who were also practitioners (ibid). Out of the eight traditional tribal healers interviewed for the study, four of them provide treatment services for diabetes. Among the other four traditional tribal healers, diabetes is still “a new disease.” Therefore, they did not provide treatment for it. The illnesses commonly treated by the traditional healers interviewed include- traditional illnesses (discussed in chapter four), gastritis, hypertension, diabetes, cancer, stroke, gastrointestinal problems, skin diseases, body aches, kidney stones, headaches, cough, bowel disorders, among the infants, reproductive tract infections and asthma.

Albert (2014:148) argues “Khasi tribal medicine is not a static system restricted to what is learned from ancestors but a dynamic one where healers continually ‘experiment’ with therapies.” Tribal healers in the present study also shared that they mainly learned the practice from their ancestors based on experiments. For instance, Jenny, aged 56, a traditional healer, shared that based on her own experience of being diagnosed with diabetes, she started experimenting with the treatment using the herbs she is familiar with. She said:

I got the herb from the *hali* (rice field), and it is called a *khmut sim* (bird’s beak). I used both the roots and the leaves. The other one is a fruit known as *pyrem*, I used its roots but have not used the fruits yet. For both sugar and BP, I used these. Whenever I feel like my BP is high and when I go to check it is high, I used to take these herbal medicines which I have. I used to get into the rice field after the harvesting season (mostly in October-November) and collect the herbs; after that, it is also available in April-May. But if you cannot recognize it properly, you might confuse it with *phleng* (another herb), as both are similar. In the morning, when I wake up very early when the dew is still there, I used to go to the rice field, but one has to be very careful; otherwise, you will not recognize it.

The use of plants and herbs in treating ailments among tribal communities is documented in the study conducted by Rath and Acharya (2006) among the tribal communities in the Mayurbhanj areas of Orissa. In their study, they found that different types of plants are used by tribal healers for different diseases using their knowledge of the herbs and the necessary doses.

Besides the eight traditional tribal healers interviewed, there are many other healers in different villages from whom women reported seeking treatment. These villages are located within the district, such as Mookyndur village, Nongkhroh village, Mynso village, Amlarem village, and outside the district. The following section discusses some observations made of them:

6.2.5 Role of Unqualified Medical Practitioners:

Unqualified Medical Practitioners do not possess any medical degree but practice medicine based on the knowledge they gain while assisting the qualified medical practitioner (Chandra & Bhattacharya, 2019). In the area covered by Rakabah HWC, two unqualified practitioners Dr. Ladang, an Assamese, and Dr. Bthuh, were also reported. People in the community shared that a few years ago, Dr. Ladang had come to Bambthong, one of the villages under Rakabah HWC, to set up a clinic. They considered Dr. Ladang as an MBBS doctor whose services are very popular, and people trust him enormously. Many people from the nearby villages rush to him to seek treatment. According to the people in the community, Dr. Ladang is very effective, so some people are jealous of him. These people supported Dr. Bthuh more, so Dr. Ladang returned to his village in Lakarew, Assam, and Dr. Bthuh became the sole provider of services for almost all types of illnesses in the community, including diabetes. However, some people who are happy with the services provided by Dr. Ladang do not mind reserving a cab and spend for the travel fare to get the services from him in his village in Assam. Dr. Bthuh is a non-Pnar and originally from outside the state, but people in the community said they do not know the name of his place. They said he used to come to their village after ‘traveling in a *rel*’ (referring to train) for two to three days. Attempts were made to get in touch with these doctors. However, none of the respondents shared the mobile number or the clinic’s location from where they are providing care. Hence, it was not possible to interview them. Two women in the present study shared that they had access to the treatment provided by these UMPs for general illnesses and diabetes.

6.3 Perspectives of Healthcare Providers on Diabetes and its Management:

Healthcare providers interviewed in the present study have different explanations about diabetes in rural areas. Their perspectives are discussed in this section thematically as follows:

6.3.1 Perception of the Prevalence and Risk Factors of Diabetes in Villages:

6.3.1.1 Perception of Doctors on the Prevalence of Diabetes in Villages:

One of the reasons for not conducting screening at the village level is the doctors' belief that the prevalence of diabetes in the villages is low or the detection rate is low. Dr. Hannah, an allopathic doctor said:

Based on my experience, only a few patients were diagnosed with diabetes at the PHC and are from the well-to-do family. Diabetes is uncommon in the community, except in a few villages such as Nartiang, Mynsngad, and Nongjingi.

The other allopathic doctor, Dr. Pynhun shared that diabetes is uncommon in the village as “people in the villages are doing hard labor by going to the field and carrying heavy weight such as water, firewood while at the same time climbing hilly terrain.” On the one hand, healthcare providers perceived low awareness about multiple risk factors for diabetes in the community. On the other, the fact that people given their work on farms were seen as physically active, there was a denial of the prevalence of diabetes in the rural areas. Thus, one of the dominant understandings is the belief that diabetes is a disease widely prevalent in urban areas. Eleanor, an MLHP also shared: “We do not have many diabetes cases here as the people are doing hard work like farming, in villages we hardly see diabetes cases, but there are many people with hypertension.”

Ramachandran et al. (2004) in their study entitled “Detecting Undiagnosed Diabetes in Urban Asian Indians-Role of Opportunistic Screening,” found that most of the newly diagnosed diabetes among their participants were asymptomatic. Therefore, according to the authors, opportunistic screening of asymptomatic individuals is essential to detect most people who are currently undiagnosed for diabetes. The prevalence of undiagnosed diabetes is high in urban and rural areas, with three undiagnosed individuals per known case (Unnikrishnan et al., 2016). Similarly, Venugopal et al. (2015), in their study on “opportunistic screening for diabetes mellitus among adults attending a primary health center in Puducherry,” stated the importance of opportunistic screening because more than half of diabetes cases in the community are undiagnosed. Given the high percentage of undiagnosed diabetes, screening only those with

symptoms may prevent the identification of new cases of diabetes (Anusuya et al., 2018; WHO, 2003).

6.3.1.2 Limited Awareness About the Risk Factors of Diabetes among People:

Interviews with health workers at JCH, Ialong confirmed how they also faced challenges in creating awareness about multiple risk factors for diabetes. Dr. Kilang, blamed the people for their lack of awareness: For instance, he shared:

There is a lack of awareness at the grassroots level. People are not aware of the multiple factors. They do not even know what to eat and what not to eat and are not aware of the risk factors for NCDs.

Lakynti, aged 30, a staff nurse at JCH, Ialong expressed her desire to provide health education to patients related to diabetes, but she could not because she is overburdened with work. She shared:

We wanted to give health education about NCDs to the patients, but we do not have the time. People used to say we do not take sugar, we never drink tea, and I find that awareness regarding diabetes is still lacking among people. We need to give a health talk about the multiple causes of diabetes.

This is because the nurses recruited under the NPCDCS program shared that besides the duty in the NCD clinic, they are also allotted night duty in the hospital. Due to this, it is difficult for them to make time and provide health education to the patients.

6.3.1.3 Too Much Consumption of Carbohydrates as a Risk Factor for Diabetes in Rural Areas:

It is a well-known fact that consuming very high quantities of rice is not advisable for patients with diabetes. However, in the villages of Meghalaya, people consume rice three to four times a day, resulting in too many carbohydrates and starch. State health officials shared that the risk of diabetes in rural areas is because of the high consumption of rice, especially red rice and potato. For instance, Dr. Silva shared:

People are not living a healthy lifestyle; they eat whatever they like. You should see how they eat rice. Most people will have a plate full of rice and a big piece of meat. This will be the cause of diabetes. They are not aware that if you are taking so much starch, it will increase your glucose. But their staple food is rice, and how people eat rice in the villages is terrifying. They used to eat lots of rice and only two pieces of *ktung* (a variety of dried fish commonly eaten by both the Pnar and Khasi communities, especially among the low-income group).

Similarly, a medicine specialist, Dr. Raymond, aged 41, a medicine specialist who works at Newlife Hospital Shillong, also shared:

It is due to our lifestyle; our food contains too many carbohydrates, such as rice, and we eat lots of meat too. Every day we eat meat almost two times a day. In rural areas, people eat rice three to four times a day, morning when they wake up, in the daytime, evening, and night. Along with rice in the rural areas, they consume lots of potatoes too. You will find that rice and potato are their favorites in the villages.

Further, Tom said: “In rural areas, they eat an imbalanced diet like an excessive amount of starch but less protein and other nutrients.”

Dr. Danny, aged 35, a medicine specialist at Amar Hospital in Shillong, provided another explanation regarding the increased prevalence of NCD in the state. He said:

The rise in the prevalence of NCDs, especially diabetes, is due to changes in patients' lifestyles in urban and rural populations- regarding food habits, nature of work, physical exertion, affordable means of transport, and better roads. More importantly, there is also a lack of awareness regarding preventing NCDs in rural areas. There is also a new work culture where one works extra hours to climb the economic and social ladder but forgets to give attention to health-promoting and disease-preventing activities.

As noted from the above interview, the explanation given by doctors regarding the risk factors of diabetes is mostly oriented toward biomedical sciences. Accordingly, treatment, especially in dietary advice, exercise, and medication adherence, is given to patients with diabetes.

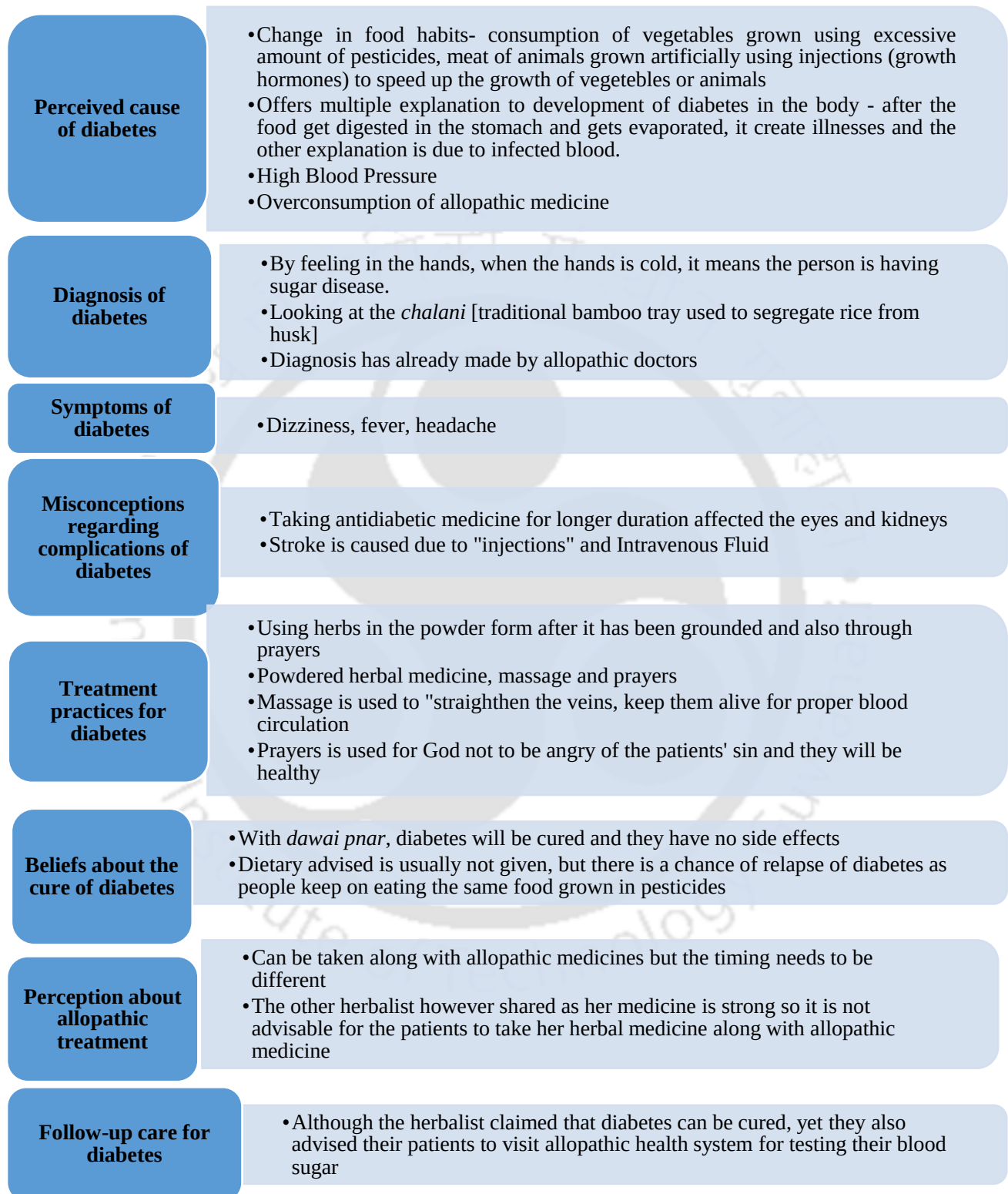
6.3.2 Perspectives of the Folk Sector Practitioners on Diabetes and its Management:

In the study villages, out of the four traditional tribal healers, three of them provide treatment for diabetes through herbs only, whereas the other one treats using a mix of Ayurvedic medicine, herbs, and allopathic medicine. Thus, these three are also considered herbalists. Herbalists most often made the diagnosis and then prescribed herbal medicines (Kleinman, 1980). Most herbalists or traditional tribal healers in the present study either have low levels of education or are illiterate. According to them, they got the skills of treating people from the previous generations, God-gifted or through their dreams. Traditional tribal healer possesses “secret knowledge,” reputed to be passed from generation to generation and jealously guarded against outsiders (Kleinman, 1980:65). Findings from the interviews with the herbalists are summarized thematically in Figure 6.6. All three herbalists believed that diabetes was increasing in their village

or town. These include Wahiajer Village, Ummulong Village and Jowai Town. This is the reason that made them start treatment services for diabetes. One of the herbalists Dr. Guwan, aged 56, has practiced for 33 years and received an honorary doctorate as Doctor of Traditional Medicine (DTM) and Doctor of Medicinal and Herbal Sciences (DMHS) from a University in Shillong shared said: “Why do we have to make this diabetes medicine (Syrup made of wild herbs) is because the number of people with diabetes is increasing.” Researchers worldwide have widely documented the use of herbs as diabetes medicine by traditional healers. These ethnobotanical studies show that some herbs have been proven scientifically to have antidiabetic properties (Keter & Mutiso, 2011; Yaseen et al., 2015; Mrabti et al., 2021). The herbalists also shared that people switched to their treatment only when the treatment they received from the professional sector failed to relieve their symptoms. Given that diabetes is a chronic disease, therefore patients usually perceive that the delay in cure is because of the failure of Western medicine. Nonetheless, the traditional healers or herbalists again referred patients back to the biomedical doctors if patients did not find their treatment helpful.

Findings from the present study also support other existing literature on perspectives of traditional health in the health-seeking behavior of people with diabetes (Atwine & Hjelm, 2016). In the study conducted by Hammond et al. (2019) in Senegal to understand the traditional healers’ beliefs in treating diabetes, they also found few claims to cure diabetes. Treatment modalities they also use include powdered herbal medicine from leaves, roots or branches of herbs and prayers.

Figure 6.6 Summary of perspectives of the herbalists on diabetes and its management



Source: Diagram developed based on field interviews with herbalists

6.3.3 Perspectives of Healthcare Professionals on Traditional Healers:

Healthcare professionals in the study have their perceptions about traditional tribal healers. Therefore, it is important to understand their perception of tribal healers as they are largely involved in framing public health policies. Concerning traditional medicine, Dr. Silva said:

One thing is that we are tribal, and being rural, we follow traditional medicine, and we will not be able to take that away from the people in villages. They still trust the traditional healers, and as you know, our villagers largely depend on them, especially for cancer. That is why they delay seeking treatment, and when they come to the hospital, they come with so many complications. This is the major problem. Tribal everywhere utilize traditional medicine. That is what happens. But we need to make the people aware that if they go and take traditional medicine, it may cause more harm to their system and to the illness itself. Some have understood, whereas some do not.

She continues:

They make use of different herbs, telling people to use them as this will decrease their blood sugar. This is very hard because, after all, tribal areas are like that. With this alternative medicine, we cannot do anything. We cannot tell them not to give right. Even in urban areas, so many people still believe them and go to the rural areas to search for medicine. It is hard. Everyone claims that their medicine can cure, and this herbal medicine continues.

The official also shared that the state has not yet collaborated with the traditional healers. Still, there were instances when they both had a meeting and instructed the traditional tribal healer to refer cases such as malaria to the PHC/CHCs. Concerning the regulation of the practice of traditional tribal healers, Dr. Silva said:

It is not that we cannot do anything (regarding the traditional healer). It is the people's choice. We can only say without a doubt that seeking healthcare from other alternative medicine rather than allopathic ones is a choice. It is the people's choice, and now the government is integrating with AYUSH. Traditional tribal healers always said that allopathic medicine had got many side effects. But herbal medicine does not have side effects, and this way, people will be more convinced to go to them. But how will we know those herbal medicines are not even tested, unlike ours (allopathic medicine), which is *pakka* testing? That is why we know which one's cause diarrhea and so on. That is why we always said if you take too much of this, these are the side effects- dizziness, itching like that but not with herbal medicine. No study shows their side effect, but they only attract people by claiming that this (Allopathic medicine) has many side effects, but we do not have them because we use plants. These people (traditional tribal healers) have become experts in explaining to the people. It poses a challenge for us because you cannot stop them. That is the right of the person. Nobody can say no if he wants to shift, so these are the challenges. Even until now, nobody has given the success rate of AYUSH medicine, nobody has done the study for that. What is their success rate in treating cancer, treating diabetes? They should be having it right.

Nobody will take responsibility when a patient dies. Ideally, they should document the success and failure rates they have to understand their own medicine and how they can make so many claims without evidence.

The above narrative clearly shows the perception of allopathic professionals toward traditional medicine. Traditional medicine is seen as the right of the people and something that cannot be prevented from its utilization by the people. However, health professionals also doubt the efficacy of traditional medicine. Further, the lack of evidence regarding the side effects of traditional medicine is one of the reasons for the negative attitude of health professionals toward traditional medicine.

Rinjin, aged 38, an officer working with an International Developmental Organization, shared that easy accessibility to traditional tribal healers is one of the determinants of using traditional medicine. She said:

This is because of accessibility, and the services of traditional healers have been there for ages. They have become part of the family tradition. That is why the community's network of faith-based healers is very strong. Earlier in the health system, it was just the ASHAs; even the ASHAs were introduced only in 2005. Still, the traditional healers were there for ages and are a part of the community's family. So, they have a strong base in the community. Because of that, people believe in them, and they get cured. Although there is no study to prove the side effects of their medicine, the evidence is there with the community, which is the belief of the people themselves. They feel you know *iatoh nusib* (their luck matches their treatment), so it is all right.

However, Dr. Danny, aged 35, medicine specialist at Amar Hospital, considered traditional tribal medicine ineffective in treating diabetes. He said:

A large number of patients are using traditional medications, which are supposedly useful in the treatment of diabetes. In my experience, they do not work and delay patients' visits to hospitals.

The narratives shared above show that healthcare providers in the professional sector doubt the efficacy of the treatment provided by traditional healers as they lack evidence of the side effects of the drugs. Arthur Kleinman (1980) argues that the professional socialization of modern health professionals causes them to regard their notions as rational and to consider those of patients, the lay public, and other professional and folk practitioners as "irrational and unscientific" (Kleinman, 1980:57).

6.3.4 Health care Providers' Perspectives on Barriers and Challenges in the Prevention and Control of Diabetes:

The sub-section discusses the barriers and challenges faced by the ASHAs, ANMs, and MLHPs at the community level and those faced by the healthcare providers at the PHC, District Hospital, and private health facilities. The perspectives of healthcare providers are crucial to understand as they are the ones who provide direct healthcare services to patients. The barriers and challenges faced by them need to be taken into consideration to improve diabetes care and management. These are discussed thematically as follows.

6.3.4.1 Poor Accommodation Facilities for the Health Workers at the HWCs:

In the field, it was observed that HWCs buildings are constructed close to the old SC building. Electricity is available at all HWCs, but it is very erratic, and there is no piped-water connection except in three HWCs. The residential facilities for the ANMs and the MLHPs are poor except in four HWCs, which are comparatively better. For instance, at one of the HWCs, the roof of the building was dilapidated. Ella, an MLHP shared:

A snake fell one night when the previous MLHP who resigned was asleep in this room. After that incident, the MLHP was scared to live in the quarters. She would go and stay at the relative's house. So, it is difficult for us to stay in this house as it is still not repaired.

Given the poor condition of the residential quarters, the health workers have rented a small room for a monthly payment of INR 2000/- (USD 24.11) in the village. As the staff finds it difficult to stay at the residential quarters available at the HWC, it is very difficult to ensure continuous service delivery for the patients.

The fact that SCs are located in rural areas demotivates health workers from living there unless he or she is committed to serving the people in the rural communities. With the lack of proper basic amenities available in the SHCs-HWCs, it became all the less attractive for them to stay in the Sub-Centres (Dash & Panda, 2017). The non-availability of ANMs at the SCs affected the 24*7 service delivery. In the case of screening, motivating people to come to the SHCs-HWCs required rapport building with the community, especially the village headman, to promote trust among the people in the community. For instance, Ella, an MLHP said: "Although we had called people for the screening, we doubt they will come as we are new, so it is difficult to call and convince the people to come." The ANM and the MLHP also express their apprehensiveness

regarding conducting the screening as they are yet to be trained for the program.

6.3.4.2 Poor Health Infrastructure Affecting Service Delivery NCD Program:

At the village level, ensuring proper space for conducting screening activities under the program is a big challenge. For instance, in one of the HWCs visited in 2020, the residential quarter was used to screen NCDs. At the PHC, screening of NCDs should be conducted in their existing infrastructure, according to the operational guidelines of the NPCDCS program. However, it was observed that in Nartiang PHC, the emergency room is being utilized to screen NCDs. There are two buildings in the PHC- the old building provides services to all common illnesses, and the new building, also known as the Level-II facility, is a maternal and newborn care unit. The existing infrastructure at the PHC needs to be properly organized for effective service delivery of NCD care, including diabetes. The staff nurse assigned to NCD screening must also perform other activities such as attending emergency cases, dressing, administering injections to OPD patients, etc. Therefore, this could be the reason for utilizing the emergency room for a screening of NCD, as it will be easier for the nurse on duty to handle the cases together and need not move from one room to the other. Similarly, at JCH, Ialong, no separate room is allotted as an NCD clinic due to space constraints in the hospital. This creates many challenges in organizing service delivery for NCDs, including diabetes at the District Hospital.

6.3.4.3 Inadequate Diagnostic Testing Facilities:

Screening for complications of diabetes, such as those related to eye and foot ulcers, is almost absent in public health facilities, and even the basic diagnostic tests are also unavailable. Dr. Kilang said:

The laboratory or diagnostic tests are inadequate. The Kidney Function Test (KFTs) and Liver Function Test (LFT) are unavailable. The test conducted here differs from those available at the PHC level.

Similarly, another medicine specialist, Dr. Yowan shared similar narratives:

Patients diagnosed with diabetes have a higher chance of developing diabetic retinopathy after five years. After ten years, it can lead to diabetic neuropathy, nephropathy, or micro and macrovascular complications. However, the tests which are required to evaluate diabetes complications are also not available at the hospital. A lack of testing facilities for basic investigation, such as KFT, LFT, HbA1c, etc., is a major barrier to screening diabetes complications.

At JCH, Ialong, although some doctors advise HbA1c, some patients do not get it tested due to financial constraints as they have to do it in private diagnostic centers. However, in 2022 when the third phase of fieldwork was conducted, it was found out from women's medical records that the HbA1c test was available at JCH, Ialong. However, other tests, such as KFTs/LFTs, must be available in a district hospital as per the Indian Public Health Standards guidelines. Diabetes is associated with many complications, such as those affecting the eyes, the heart, and other neurological conditions (Venkataraman et al., 2009). Therefore, ensuring the availability of these diagnostic tests at district hospitals is crucial.

The fact that the program encouraged outsourcing laboratory investigations at district hospitals, which are not available at the hospital, is a matter of concern. The National Health Policy of 2017 encourages strategic purchasing of diagnostics from private health facilities (GoI, 2017). The doctors have no choice but to refer the patients to private facilities to conduct the tests. The HbA1c is charged INR 500/- (USD 6.03) in a private diagnostic center in private health facilities. This acts as a barrier to complying with the advice as most patients who visit the public health facilities are from the rural and remote areas of the district and belong to the low-income group.

6.3.4.4 Poor follow-up leading to uncontrolled blood glucose levels:

The main index, which physician uses to judge a person's overall diabetes control, is glycated hemoglobin (HbA1c). Simply put, glycated hemoglobin measures how many hemoglobin molecules have a glucose molecule attached. HbA1c was introduced in the 1980s, and since then, it has become an important parameter to consider in clinical practice. Diagnosis of diabetes is usually made if the HbA1c level is more than or equal to 6.5%. (WHO, 2011a). If the glycated hemoglobin level is low, a person's blood sugar is considered relatively well-controlled in the past two or three months. However, if the glycated level is high, blood sugar fluctuates more than expected (Weaver, 2018). Commenting on the poor control of blood glucose among patients, Dr. Samarjit, aged 46, a medicine specialist at Healing Hospital, Shillong, said:

In India, less than 20% have good blood glucose control, and more than 20% have HbA1c of more than 9% (which is very high and indicates poor blood glucose control). The reason is due to no adherence to the therapy, ignorance, and patients do not want to get insulin even when it is in the end stage. They have a misconception about the use of insulin, which is due to their lack of knowledge.

Given the fact that diabetes is a chronic disease, therefore continuous and long-term treatment is required. The poor follow-up, thereby leading to uncontrolled blood sugar, was reported by many doctors interviewed. In the present study, specialists shared that women are more likely to comply with treatment. For instance, Dr. Samarjit said: “Women are more likely to comply with treatment. The reason is that they are more disciplined and punctual.” Similarly, the study conducted by McGill et al. (2013) found that women have increased adherence to diabetes care, such as high healthcare utilization, better diet, and better self-monitoring of blood glucose compared to men. Despite adherence to treatment among women, the authors doubted the reasons for poor glycaemic control among women and the less likely to achieve glycated hemoglobin goals than men. The authors, therefore, concluded that higher insulin doses might be needed for women than men do and that there is a need to individualize therapy, especially for women (McGill et al., 2013). These studies, however, ignore the structural issues women face that need solutions beyond medication, such as chronic stress due to poverty.

6.3.4.5 Overburdened ASHAs:

While conducting the population enumeration, ASHAs have to visit the same house multiple times. This is because some houses were locked, and sometimes the target individual aged 30 years and above is not at home. This makes it difficult to complete the population enumeration on time. Phyrnai, aged 45, an ASHA, said:

We cannot finish the work on time because most of the people are not at home during day time, some also said they are lazy to go and get the epic (voter ID) as they locked it in their drawer, so we have to visit again and again, and hence our work gets delayed. Further, men will never be at home, and when we need to fill in their voter or Aadhar ID number, we have to request whoever is there in the house to call them to inform us of the epic (or voter ID) number (needed for filling the CBAC form) because they used to take it where ever they go. It is not difficult for those who are responsible, but it is a challenge for those who are not.

In addition to other services, the ASHAs and the ANMs are expected to undertake follow-up care for patients diagnosed with diabetes in their villages since 2019, when the population-based screening for NCDs was implemented. With many responsibilities, it is hard for the ASHAs to accomplish such responsibilities. The delay in population enumeration, low awareness about the program in the community, and poor follow-up could be because ASHAs were busy with other public health programs, especially during the COVID-19 pandemic.

6.3.4.6 Low Community Participation in Population-Based Screening for Diabetes:

The common challenge observed in all the twelve SHC-HWCs visited is the poor response by the people to attend the screening, even after the ASHAs mobilized them. There is a disparity in the number of people attending the screening in the seven sites. The total number of people who attended the screening ranges from one (Mynkrem HWC) to forty-five (Nartiang AWC). The low attendance of people at the screening days organized by the HWCs could be because of the overlapped timing with that of the people working in the farms. For instance, Leki, aged 68, woman and a farmer who came to the HWC to check her blood pressure, said: “People are not coming to the sub-centre for the screening as everybody went to the field. This is when everyone is busy harvesting ginger, turmeric, and brooms.”

There could be numerous reasons for people not attending the screening. These include a lack of awareness about the screening program, low priority given to health by the people, and people who perceive that they are healthy and do not need it. The three symptoms of diabetes are the three Ps- Polyuria or increased urination, Polydipsia or increased thirst, and Polyphagia or increased hunger (ADA, 2002: S22) might be misinterpreted by people as normal. Regarding the misinterpretation of symptoms, Dr. Elizabeth said: “People in the village think that they frequently urinate because they drink too much water, and they feel hungry frequently because their appetite is good.”

During the COVID-19 pandemic, mobilizing people for screening was a big challenge. This is because the village people believed that health workers were undertaking tests for COVID-19. For instance, the ASHA of one of the villages even sought the permission of the village headman to permit the people to attend the screening conducted on 14th December 2020. But the people were still reluctant to come to the Anganwadi Centre, where the screening was conducted. There were fears and misinformation about the test, and few people in one village perceived it as COVID-19. At another HWC, the male MLHP informed that the ASHA of the village had selected and called people for the screening, but nobody came. The MLHP tried his best to contact people and mobilized them to come to the screening, but still, no one came as people were busy cleaning their village because it was Christmas time.

Dyavarishetty & Kowli, (2016) argue that the lack of interest shown by the people reflects

the lack of attention to their health unless they become symptomatic. The limited awareness about diabetes and its prevention and control program among the community could be the reason for low participation in the screening program. Discussions with frontline workers regarding the low awareness about the program reveal that efforts were made to create awareness about the program, but the people do not respond. For instance, Ella an MLHP shared: “People accepted health messages which they like and rejected which they do not like.”

Some people who attended the screening refused to get the RBS test done as they were afraid to get their fingers pricked. This was observed during the population-based screening conducted in Nongjngi and Anganwadi centre of Nartiang village, at the Nartiang PHC, and JCH, Ialong. Patients assumed that they did not have such health problems. For instance, Maiti, aged 38, a daily wage labourer, who attended the screening on the 12th of January 2021 at Nartiang Anganwadi Centre, said: “I do not want it; I am afraid of it.... I am feeling well.... there is no such problem with me.” The fears related to the testing can only be eliminated when people in the community are made aware of the program and its importance in preventing complications due to the disease early.

Dyavarishetty & Kowli, (2016) mentioned in their study conducted in Mumbai, India, that limited awareness about the importance of screening, poverty, time constraints, low priority, and neglect of one’s health are some factors that prevent people from attending screening. WHO (2003) has found that the reluctance of people to attend the screening could be because of an inadequate explanation of the reasons for screening or due to the absence of a formal support system for those attending the screening. Poor experience with previous screening, anxiousness about the process and the result of the screening test, poor understanding about the purpose of the screening, inability to give the time for the screening, and the perception that diabetes has low risk are the barriers to attending the screening (Timm et al., 2020). Therefore, the frontline workers must interact with the community and explain diabetes to encourage them to attend the screening. Unless the importance of health promotion and prevention of illnesses like diabetes are explained to the people, it will be difficult for the program to achieve success (Dyavarishetty & Kowli, 2016).

6.3.4.7 Conflicting Timing of Frontline Workers at HWCs with Patients:

For diabetes, patients considered that checking their fasting blood glucose would give them better results. Therefore, they preferred visiting the HWC in the morning empty stomach, which used to be around 6:30-7:00 am. This is because the people leave for work on the farms after that. However, Fenny, aged 40, an ANM who resides in the HWC residential quarter and had worked for 20 years, complaint instead and said:

One morning, a woman came to the HWC around 6 am and told me to check her blood sugar. I was very irritated. How could she come so early when I was still sleeping? She kept waking me up, so I had no choice but to wake up and check her blood sugar. People here are always like this, they never come in the daytime when we are here, and they only come early in the morning before going to their field and after returning. It is very difficult; they are only concerned about their work.

One of the objectives of the HWCs is to reduce the out-of-pocket expenditure for the treatment of NCDs, especially in providing free drugs and diagnostics. The narrative shows that even when there is a residential quarter for ANMs to provide continuous services, their attitude towards the people seems insensitive, pushing poor women away from public health facilities.

6.3.4.8 Vacant posts and Frequent Transfers:

The availability of human resources is crucial for the effective delivery of services in health facilities, including screening for diabetes. For the screening to be successful availability of a trained health workforce is crucial. However, numerous challenges have been reported in the field related to Human Resources. For instance, in one of the HWCs, the post of the ANM is vacant as the ANM who worked there requested a transfer due to personal issues. Similarly, the other two health workers at other HWCs made a transfer request as new HWCs will be operationalized in their village. The desire to live in a particular place is a common explanation for inconsistent transfer other than the desire for higher income (Schaff & Freedman, 2015). In case of transfers or vacant posts, the existing staff at the HWC have to perform all the activities, which affects the quality and performance as many times they are overburdened. For instance, Twinkle, aged 33, an MLHP, said: “As I have to do all the work alone, hence I cannot fully give my commitment to the NCD program.” Concerning the frequent transfers of the health workers, the people in the village commented: “The government is posting staff here just like how the advertisement is done. One day, one will come, and we will see another new face the next time.”

It is also difficult to retain health workers in rural and remote areas to continue working at the HWCs. For instance, in one of the HWCs visited for the study, it became clear that whenever the MLHP gets a permanent government job, they leave the contractual job of MLHP. The high staff turnover comes with a huge cost as the gap needs to be filled and becomes costlier if the staff have specialized skills. The new health worker must be again trained to fill the gaps and ensure continuity of service delivery. The impact of transfers and vacant posts affects the service delivery in rural and remote areas due to the smaller number of health workers. In rural areas, the workforce may be widely dispersed, and even one vacant post may significantly negatively impact access to health services for the local population as the staff is working in remote isolation (WHO,2020a).

At JCH, Ialong frequent transfers of medical superintendents and senior doctors have led to a lack of accountability and responsibility in taking ownership of the hospital's medical equipment. This has therefore led to a disruption in the delivery of services. For instance, the non-availability of advanced diagnostic tests at JCH, Ialong was because the “machine became dysfunctional.” Concerning its repair, Dr. Kilang said:

The problem is due to transfers. Today you see me here. If you come next time, I will not be here anymore. I might be in another hospital. It is not like in a private hospital where you see the same person even if you come after many years, and as a result- he or she ensures that every problem gets solved. Here administrative head keeps on changing as the Medical Superintendent are those who are about to get promotion-they served for a few years in the hospital and then wait for a promotion order. So, no serious efforts are being made to get the machines repaired as it takes much time due to the many paperwork which has to go through many levels.

Challenges due to frequent transfers have been widely studied by scholars working on public health. Schaaf & Freedman (2015:122) listed numerous challenges due to frequent staff transfers. These include “weakening of health care service delivery as it undermines the functions of the health system, demotivates the other health care worker, leads to poor cooperation within and among health care cadres, delays program implementation, lack of accountable relationships between health care workers and administrators, and the communities, inability to monitor health care worker performance accurately and also hamper rational training, and recruitment plans.”

6.3.4.9 Absence of Specialists, Dietitians, and Counselors at the District Hospital:

At JCH, Ialong, there is no cardiologist or other specialist who would handle complicated cases of NCDs, including diabetes. The post of dietician is vacant in the hospital. Dietary advice for patients living with diabetes is usually given to the physician. Dr. Yowan said:

We need a dietitian, however, not only for diabetes but also for other diseases such as Chronic Kidney Disease, Cancers. Dietitian knows better regarding the diet. We, doctors, only study a few portions of the nutrition subject. Gestational Diabetes Mellitus does not need medical treatment but only through diet or Medical Nutrition Therapy (MNT).

When asked about the vacant post of a dietician at the public district hospital, Dr. Anvi, aged 54, a senior health official, said: “The hospital must write to the state if they need one.” Even the counselor post has been vacant at the district hospital for one year. This is because the earlier staff has resigned, hence recruiting new staff time and again is a challenge for the district health administration. Nonetheless, appointing vacant posts is crucial to ensure that patients with diabetes are given comprehensive care.

The lack of specialists in public health facilities is well documented (George, 2020; Rao et al., 2011). Unnikrishnan et al. (2016) argues that while in urban areas, there is the availability of well-equipped clinics dedicated to providing care for diabetes in India, the situation in rural areas is worse. Like any other specialists, diabetes specialists are available exclusively in urban areas. This is a major barrier to providing care for people living with diabetes in rural areas because diabetes affects the poor, who lack the financial capacity to pay for managing and treating diabetes complications (Unnikrishnan et al., 2016).

6.3.4.10 “Clash of Information” Between that Received from the Doctors and the Community:

The main challenge, as shared by most medical officers and medicine specialists in managing diabetes, is patients foregoing their advice. According to Dr. Matthew, aged 32, an allopathic doctor, the counselling they gave patients has been “whitewashed” by the information women received from community members, such as their friends, relatives, and family. The perception of doctors might hold to a certain extent, as findings showed that women living with diabetes followed those dietary practices not exclusively related to what their doctors or dietitians advised them. When they are in the community and interact with their friends and family members,

they will listen to that advice instead, which might have come from different sources. This concern was also raised by health officials of the State NCD cell- they called it a “clash of information” between the awareness they gave them and what the people hear from the community. This, according to Arthur Kleinman (1988), the medical anthropologist, is known as the “lay arena of care” that includes advice from friends and others about what to do, when to seek professional care, where to go for it, and whether to follow the advice of current professional caregivers or change to other practitioners (Kleinman, 1988: 294).

6.3.4.11 Financial Constraints as a Barrier to the Treatment of Diabetes:

Given the higher care costs at private health facilities, seeking care from the private sector can be a barrier for poor people with diabetes. Dr. Anil, aged 42, a medicine specialist at Lifeline Hospital, Jowai, said:

Cost is indeed a hindrance to seeking diabetes treatment. Most patients with diabetes seek care on an OPD basis, where the Megha Health Insurance Scheme (MHIS) card is not applicable; they have to spend for treatment out of their pocket only.

The diabetes educator at Amar hospital in Shillong also shared that poor follow-up at their hospital is seen mostly among people from low-income groups. She also shared that this could be because they are facing financial constraints, especially for patients from remote villages of West Jaintia Hills District who had to incur huge travel expenditures to reach Shillong.

6.3.4.12 Lack of compliance to Dietary Advice by Patients:

Given the high rice consumption, patients suffering from diabetes are advised by doctors to introduce the consumption of rotis round flat bread made up of wheat flour. Roti is popularly known as *Atta* in the study area. However, many patients find it extremely difficult to make this transition for various reasons. According to Dr. Raymond, aged 41, a medicine specialist at Newlife Hospital, Shillong said:

The problem with diet management is difficulty eating *atta* as we are not used to it. We are used to eating rice. But there is another way, and the other option is to boil the rice two or three times to remove the excess carbohydrate from the rice.

Further, Dr. Margaret, aged 52, a consultant for diabetes at Edwin Hospital, Jowai, said: “Even if we advised them to eat chapatti- they could only do so for a maximum of one week, but it is understandable as we are used to eating rice since childhood.”

Rice, as discussed in chapter four, is the staple food of people in the West Jaintia Hills district. *Kho-so*, or the local red rice, is commonly eaten by people in rural areas as they cultivate it in their agricultural fields. However, respondents with diabetes shared that their doctor advised them not to eat it and instead switch to either *atta* or white rice, available through the Fair Price Shop or purchased from the market. The other alternative to red rice that the respondents mentioned is brown rice. Red rice cultivation and consumption are not possible for people who do not own any agricultural field. In this case, the households must depend on the ration or white rice sold at the market.

All the dietitians shared that there are different alternatives or ways to manage their diet, but they do not have the knowledge or the means to do so. For instance, even if they cannot prepare *atta*, they can still make pancakes from wheat flour. Rinku, aged 47, a dietitian at Healing Hospital, Shillong, shared:

People here do not know the art of cooking. They can make and eat pancakes using wheat flour, roast the *atta*, and make *sooji halwa*. For urban people, they have access to all the information regarding what to eat and what not to eat. Still, for rural people, it is very difficult to educate them as they do not even know what a *tawa* is, and some do not even own a pressure cooker. However, these things are very important in preparing food. There are varieties of food that they can eat instead of red rice, such as oats, *shira* (rice flake), and brown rice, as it has lots of fiber, but they do not have the means and the motivation to eat.

Thus, the narratives of healthcare providers clearly show the biomedical approach to managing diabetes. The approach is highly individualistic, where women are blamed for their poor knowledge of diabetes and for not listening to the advice of doctors and other healthcare professionals.

6.4 Summary:

The present chapter discusses the range of services available in different systems of medicine for the prevention and treatment of diabetes. In public health facilities, the prevention and control program for diabetes is implemented both at the primary and secondary levels of care.

This encompasses both preventive and curative aspects of care. Findings show numerous gaps in the implementation of the program, such as challenges in conducting the population enumeration by the ASHAs, inadequate infrastructure for the screening, and poor definition for referral of suspected cases of diabetes. Besides these, the inherent health systems challenges, such as shortages of human resources, poor and inadequate training, and irregular supply of consumables required for the screening and diagnosis of diabetes, were also noted from the field. The study shows that for the smooth implementation of the program, there needs to be an orientation of the program and sensitize the healthcare providers regarding the challenges due to the increase in the burden of NCDs, including diabetes. Screening for complications of diabetes at the secondary health facility is also absent, indicating the poor quality of services provided for diabetes at the district hospital.

In West Jaintia Hills District, none of the private hospitals have a dietitian or counselor to provide dietary counselling to women with diabetes and pre-diabetes. This further indicates the lack of priority given to diabetes care, which may also be explained by the preconceived notion that diabetes is absent in villages, as almost 80 percent of the population lives in rural areas. The explanation concerning diabetes by healthcare providers on prevalence, risk factors, awareness, and treatment compliance for diabetes shows that diabetes is a problem of the individual, and it is them that needs to be more responsible. The diabetes educator at Amar Hospital, Riniki, aged 32, shared that 70 percent of the task is by the people, whereas the remaining 30 percent is from healthcare facilities. Most biomedical doctors, however, ignore the other structural challenges the patients face in managing their diabetes.

Similarly, healthcare practitioners in the folk sector have different explanations concerning the prevention and risk factors of diabetes. Most attribute the cause to the change in dietary practices and consumption of allopathic medicines. They have limited knowledge regarding the symptoms of diabetes and even misunderstand the complications of diabetes, such as those affecting the eyes and kidneys due to continuous and long-term medications. Traditional healers use different treatment modalities to treat diabetes. These include herbs, prayers, and massage. Although few of them are diagnosed with diabetes, they also rely on the report of biomedical doctors, which their patients brought.

Thus, the present chapter shows that there are multiple sources of treatment for diabetes both within and outside the district. At public health facilities, an attempt has been made for early detection of diabetes through screening, which is a preventive aspect of care. In the following chapter Chapter Six, we will discuss women's experiences in utilizing the services provided by the different systems of medicine for the care and management of diabetes.



Chapter Seven

Utilization of Health Services for Diabetes: Narratives of Women from Field

Introduction:

The present chapter aims to understand health services utilization for diabetes care through narratives of women from the field.⁶⁴ In doing so, I made an attempt to discuss the different sources of health services accessed and utilized by the tribal women living in rural areas of West Jaintia Hills District, Meghalaya, for diabetes care and management. The present chapter also discusses the influence of gender on access, treatment seeking, and utilization of health services for diabetes care. It also explains the experiences and challenges faced by women in seeking diabetes care. Several socioeconomic, cultural, physical, and political factors influence the utilization of health care services. The households' income, poverty, and societal inequality also determine the access and utilization of health services. Most importantly, gender is also a critical aspect in determining access and utilization of health services (Buor, 2004).

The present chapter is divided into five sections. Section 7.1 discusses the framework used to understand the utilization of health services. The utilization of health services for treating diabetes in terms of the initial diagnosis, treatment, and follow-up sources, along with women's experiences, is discussed in Section 7.2. Section 7.3 focuses on women's health-seeking behaviour in deciding when and where to seek treatment. Section 7.4 discusses the factors influencing the utilization of health care services for diabetes. Section 7.5 discusses the barriers to utilizing healthcare services for diabetes during the COVID-19 pandemic.

7.1 Framework of Medical Care Utilization:

According to Andersen and Newman's (2005) framework of medical care utilization, the individual determinants of health service utilization consist of three components. The first is the predisposing component, where people with specific characteristics are more likely to use services than others. These characteristics include demographic indicators such as age, sex, marital status, and past illness; social structures, which encompass education, race, occupation, family size,

⁶⁴ Besides narratives of women, the present chapter is also based on interviews conducted with their primary caregivers. The background characteristics of caregivers is enclosed in Annexure 15.

ethnicity, religion, residence and mobility, and beliefs (Andersen & Newman, 2005:15). Beliefs comprises of knowledge and perception about diseases, cultural practices related to health and illness, perceptions about the treatment of illnesses. These were discussed in detail in Chapter Four. Moreover, besides these predisposing factors, the availability of means that enable the individual to use services is also necessary. The second is, therefore, the enabling component, which constitutes income, health insurance, type, and access to a regular source of care at the family level. At the community level, the enabling component includes the availability of health personnel and health facilities to serve the population, the affordability of health services, and the region where the family lives, whether rural or urban. Local norms on how medicine should be practiced or contradict the community also influence the behaviour of individuals (Andersen & Newman, 2005:15-16). The illness level is the third component that determines health services utilization at the individual level. In a situation where both predisposing and enabling factors are present, the perception by the individual or family that illness is present or likely to occur is necessary to utilize health services. The level of illness, such as an individual's experiences with symptoms or disability, determines the immediate reason for using health services. Within this framework, clinical evaluation of illness is also included because when individuals seek care from the formal system, the nature and extent of care provided are partially determined by the formal health system (Andersen and Newman, 2005:16). Taking insights from this framework, the findings from the study were analyzed, and those are presented in this chapter.

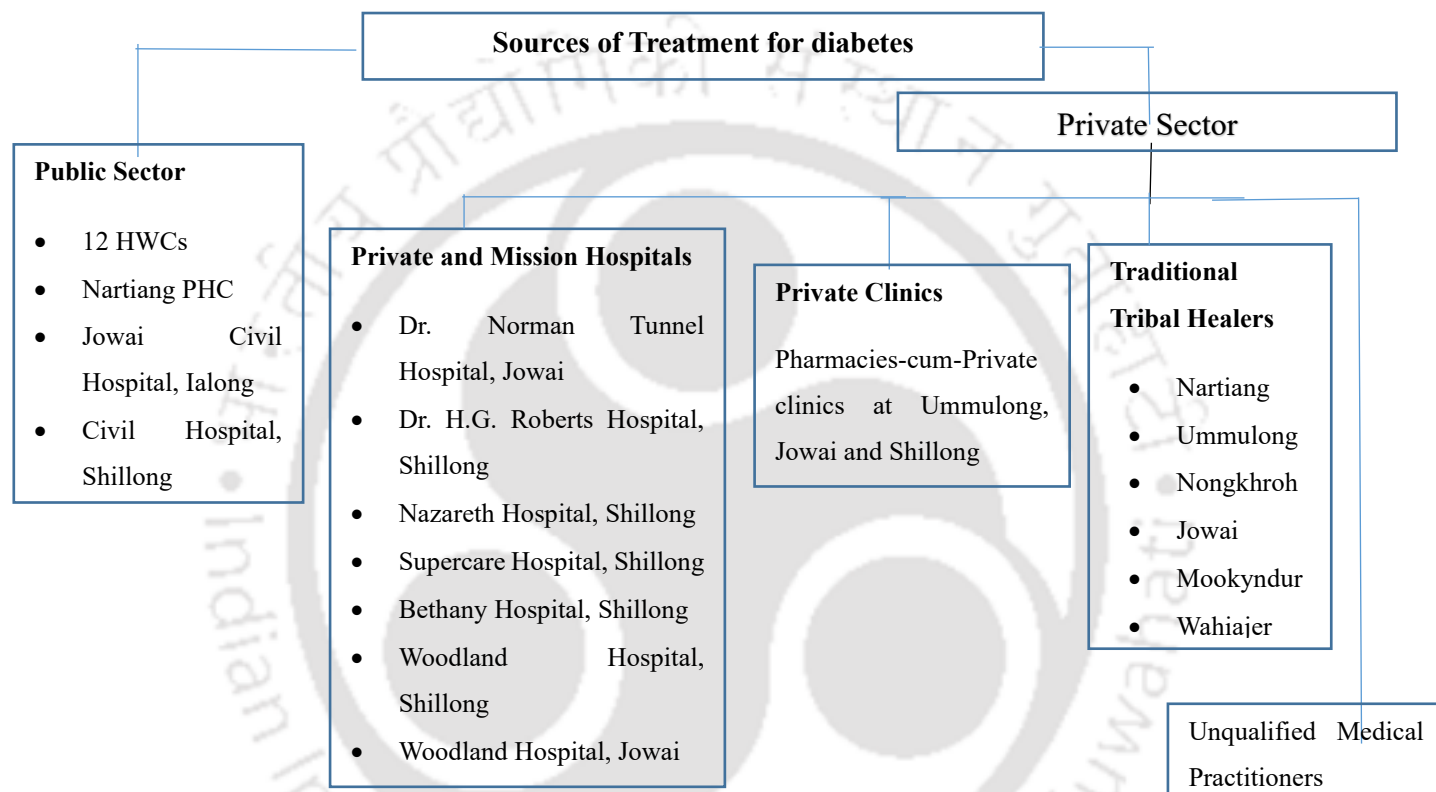
7.2 Treatment Seeking Sources for Diabetes and Experiences of Women:

7.2.1 Treatment Seeking Sources of Women:

After realizing the severity of their symptoms, women consider the need to seek treatment. The sources of treatment are decided based on the suggestions made by their friends, family, or relatives, which Kleinman (1980:50) refers to as the “popular sector.” In this section, the mapping of healthcare facilities which, according to Kleinman (1980:53), constitutes the “professional” or “folk sector,” accessed by women and their experiences through narratives, will be presented first. Figure 6.1 shows that women accessed different levels of health services delivery at public and private facilities depending on the lay referral made by their friends, neighbors, family, or relatives. While the public sector includes the three tiers of the health system as discussed in Chapter Four,

the private sector can be categorized into- private hospitals, informal practitioners, traditional healers, pharmacies, diagnostic centers, and clinics (Klinton, 2020). Although, Figure 7.1 shows the real names of private health facilities, however in women's narratives, I have replaced it with a pseudonym to protect their identity.

Figure 7.1 Treatment-seeking sources of women living with diabetes in rural areas of West Jaintia Hills, District, Meghalaya



Source: Diagram developed based on fieldnotes

The health facilities where the initial diagnosis of diabetes was made are presented briefly in Table 7.1. A large section (29.58%) of the diagnosis for diabetes was made at private pharmacy-cum-allopathic clinics, which is followed by private hospitals (23.94%) and District hospitals (16.90%). It is important to note that according to the information shared by women, most of the diagnoses were made accidentally. This means that women had attended the health facilities for other illnesses and were diagnosed with diabetes.

Table 7.1 Sources of initial diagnosis for diabetes among Women

Type of Health Facilities	Levels of Health Facilities	Initial Diagnosis	
		Frequency	Percentage
Public Health Facilities [Total= 30.99%]	Health and Wellness Centres	2	2.82
	Primary Health Centre/ Community Health Centre	8	11.27
	District Hospital/NEIGRIHMS	12	16.90
Private Health Facilities [Total= 56.34%]	Pharmacy-cum-Allopathic clinics	21	29.58
	Ayurvedic clinics	2	2.82
	Private Hospitals	17	23.94
	Eye screening camp/center	6	8.45
Cannot Recall	-	3	4.23
	Total	71	100

Source: Compiled based on field interviews

Table 7.2 describes the sources of treatment follow-up for diabetes among women. Table 7.2 is not mutually exclusive as women resort to multiple treatment sources simultaneously. However, to understand where women largely depend for follow-up of diabetes, these facilities were categorized into seven groups, as shown in Table 7.2. For follow-up, majority (32.39%) of the women were found to utilize only private health facilities, followed by 19.72 percent of women who only depend on public health facilities. Few women (n=4) utilize multiple treatment sources, such as private clinics, public health facilities, and traditional tribal healers. About 7.04 percent of women continued to purchase antidiabetic medicine using the old prescription slip and monitor their blood sugar at home or at the HWCs. However, out of five, two shared that they did not monitor their RBS regularly. It is also important to note that about 12.68 percent of women had stopped seeking diabetes treatment. They perceive their diabetes as “cured” or “diagnosis was wrong.” The details about the experiences with the utilization of health care services at different types of health facilities, as narrated by women, are discussed in the following sub-section.

Table 7.2 Sources of treatment follow-up for diabetes among Women

Type of Health Facilities	Treatment follow-up	
	Frequency	Percentage
Public Health Facilities Only (HWCs/PHC/CHC/DH)	14	19.72
Private Health Facilities Only (Pharmacy-cum-Allopathic clinics/Ayurvedic clinics/Private and Mission Hospitals)	23	32.39
Public and Private (Allopathic and Ayurvedic clinics/hospitals)	12	16.90
Public, Private (Allopathic and Ayurvedic clinics/hospitals), and Traditional Tribal Healers/UMPs	4	5.63

Public and Traditional Tribal Healers/UMPs	4	5.63
Purchase medicine from the Pharmacy using old prescription and RBS monitor at home or public health facilities	5	7.04
Stopped Treatment Follow-up	9	12.68
Total	71	100

Source: Compiled based on field interviews

7.2.2 Women's Experiences with the Utilization of Healthcare Services for the Treatment of Diabetes:

7.2.2.1 Public Health Facilities:

The pattern of utilization of public healthcare facilities is no doubt influenced by cultural and behavioral factors. Still, the political economy's lens helps explain the utilization of healthcare services. Besides the social determinants of health, underutilization of public health services also leads to poor health status and high treatment expenditure (Verma et al., 2018). Physical access and affordability determine a greater likelihood of public health facility use. However, Oosterhoff et al. (2021) found that patients in Meghalaya incurred high out-of-pocket expenditure (OOPE) despite physical access to public health facilities. The reason for high OOPE was that patients were asked to do laboratory tests at private laboratories and they had to purchase drugs from private pharmacies. The present study found that almost 31 percent of women were diagnosed with diabetes at public health facilities. Around 20 percent solely depend on public health facilities for follow-up treatment for diabetes (Table 7.1 and 7.2). These women largely belong to low-income groups such as farmers, daily wage laborers, and elderly dependent women. The underutilization of public health facilities is largely attributed to their poor availability across different regions, especially in rural areas. Further, the pattern of utilization is determined by factors such as "the levels of poverty and underdevelopment in the district, the degree of access to public healthcare facilities, and the availability of required healthcare services in the facility" (Verma et al., 2018:60).

a) Limited availability of diagnostic services and irregularity in the supply of antidiabetic medicine at public health facilities:

Most women previously hospitalized at JCH Ialong utilize the hospital's outpatient department (OPD) services for follow-up treatment. However, they shared that they were referred

to do all the investigations in private health facilities such as Lifeline Hospital or private diagnostic centres in Jowai. Moreover, they were advised to purchase most medicines from private pharmacies outside JCH, Ialong. Therefore, this leads to huge out-of-pocket expenditures for women. For instance, Tipsngi, aged 38, a daily wage laborer who was diagnosed with diabetes in 2018, shared:

The total expenditure we paid for the hospitalization was almost (INR) 17,000/- (USD 204.48) for the diagnostic tests; we have to do it all in the other private hospital. Even for medicines, we must purchase them from private pharmacies outside the hospital.

The range of services being offered at public health facilities for diabetes at the District Hospital was inadequate when compared to that in the private hospitals. When fieldwork was conducted, it was observed that the tests available at JCH, Ialong were RBS, FBS, and PPBS. The rest, such as HbA1c, KFT, and LFT, were being referred away. Drugs and diagnostics account for significant OOOPE in public healthcare facilities. Extremely high out-of-pocket health expenditures can push households below the poverty line (Wagstaff et al., 2020). Also, significant amount of user fee is being charged particularly for diagnostics. Women who seek treatment for diabetes from the PHC shared that they do not have to incur any expenditure either for antidiabetic medicines or diagnostic tests as they are free of cost. However, irregularity in the supply of antidiabetic medicine and consumables for testing blood sugar was reported by women, they said it was a challenge in seeking treatment from the PHC and even the HWCs. In such cases, visiting healthcare facilities at the village level is seen by patients as a waste of time and it is not guiding them through the “ideal care-seeking pathway” (Verma et al., 2018:59). Women reported that they were not screened for complications of diabetes, such as those related to kidneys, eyes, heart, and nerves.

b) Irregular Interaction with Healthcare Providers:

At the public health facilities, there are also frequent changes of doctors, and this was reported as one of the reasons for poor satisfaction with the services delivered at JCH, Ialong. However, other respondents (n=14) from the low-income group have no choice but to depend on public health facilities. For instance, Chiang, aged 55, a daily wage labourer, was diagnosed with diabetes in 2017 at JCH, Ialong. Since then, she has been seeking treatment from JCH, Ialong itself. However, she raised her concerns regarding the frequent change of doctors at the hospital. She said:

You see, now the doctors who used to test me are not there anymore. It is difficult for me to explain to the new doctor; sometimes there is a young male doctor, and sometimes a female doctor. How will they understand my problems, they only look at the old prescription. How will they know if they have to increase or decrease the dose, they just prescribed the medicine. Now they told me to go up and then go down the hospital. We, patients, are also confused. I can understand if it is only once or twice, but every time I go there, I get confused because I did not get to see the same doctor. I do not understand it...sometimes I used to think...I will die...

Chiang shared that her interaction with the physician is very limited, and before she could explain her symptoms to the doctor, the doctor already completed writing the prescription. Asha George (2010:23) argues that poor communication and interaction quality between patients and providers significantly determines patients' poor satisfaction with public health facilities. Moreover, the social relations based on a hierarchy between patients and providers are a barrier for patients to raise their voices or concerns within hospital spaces (ibid). Doctors usually do not give enough time for patients to explain their symptoms and experiences. They would have completed prescribing the test and medicines while patients are still explaining their problems (ibid). Whereas this is not the case in private clinics, women shared that their doctors listened to them with patients when they visited their clinics.

7.2.2.2 Private Clinics and Hospitals:

Table 7.1 shows that around 56.34 percent women were diagnosed with diabetes at private health facilities, and around 32.39 percent of women utilize only private health facilities for treatment follow-up of diabetes. The average expenditure for diabetes treatment follow-up at private clinics, as reported by women, was INR 1,000/- (USD 12.05) per month which included both medicines and diagnostics. Women utilizing private health facilities mostly belong to high-income groups. Although, it may be mentioned that even those in the low-income group have no choice but to visit a private health facility when their symptoms become severe. There are numerous reasons for utilizing private clinics or hospitals, as shared by women. These include:

a) Convenient Timing to visit Private Clinics:

Some women in the study perceive that checking their fasting blood glucose early in the morning would give them a better result. Therefore, they preferred to visit the HWCs early morning and with an empty stomach, around 6:30-7:00 am. However, in most cases, HWCs do not operate so early in the morning as the frontline workers will only reach the HWCs by 10:30-11:00

am, except in a few HWCs where these frontline workers reside in the staff residential quarters. Therefore, it is difficult for women to access the tests, especially when they also have to go to work in the field or to the market in the morning. Given this reason, women prefer to visit the private clinic or hospital where doctors usually arrive and start treating patients by 7:30-8:00 am. For instance, Manda, aged 56, shopkeeper selling pork, who was diagnosed with diabetes in 2019 at the private clinic of Dr. Mark, shared:

It is more convenient to visit the private clinic because the doctor at the clinic knew that I have a sugar disease and I will come empty stomach, so I did not have to wait long. The doctor will call me first. The doctor is considerate because I used to eat food early, and I would feel hungry. Hence, I am being called to the consultation room before any other patient to have food soon after the test.

Manda lives at Mynsngad village near Mynsngad HWC, 5.6 km from Nartiang PHC and 11 km from Ummulong. Although her house is near the HWC, she never visits it. She said that she has to wait until 11 am for the sub-centre to open; therefore, she finds it more convenient to visit the private clinics. She has to leave for the market early, and waiting for the health workers would mean wasting one full working day. Similarly, other women who belong to high-income groups and can afford to visit private hospitals regularly for follow-up treatment of diabetes shared a similar narrative. They said, “In Shillong, we do not have to wait till 11:00 am. Even if we go to Shillong with an empty stomach, they will check our sugar when we reach the hospital around 8:30 am.”

b) Unpleasant Experiences with the Public Health Facilities:

The other reason for low-income women choosing private health facilities is that they could not often purchase medicines or do diagnostic tests at public health facilities. Wulcy, aged 53, daily wage laborer, and was diagnosed with diabetes in 2019, shared:

I did try to go to a government hospital, it is not like I do not go, but I did not get the medicine from Civil (Civil Hospital Shillong) every time I go there. I first went to Civil only, but I did not get the sugar medicine, and the second time I went also, I did not get the sugar medicine. As we are poor, my first treatment source was Civil only. Even I told the doctor that I do not have enough money. But when I went there, I did not get the medicine, the doctors only wrote it on the slip, and then I had to buy from the Peter pharmacy at Police Bazaar (Shillong). If it is always like this, I have to go to places where I can get both doctor and medicine together. Because I never got the sugar medicine from Civil, I am stuck with Dr. Andreas (allopathic private clinic) and stopped going to Civil.

This narrative clearly shows that women were dissatisfied with the fragmented nature of services at public health facilities and preferred visiting health facilities where they can avail comprehensive services. Despite being poor, Wulcy shared that she still chose to travel to Shillong, almost 60 km from her village, to access the private clinic of Dr. Anthony. She learned about Dr. Anthony from her neighbors, friends, and relatives who are also living with diabetes and are seeking treatment from him. It may be mentioned that most women with diabetes who lives in Wahiajer village, where Wulcy lives, seek treatment from Dr. Anthony in Shillong. The reason is that they consider it *iatoh nusib* or their luck matches his treatment. Moreover, they also shared that the doctor is kind enough to patiently explain, and jot down the dietary advice in detail.

7.2.2.3 Traditional Tribal Healers:

It is important to note that in Meghalaya, there is a preference for traditional healers, particularly in the context of minor ailments such as fevers, malaria, diarrheal disorders, gastric problems, injuries, jaundice, and fractures (Albert, 2014). However, in villages, people also depended on allopathic medicines for chronic illness, as evident from the present study's findings. It was observed from the field study that women would simultaneously seek care from both biomedicine and traditional healers, depending on their response to the therapy of their first choice. If they do not get relief from allopathy, they visit the tribal healers. The traditional healers were easily accessible in the villages or the weekly markets. This saved the patients a lot of travel costs and time. Given the mountainous and hilly terrain of the state, most of the villages are scattered and sparsely populated. In most cases, the public health facilities were very far from the houses of people residing in remote villages.

a) Preference for Utilization of Services of Traditional Healers:

Table 7.2 shows that few (n=8) women access the services of traditional tribal healers for diabetes care along with the allopathic system of medicine, as they consider it to be *iatoh nusib* or their luck matches the treatment provided by the traditional tribal healers. For instance, Ristina, aged 67, a widow, studied up to class III and sold vegetables to earn her livelihood. She shared that she had used the service of a traditional tribal healer for diabetes. She said the sugar medicine given to her by the traditional tribal healer at Nartiang village is helping her a lot. According to her:

For one year, I took medicine from Wanmi (a traditional tribal healer), which greatly helped me. It was only after I took his medicine that I was able to go to the field. But I could not take his medicine for one year due to the lockdown (second wave in 2021). He went to a different village to provide services, so during the lockdown he could not come to Nartiang. He was stuck at Khliehriat (the headquarter of East Jaintia Hills District, where he had gone to provide services). I used to mix the medicine he gave with water and have it twice daily.

Ristina shared that the traditional healer she visited did not quote any amount for the sugar medicine and he used to pay him based on her ability to pay any amount. Besides the fact that she finds his medicine effective, she he visited the traditional tribal healer because of the flexibility in paying for the treatment.

b) Reasons for Non-Utilization of Traditional Tribal Medicine for Diabetes:

Women's economic status and level of education have played an important role in the utilization of the services of a modern doctor and not depending on tribal traditional healers. For instance, Emma, aged 66, widow and retired bank employee, shared:

I have never visited them, as I do not understand this *dawai pnar* (Pnar or traditional medicine). I am also not going to *doktor pnar* (traditional healers) because I am taking *dawai phareng* (allopathic medicine). I am seeking treatment from *doktor phareng* continuously, so how will I go to *dawai pnar*? How will I take both medicines together? Since my diagnosis was already by *doktor phareng* (allopathic doctor), I am continuing my treatment from them only.

Secondly, women suffering from diabetes believe that allopathic medicine is better for chronic illnesses because the tribal healers give multiple explanations for the disease and create confusion and stress. Manisha, aged 66, owner of a small shop selling pork, was diagnosed with diabetes in 2019. She does not go to *doktor pnar* but to an allopathic doctor, shared:

If I go *pnar* doctor, they will say I got the disease from this and that, from here and there, especially for sugar and BP. The *doktor pnar* will say that I got this illness from somewhere, and I will think of many things and I do not want to know those things. However, if I go to the *doktor phareng*, they will tell me to take a particular medicine and my soul will be satisfied. I am more comfortable with seeking treatment from Dr. Mark in Ummulong (allopathic private clinic).

The reasons for not utilizing the services of traditional tribal healers include women were not aware that tribal healers provide diabetes treatment, and some women do not believe in them. For

instance, Daphi aged 55, a single mother working as a primary school teacher in a private school, shared:

I do not believe in *Kombiraij* (traditional healers), the one who used to do magic. I do not believe in him as a Christian; I do not believe in those things. My mother also did not believe in such things. She hated them the most. I used to tell him that I only needed diabetes medicine, I did not want you to do any magic...

Daphi considers traditional tribal healers all the same and treats them using “magic.” In contrast, other folk healers provide herbal treatment and use prayers at the same time, regardless of the religion they belong to. Some traditional tribal healers of the indigenous religion also pray to God and make sacrifices to treat illnesses. None of the women with diabetes report this healing practice in the present study. Traditional healers who follow Christianity also pray to God or Jesus, besides providing herbal medicine.

7.2.2.4 Unqualified Medical Practitioners:

Women in the present study also shared that they had access to the treatment provided by unqualified medical practitioners (UMPs) for general illnesses. However, only two women utilize their services for diabetes. Julie, aged 68, did not receive a formal education and used to work as a tailor, but due to her old age, she shifted her occupation to being a shopkeeper, selling shoes in her village. She was diagnosed with diabetes through the eye screening camp. The screening camp was conducted in her village, Umladang, by the healthcare providers of Ummulong CHC and from the District Medical and Health Officers’ office, Jowai, but she cannot recall the year. According to her narrative, she had resorted to multiple systems of medicine to treat diabetes. She continued the treatment after an allopathic doctor confirmed the diagnosis in his private clinic. However, as her symptoms persist and she feels uncomfortable, she is “searching for a wiser one” to cure her illness. As she narrated:

I searched everywhere for the wise ones for treatment and found Dr. Bhoi- the Ladang⁶⁵ (referring to an unqualified practitioner). The Ladang told me I could stop taking sugar medicine because my sugar has disappeared. But, because I was afraid that the Bhoi (referring to the same unqualified medical practitioner with a different name) might lie to

⁶⁵ In the village, doctors are usually known by their last names or the name of the place they originated, the real names of doctors are unknown to most people. In this case, Julie also refers to the UMP as Bhoi or Lakarew, which is the name of the doctor's place. She knew about this doctor as he had come to her village to start a clinic. During fieldwork, the doctor did not visit Umladang village. Therefore, I was not able to meet him.

me and that my sugar had not disappeared, so I went to meet (Dr.) Mark at Ummulong. When I met him yesterday (13 July 202), he told me I do not have the sugar anymore, and that is how I believed. Otherwise, I will not believe him (referring to “Dr. Bhoi”).

Although the UMP provided her with the treatment, she was still doubtful of him and went to verify the information back to the private clinic of the allopathic doctor where she first sought treatment. This health-seeking behavior of Julie also shows that the financial support she got from her husband, who works as a cow trader, enables her to visit and pay for the travel and treatment expenditure. Her village Umladang, borders Assam, and to visit the UMP, she reserved a vehicle for INR 1,000/- (USD 12.05) to reach his village, which is far and located in Assam. For the medicine and consultation, she paid around INR 2500/- (USD 30.06).

The choice of healthcare provider is determined by the access and ability to afford healthcare services (Verma et al., 2018). Most of the women in the present study used multiple sources of treatment for diabetes. The reasons for visiting multiple providers are numerous. George (2010: 23) argues that patients will learn more about the treatment provided through a “network of friends, pharmacists,” and informal providers, who act as “cultural brokers,” assisting them in explaining and guiding them in seeking care from different sources. In the community, patients will discuss themselves and share their interactions with healthcare providers.

Women’s narratives reveal their unpleasant experiences in the utilization of diabetes care at the public health facilities due to irregularity in availability of services. Whereas in private health facilities, women do not encounter these challenges and they can visit the physician any time whenever they are free from work. Further, unlike in public health facilities where there is frequent change of doctors, such problem is not report at private health facilities. Nonetheless, the quality of diabetes care provided at both public and private health facilities in West Jaintia Hills is poor.

7.3 Treatment-Seeking Behaviour among Women: Decision When and Where to Seek Treatment for Diabetes:

Health-seeking behavior and its determinants explained by Arthur Kleinman (1980), the medical anthropologist is in congruence with Andersen and Newman's (2005) individual determinants of medical utilization framework. Age, sex, family role, occupation, education, family's socio-economic status, past experiences with health care, type and severity of symptoms, and proximity to particular treatment sources were some of the determinants of health-seeking

behavior identified by Kleinman (1980). How these determinants interplay to influence treatment-seeking behavior for diabetes is explained through the case study of Mimi Tyngkra.

Mimi, aged 57, does not receive any formal education, and works as a farmer. She practices the indigenous religion and lives in Longthma village, 25 km from the nearest PHC and 45 km from Jowai, the district headquarters. She is a widow as her husband passed away in 2003. She has five daughters and two sons. Except for her youngest daughter, who is 20 years old and is living with her, her other children are married. She was diagnosed with hypertension and diabetes in 2001, when she was 37 years old, at Edwin Hospital, Jowai. As she narrated:

It has been more than 20 years since I got this sugar illness. It all began like this, I used to feel very sleepy in the daytime after having lunch, and I could not go to the field anymore. But I found it difficult to sleep because of dizziness and my hands and feet were paining, and the veins got entangled. I started feeling tingling in my body, hands, and leg, but I do not know why. As my whole body was tingling and I became very ill, my children took me to Mission Hospital. After they did all the blood tests, the doctors found that it was due to sugar and BP. Since then, whenever we visited any hospital because of these symptoms, the doctors say it is due to BP and sugar.

Since Mimi was diagnosed with diabetes, she has been hospitalized frequently due to uncontrolled BP and blood sugar. She said- “My sugar will always be more than 300-400 (mg/dl). My BP will be around 180 or 190 or 200 or more than 200 (mg/dl).” She does not suffer from any other illness besides hypertension and diabetes. Given that Mimi had been living with hypertension and diabetes for more than 20 years, based on her experience, she could understand the symptoms of hypertension and diabetes. She said:

Whenever my sugar increases, there will be a tingling sensation ‘*mur mur*’ (an expressive word used to describe more about that feeling) in my hands and feet. It will be tingling like that. Then my head and body become heavy and aching, and I cannot walk. But, after taking the sugar medicine, the doctor gave me, my sugar decreased.

The narratives provided by Mimi show how she is trying to analyze her illness history and how she considers medical treatment effective in controlling her blood sugar. In analyzing progression of her sickness, she further shared how and when she decided to seek treatment:

When I eat red rice, I could feel it is affecting me, I feel heavy, and I could not go to the field anymore. I do not drink tea as it is affecting me. I am afraid to eat fatty and oily foods, meat, and sweets. I only eat tasteless and boiled foods. My sugar level will increase if I eat any food I am advised to avoid. When I felt it is affecting me, I used to go to the hospital. I decided when and which hospital to go.

However, the decision regarding where to seek treatment was made based on her financial condition when her symptoms became severe. The source of her treatment expenditure is her income from her grocery store and agricultural produce that she sells. She said:

When I had money, I used to go to Edwin Hospital in Jowai and got admitted there, but when I do not have the money, I go to Civil (Jowai Civil Hospital, alone). In Edwin Hospital, we have to pay everything from our pocket- the medicine and the admission charges, but in Civil, we do not have to pay for everything. However, once I got admitted, I became well.

The treatment follow-up for diabetes also depends on her ability to afford to pay for it, as she shared that it is very costly, and the fact that she lives in the remotest village also increases her travel expenditure to Jowai. She shared:

Even for a check-up, Edwin Hospital used to charge me (INR) 5,000-6,000/- (USD 60.27-72.33) per visit. I have stopped going for a checkup for two months (April-June 2021) because I do not have the time to go due to work, and I do not have money. It always costs (INR) 5,000-6, 000/- (USD 60.27-72.33), so I feel tired, it is too expensive. Every time I go for a check-up to Jowai, the driver used to charge (INR) 1000-1200/- (USD 12.05-14.47) because while going, it is difficult to get a cab. While returning if I fortunately happen to get the same car, I do not need to pay. If it is with other car drivers then I have to book again (INR) 1, 000/- (USD 12.05) if we get the medicine late. This made me suffer financially, and I had to sell whatever property I had because with the kind of work I am doing it is difficult even to sustain myself. What work will we get, we villagers, if only we get a job that enables us to buy at least enough food?

The outbreak of the COVID-19 pandemic and the consequent lockdown is another barrier to her follow-up treatments. This is why her RBS (521mg/dl) and BP (190/80mm of Hg) were found to be very high when checked on the day the interview was conducted. She was suggested to visit the nearest PHC for immediate treatment, but it was under a micro-containment zone due to the increased number of COVID-19 patients. The other challenge was that, as it was afternoon, no more local vehicles available to go to Jowai town. Usually, most local vehicles leave the village early as passengers are mostly small traders who have to reach the market early in the morning. Mimi has no choice but to drink the passion fruit leaves, instead to control her blood sugar.

Family dynamics also determine the kind of support one gets or does not get from family members. In the case of Mimi, given that she had to be admitted to the hospital multiple times a year, even her children had given up supporting her. She said:

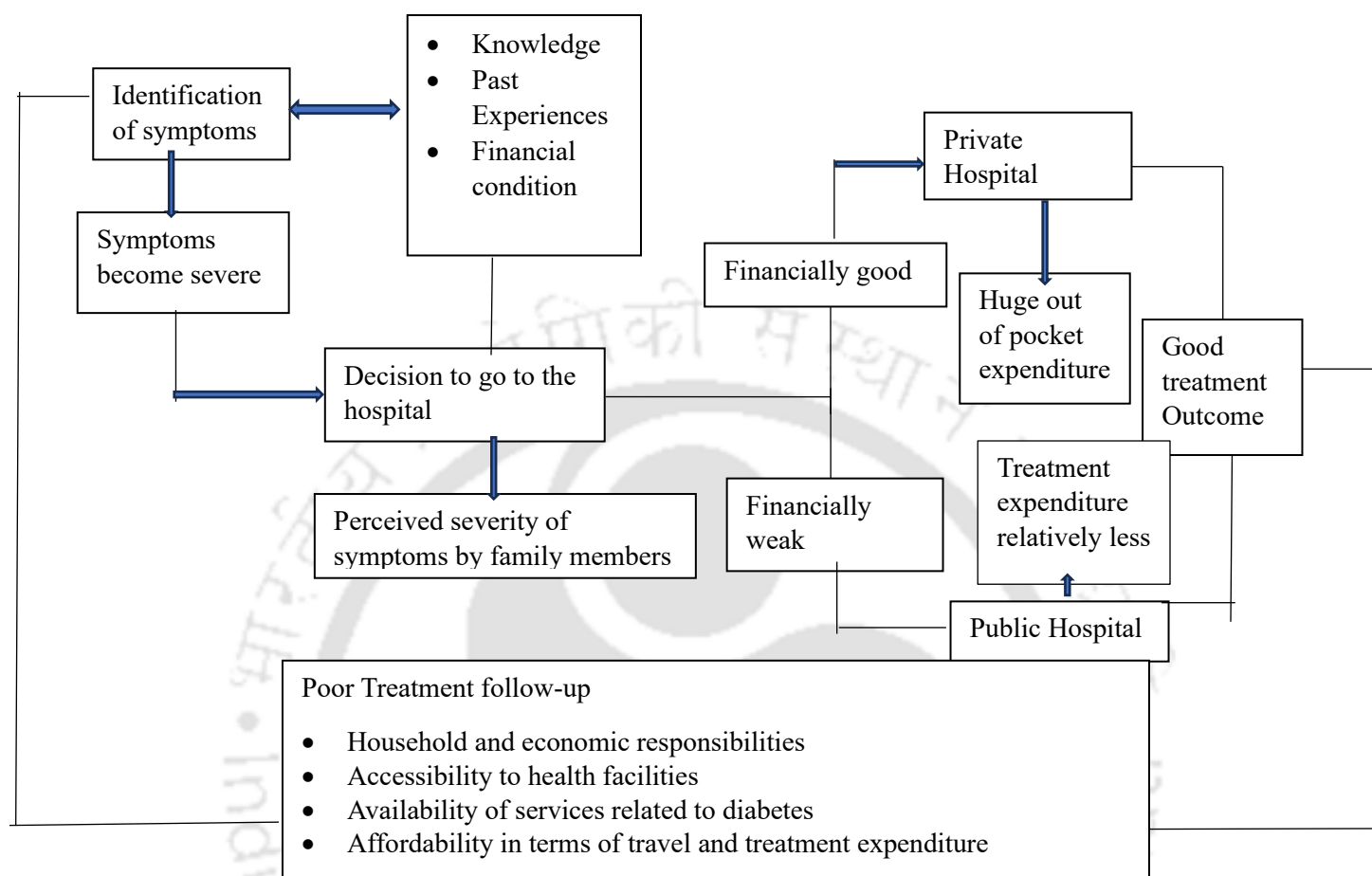
As I used to be hospitalized three to four times a year, my children are tired of taking me to the hospital. My children told me to stop going so we do not have to spend money. They

said- “whenever we get money, we do not know where this mother went and threw it, where is she spending the money, but she always used to go and throw the money to Edwin Hospital.” This is why, whenever I felt sick, I used to get in the local car and go to Edwin Hospital by myself. I would not even tell my children.

Her past experiences of getting relief after the treatment she received during hospitalization also prompted her to seek treatment all by herself. The proximity to particular treatment sources is also one of the determinants of health-seeking behavior. Mimi's village is located more than 5 km from the HWC, in a hilly area with rugged and crooked roads. There are no local vehicles to go up to the HWC, which makes it very challenging for her to go and get her RBS regularly monitored. She also considers visiting HWC as a waste of time, given her experience of the irregularity in the medicine supply at the public health facilities she had visited. Besides the treatment she had accessed from public and private hospitals, Mimi utilizes alternatives such as herbal medicine and home remedies such as consuming wild fruits and vegetables. She said, “Like a child, I obeyed everything my neighbor and friends advised me”. She considers herself to be the only one with bad luck that she got diabetes, according to her, nobody in her clan has diabetes and thus expresses her anger towards the disease, saying- “God has written it, and it is my bad luck that I will get this *kjut mrad*” (*kjut* means illness and *mrاد* refers to animals).

The narratives of Mimi represent the case of other women living with diabetes in the present study. Figure 7.2 below summarizes the findings related to women's health-seeking behavior diagrammatically. However, the narratives of other women are discussed further in the next section on how each factor influences the utilization of health care services for treating diabetes.

Figure 7.2 Health seeking behavior presented diagrammatically based on narratives of Women



Source: Diagram drawn based on narratives of women

7.4 Factors Influencing Utilization of Health Services for Diabetes among Pnar Women:

7.4.1 Impact of Education on the Utilization of Services for the Treatment of Diabetes:

It is argued that “knowledge is the best pill and the best vaccine (GoI, 2018a:138).” Thus, people with higher education and knowledge tend to perceive the benefits of preventive care and treatment to be higher, but the rest of the population might not perceive the same (Sundar & Sharma, 2002). In the present study, almost 55 percent of women did not receive formal education. Education or health literacy can influence knowledge about diabetes and its prevention. Findings from the present study show that the educational level of women does not seem to directly impact

the utilization of services for the treatment of diabetes. This could be because of other factors, such as past illness experiences and knowledge about the disease. For instance, Syntiew, aged 55, widow, used to go to Nartiang PHC regularly for follow-up of diabetes. She did not get the opportunity to go to school and used to work as a daily wage laborer at the stone quarry site. She was diagnosed with diabetes in 2020 at Nartiang PHC. When asked about what motivates her to go for follow-up, she said:

It is because I wanted to go with all my heart. People told me, “Why do you always go to the dispensary (Nartiang PHC)? Are you not scared of COVID-19?” I replied to them, “no, I do not feel scared it is for my health...”

The understanding that now her health is crucial comes from the Medical Officer who treated her and said, “You got a very difficult disease.” Syntiew said:

It was the first time he (Dr. Pynhun) found that illness. He gave a shocking response, and I was really scared. He said I have sugar disease and need to start caring for what I eat. The disease was found at (440 mg/dl)...

Vlassoff (2007:48) argues that the extent to which women are being kept away from school or excluded from taking part in public matters, as social factors affect women’s knowledge about health problems and their prevention and treatment. This argument could also hold in some sense because women respondents perceived diabetes as a short-term illness. Out of the total number (n=39) of women who have no schooling, only a few (n=13) reported not going for regular follow-ups for diabetes. They believe they are poor and illiterate, so they do not know or were not aware of the importance of regular follow-up for diabetes and that it is a chronic disease.

However, other reasons stopped women from taking treatment for diabetes regardless of their educational level. For instance, Amy, aged 44, completed higher secondary school and works as a primary school teacher under Sarva Shiksha Abhiyan (SSA) in her village, shared:

My brother who is also living with diabetes, and I stopped taking allopathic medicine a few months after we were diagnosed with diabetes. We had to switch to the Ayurvedic medicine I purchased from the drugstore. We stopped because we were scared that our kidneys would be damaged, like what happened to our mother. She also has diabetes, and because she is taking too much sugar medicine now, her kidney is damaged, and she has to do dialysis every alternate day in Shillong.

Amy and her brother aged 40, were diagnosed with diabetes in 2018 and 2019, respectively. The narratives shared by Amy indicate that she and her brother might have inherited diabetes from their mother, who might have suffered complications of diabetes. However, due to a lack of health

literacy, they perceive that their mother's kidney is affected by “too much consumption of sugar medicine.” Thus, educational status does not necessarily guarantee understanding diabetes, its treatment, and the care required. Women are influenced by what they are experiencing in the family. Women’s lack of health literacy is also reflected in the poor felt need to adopt preventive measures like attending screening for hypertension and diabetes. As a result, most women in the present study were diagnosed with diabetes accidentally and at a later stage. This finding is supported by the WHO (2020c) study on “Gender and Non-Communicable Diseases in Europe: Analysis of STEPS data,” where they found the percentage of those with low-education levels is higher in terms of not getting their blood pressure, blood glucose, and cholesterol checked than those with high-education levels.

7.4.2 Economic Constraints on Utilization of Healthcare Services for Diabetes:

Oosterhoff et al. (2021:241) argue that “poverty, illness, and out-of-pocket expenses are part of a vicious cycle that deters women from accessing healthcare services.” Most women (n=44) in the present study belong below the poverty line. The economic constraint was mentioned by some women (n=26) as one of the challenges in delaying seeking treatment. Due to financial constraints, people from lower-income groups are forced to stay at home without medical treatment (Verma et al., 2018). Findings from the field show an irregularity in treatment follow-up for diabetes among women. The reasons, as shared by women, were that they had to wait until their husbands or children received the wage or were free from work. While waiting, they have no other choice but to tolerate the symptoms, no matter how serious it is. For instance, Bial, aged 53, did not receive any formal education and works as a farmer and depends on her husband's or children’s wages to visit the private clinic of allopathic doctors in Jowai. She has nine children, and her husband works as a daily wage labourer. She lives in Khliehriat village, around 41 km from Jowai town. She was diagnosed with diabetes in 2017 at a private clinic of an allopathic doctor. She said:

I used to feel the pain, and it was biting. There are times when there is pain, and my heart weakens. As I do not have the money so, I am tolerating it. When I cannot tolerate it anymore for two-three months, then I go. When my children get their daily wage, I can seek care, as they will give me the money...when they do not get the wage, then I cannot go.

Oosterhoff et al. (2021) found that men in Meghalaya, questioned their wives for asking money to purchase medicines for Sexually Transmitted Infections (STIs). However, this was not found in

the present study. Most married women shared that the only support their husbands provide to them when it comes to diabetes is financial support. The other source of financial support is their children working as daily wage laborers. Verma et al. (2018) observed majority of the population have to stay at home without treatment for their illnesses due to poverty. Poor women in the present study depend mainly on the public sector despite its limitations. When they cannot afford to undergo treatment for further complications, they have no choice but to remain home. The decision to utilize health care services is influenced by the person's perception of the costs and benefits of utilizing the services. The costs include treatment expenditure and loss of wages. The availability of health services and the ability to pay for them also influence the decision to utilize health care services (Sundar & Sharma 2002).

7.4.3 Overcoming Geographical Barriers to get Treatment:

Given Meghalaya's remote and mountainous terrain, a well-connected road from interior villages to the cities and towns is one of the important determinants in accessing healthcare roads. Many of the villages are located on the hills or in sparsely populated areas, creating extreme difficulties for people visiting the health facilities. It is particularly relevant in Meghalaya, where over 80 percent of the population lives in rural areas (Nayak & Thomas, 2007; Census of India, 2011). People living in the state face not only the problem of inadequate amenities but also the problem of accessing these facilities due to the distance factors. Though primary schools and safe drinking water were provided in the State within a radius of about half a kilometer, the facilities like primary health center, veterinary center, marketplace, post office, bus stop, etc., were far away from their houses in all the districts in the state. In the East Khasi Hills and West Khasi Hills, people traveled nearly 6 kilometers to reach the nearest primary health center (Nayak & Thomas, 2007). Besides that, there was district-wise unevenness in the distribution of public health facilities. Both in India and globally, physical distance is one of the important determinants in the utilization of health care services (Sundar & Sharma, 2002). Similarly, the present study found that most of the facilities provided to the people were far away from their residence, and they had to undergo hardship to avail those facilities. This became more pronounced during the COVID-19 pandemic lockdown.

Out of 71 women interviewed, 21 reported facing challenges in traveling to health facilities, given that their village is remote and disconnected from the towns. An incident was narrated by

Bhaki Niang, aged 67, a widow who lives in Nongjngi Ionglwit village, 33 km from Jowai town. Bhaki did not receive formal education works as a farmer. However, when the interview was conducted, she had already stopped working in the field and had become financially dependent on her children. She was diagnosed with diabetes in 2019 in a private clinic of Dr. Boris in Jowai town. As her symptoms exaggerated during the second wave of the COVID-19 pandemic lockdown, she had no choice but to visit Dr. Mark, an allopathic doctor, in his private clinic at Ummulong. Ummulong is located around 11 km from her village. She said she went alone without informing her children because she did not want to bother them. As the lockdown was imposed during this time, she said that she struggled to get the vehicle, and without thinking about the vehicle for return, she hopped in a car packed with people and reached Ummulong Village, where she was charged INR 100/- (USD 1.20) for the one-way taxi fare. Even before the lockdown, the travel fare was the same, but it was reduced to INR 80/- (USD 0.96) if the number of vehicles was more. She said:

I could not tolerate it anymore, so I waited for cars there (pointing towards the village's main road) on the roadside. Then there was a car coming from there (from the adjacent village, Lumtrep) with passengers. I did not even worry about getting a car to return home as long as I got to visit the doctor. I just got in the car and went. Fortunately, while coming back, a driver in Ummulong called me. He said- "come *men* (a term used to address an elderly woman), at least you will get to reach till Nartiang. No more cars are going to Nongjngi, so come with me till Nartiang. When you reach Nartiang, you can take another car," then I just went blindly. I went alone. I did not tell my children that I was going for a check-up. Only after I left did my grandchildren tell their mother that I had gone to take medicine. When they informed her (her youngest daughter), she was in the field, as it was in the middle of the sowing season, and so she became anxious. She asked her children- 'why didn't you take my mother? How could they let her go alone? She does not even have a mobile phone. What if she dies on the way?' In my head, I said- God forbid, He will not let me die during the day, it is only till Ummulong that I went, God will not let me die during the day...I went beyond my capacity...

In rural Meghalaya, transportation was a major problem even in pre-COVID-19 times due to poor road conditions and shortages of vehicles. Only a few local vehicles (mostly Maruti 800) were available, and only in the morning, as people living in the villages used to go to the market in the nearby towns. During a health emergency, people have to reserve vehicles which is expensive. The poor functioning public health facilities in rural areas makes people in village struggle to reach towns or cities to access treatment services.

Besides these factors, women face other cultural barriers to regular treatment follow-up, which are discussed in the following subsection.

7.4.4 Double Burden of Domestic and Economic Responsibilities among Pnar Women:

Given the culture of matriliney, women in Meghalaya work outside the home besides their household activities. Thus, they are actively participating in both productive and reproductive labour. Women's engagement in economic activities outside the home, which provides income, constitutes an important aspect of productive labour. Apart from these, women are also involved in reproductive labour which is mainly done within the households and involves taking care of children, cooking, cleaning, and working on farms which is to a large extent unpaid but plays a very important role in the continuation and sustenance of the households and economy. For instance, as Vlassoff (2007: 50) argues, "Reproductive labor, in addition to reproducing the daily conditions of domestic survival, also assures the reproduction of human values, attitudes, and culture. In industrialized and developing countries, women spend considerably more time than men in reproductive, volunteer, and other unpaid labor." Further, gender differences in economic status and purchasing power affect women's health-seeking behavior and health outcomes (Vlassoff, 2007). One of the important barriers for women to seek treatment includes lower concern within the family for their health and constraints due to domestic work (Srivastava, 2010).

In addition, rural women are more likely to be subjected to traditional stereotypes about their roles and other gender norms, limiting their decision-making power and access to resources (WHO, 2020c). Women's economic demands and household responsibilities to take care of their children takes a toll on women's health, as found in the present study, thereby affecting their health and influencing the utilization of health services. In Meghalaya, children take the clan's name of their mother. Therefore, mothers have a greater responsibility towards their children (Mukhim, 2019). This further increases the responsibility of women to become economically productive so that they could raise their children, especially when she is widowed or abandoned by their husbands. Kmen, aged 67, a widow who experiences multiple symptoms, shared that she cannot go to Jowai to seek treatment because she has to care for her grandchildren. As she narrated:

Even now, while I was talking to you, it was cold on my legs, feet, and waist. It is also biting, and I have a fierce burning sensation. I told my youngest daughter I must go to Ialong rather than simply taking the treatment from Nartiang PHC. What if it does not work? If she has to take me to Ialong, no one will take care of my grandchildren. Nobody can take care of them,

I think I have to go alone, and she will stay home. But I do not know if she will be free from her work as she works in the field.

Diabetes is a chronic and irreversible illness that requires long-term medical attention (Bernell & Howard, 2016). Buor (2004) argue that as women are burdened with domestic services, their time to seek care is limited unless their condition becomes serious. Besides caring for children, women are responsible for ensuring that household needs, such as food, water, fuel, etc., are met. Most women express that they need to work hard so that they will be able to meet the needs of their children. For instance, Daphi, 55 years old, working as a Primary School teacher in a private school, expressed how she is working very hard to meet the needs of her children as her husband had abandoned her. She says:

Apart from being a school teacher, I am doing tailoring work and stitch clothes for people. I also grow vegetables on my farm so I do not need to spend money and buy from the market. I am working very hard. I am doing rice cultivation too. Even when I am this sick, I am very busy, that my health has worn out. I used to earn (INR) 12,000-13,000/- (USD 145.13-157.22) per month, but (INR)10,000/- (USD 120.93) is the amount I am sure of getting (fixed salary from teaching). As the head of the school is my cousin, even during this lockdown, she pays me, but she could not pay them. I used to spend the money on rent and food. I have to send money every week, for my children who are staying in Jowai. They are studying there. A single mother like me has to work hard and eat whatever we could afford so that I will be able to educate my children. When I look at my children, I am worried, but I thank God that my children are good. I cannot stop working hard because until now, not one of my children has gotten a job. Because they do not have a father, I must work alone. He ran away. Just think, I have six children and I have to work alone so I am stressed. I have to educate them as well. So, I will naturally be stressed...

She continues-

My children are still studying, so I have to buy them books. I used to buy one at a time for my daughter, she is studying in the science stream. I feel bad about making my children work as maids in people's houses.⁶⁶ I cannot take care of myself as I am trying to prioritize my children's needs more than mine. It is also because I am getting lots of medicine from the Civil hospital (Jowai), so I do not have to spend much. Even when I am lamenting, I am still working hard...there are times when I pretend as though I did not feel it...

Daphi shared that besides diabetes, she also has chest pain, high cholesterol levels, and sinusitis. Nevertheless, she still has to work hard to meet the needs of her children. Given her economic condition, Daphi is among the women who utilize the services available at a public health facility

⁶⁶ A common practice in the community where people who belong to low-income groups usually sends their teenage children to other people's house in towns or Shillong city to work as maids or helper and their earning usually meant to supplement the family income.

for follow-up treatment of diabetes. For her, this could be the only way to save money for her children's education as she got all the medicines from the public hospital free of cost.

To ensure Universal Health Coverage (UHC), vulnerable populations must be protected from health risks and shocks such as catastrophic healthcare expenditure, thereby preventing them from the “vicious cycle of debt, poverty, and ill health” (RamPrakash & Lingam, 2021:2). There is a need for healthcare programs and policies to pay more attention to women's health in a context where women are more likely to suffer from illnesses and hospitalization. Chronic illnesses such as NCDs are the major cause of mortality among women worldwide for the last three decades (Bonita & Beaglehole, 2014). Now NCDs are responsible for “two in every three deaths among women each year” (Bonita & Beaglehole, 2014:1). UHC schemes that sideline women's specific health needs are limited only to Sexual and Reproductive Health (SRH), which, if not addressed, could exaggerate gender inequities (RamPrakash & Lingam, 2021). There are numerous Publicly Funded Health Insurance Schemes (PFHIS) implemented in India since 2007 by both central and state governments to provide financial protection to the marginalized section of the population (Selvaraj & Karan, 2012; RamPrakash & Lingam, 2021).

In the next sub- section, I will briefly provide an overview of the Megha Health Insurance Scheme, which is followed by the narratives of women based on their experiences with the utilization of the health insurance scheme.

7.4.5 Megha Health Insurance Scheme (MHIS) and Diabetes: Financial Protection for Women Suffering from Complications of Diabetes:

In Meghalaya, the Rashtriya Swasthya Bima Yojana (RSBY), a health insurance scheme was launched by the Central Government in 2009 to provide financial assistance to individuals belonging Below Poverty Line (BPL). However, in 2012, with the launch of the Megha Health Insurance Scheme (MHIS) the RSBY was subsumed.⁶⁷ The MHIS aims to provide a universal health insurance scheme (UHS) to all residents in the State, including existing categories of RSBY beneficiaries but excluding State and central government employees. Thus, in India, the Government of Meghalaya was the first to provide universal health coverage to its entire

⁶⁷ Information collected from the State Nodal Agency for the Megha Health Insurance Scheme- Pradhan Mantri Arogya Yojana (MHIS-PM-JAY).

population, irrespective of socioeconomic status (Dutta et al., 2022). In addition to UHC, the MHIS's objective is to improve the quality of services and strengthen the public health systems. The scheme is implemented phase-wise, as shown in Table 7.3 below.

Table 7.3 Phases in the implementation of MHIS

Phases	Year	Policy Period	Amount of Coverage
Phase I	2012	May 2013 to July 2015	INR 1, 60, 000 (USD 1,924.07)
Phase II	2015	August 2015 to October 2016	INR 2,00, 000 (USD 2,405.09)
Phase III	2017	July 2017 to September 2018	INR 2, 80,000 (USD 3,367.13)
Phase IV	2019	February 2019 to August 2022	INR 5, 00, 000 (USD 6,012.72)

Source: State Nodal Agency, Megha Health Insurance Scheme- Pradhan Mantri Jan Arogya Yojana (PM-JAY), Shillong

It was in December 2018 that the Ayushman Bharat- Pradhan Mantri Jan Arogya Yojana (AB-PMJAY) was implemented in the State, and since then, the MHIS has been merged with it. The objective of the AB-PMJAY, launched by the Central Government, is to provide insurance coverage of up to INR 5 lakhs (USD 6,012.72) per family on a floater basis, regardless of family size.

7.4.5.1 Registration under MHIS-PMJAY:

In 2018, the MHIS officials visited villages, took individual photographs, and accordingly, smart cards were issued to every individual, replacing the old smart cards under MHIS. Like any other health insurance scheme, the purpose of the smart card is to enable easy access by the poor and non-literate individuals by making the scheme “cashless, paperless and portable” (Jain, 2017:10). In both public and private hospitals, the beneficiaries must register again before admission at the MHIS counter by the Arogya Mitra.⁶⁸ Depending on the patient's medical history, the Arogya Mitra in public and private hospitals “block” or allot the package under MHIS. This is followed by uploading patients' documents in the Transaction Management Software (TMS), linked between the National Health Authority, State Nodal Agency officials, District Program Manager, insurance company, and the hospitals. The claim process doctor from the insurance company will study the case carefully before they approve the package rate.⁶⁹ The process is known

⁶⁸ The word Arogya Mitra means medical friend. Arogya Mitra are appointed at each empanelled hospital, both public and private to provide support to patients both in terms of mobility and information (D'Cruze, 2020).

⁶⁹ Package Rates- There are pre-approved rates for each medical and surgical procedure, which are known as Package Rates.

as pre-authorization. If the package that was blocked and the treatment provided is not matching, this can lead to the rejection of claims. Rejected claims are reflected in the software, along with reasons for rejection.⁷⁰

In Meghalaya, the Megha Health Insurance Scheme (MHIS) was implemented in 2012 to “reduce the out-of-pocket expenditure of families enrolled under the scheme and, in the process, improve the health services of the State.”⁷¹ There is a growing burden of both communicable and NCDs in the State. As a result, this has increased out-of-pocket expenditure (OOPE) in both rural and urban areas. According to the report “National Health Accounts Estimates (2018-19),” in Meghalaya, the OOPE for OPD in public and private hospitals was INR 1073/- (USD 12.90) and INR 647/- (USD 7.78), respectively, in rural areas. The OOPE for hospitalization was INR 2201/- (USD 26.47) and INR 15,591/- (USD 187.48) in public and private hospitals, respectively, for rural areas (GoI, 2022). The present subsection, therefore, discusses women’s experiences with the utilization of the MHIS thematically.

7.4.5.2 Women’s Experiences with High OOPE due to Hospitalization Related to Diabetes Complications or other Associated NCDs:

In the present study, about twelve women residing in the study villages have a history of incurring huge out-of-pocket expenditures for hospitalization due to diabetes and other associated NCDs. Table 7.4 below briefly describes the characteristics of the twelve respondents interviewed and followed up during the study period from 2020-2022. The number of years lived with diabetes and details about comorbidity, multimorbidity, and complications, if any, are presented in Table 7.4. Seven women belong to the age group of 56-68 years. More than half of them were either separated or widowed. They are either uneducated or studied only up to the primary level. Six women were financially dependent on their children, given their old age and illness. Ten women have five or more children—their years of living with diabetes range between two to twenty years. The most common comorbidity reported by women is hypertension, although three reported vision problems, and some reported gastritis.

⁷⁰ Information based on field interviews with officials associated with the MHIS

⁷¹ Available at [Our Mission, Vision & Objectives | Megha Health Insurance Scheme \(mhis.org.in\)](https://mhis.org.in) Accessed on 10th June 2021.

Table 7. 4 Brief information about Women with diabetes who incurred high OOPe

Sl. No.	Respondents' Names	Age	Marital Status	Educational Qualification	Occupation	No. of Children	Years lived with diabetes	Complications/comorbidity
1.	Chiang	56	Married	Primary	Daily wage laborer	11	6	Hypertension Gastritis
2.	Tipsngi	38	Married	Uneducated	Daily wage laborer	3	4	Cyst in her ovary
3.	Queency	51	Married	Uneducated	Dependent	9	5	Diabetic Foot Anaemia
4.	Wani	49	Widow	Uneducated	Self-employed (Selling vegetables)	7	3	Acute Peptic Disease
5.	Dashisha	36	Separated	Uneducated	Daily wage laborer	2	3	Vision problem ⁷² Gallbladder stones, Kidney stones, Joint Pain
6.	Mimi	58	Widow	Uneducated	Farmer	7	20	Hypertension
7.	Philari	68	Widow	Uneducated	Dependent	11	6	Chronic Kidney Disease (on hemodialysis)
8.	Nini	42	Married	Primary	Self-employed non-agriculture (selling chicken)	5	6	COVID19 Gastritis
9.	Rimika	58	Widow	Uneducated	Dependent	9	19	Bedridden
10.	Ristina	67	Widow	Primary	Dependent	11	9	Hypertension Gall Bladder Stones
11.	Darilin	60	Married	Uneducated	Dependent	7	2	Hypertension Gastritis Vision Problem
12.	Rimonmi	65	Widow	Uneducated	Dependent	6	2	Vision Problem

⁷² Diagnosed as “chronic iridocyclitis” in both left and right eye with very poor vision in the right eye. She was diagnosed at Gupta Eye Center, Shillong, on 11 November 2022.

Table 7.5 Women's narratives on history of hospitalization

Sl. No.	Respondents' Names	Type of health facility last hospitalized	Condition at the time of hospitalization	Out-of-pocket expenditure (Besides the amount booked from MHIS-PMJAY Card)	Source of expenditure
1.	Chiang	Public Hospital in the District	Prolonged dizziness, Severe headache, tingling sensation, and numbness in the hands and feet	INR 10,000/- (USD 120.93) (Four days)	Borrowed from friends
2.	Tipsngi	Public Hospital in the District	She has severe pain while urinating, chills all over her body, and pain in her lower abdomen	INR 17,000/- (USD 204.48) (Seven days)	Her husband, who worked as a daily wage labourer in a sawmill, borrowed from his employer.
3.	Queency	Public Hospital in the District	Unconscious, Pain and swelling in her left ankle two weeks before the hospitalization	INR 70,000/- (USD 844.95) (Two months)	Her son-in-law, who worked as a truck driver supplying wood
4.	Wani	Public Hospital in Shillong	Admitted due to fever, tingling sensation in her hands and feet	INR 30,000/- (USD 360.75) (Two months)	Self-financed (own income and savings)
5.	Dashisha	Public Hospital in the District	Abdominal pain was detected with gall bladder and kidney stones. Accidentally diagnosed with diabetes.	INR 20,000/- (USD 240.55) (Six days)	Her sister and son paid from their daily wage as the MHIS card was under policy break.

6.	Mimi	Private Hospital in the District	Feeling of tingling sensation and whole-body pain, dizziness,	For only the hospital bill INR 5,700/- (USD 68.56) (INR 3,600/- (USD 43.30) booked from her “smart card,” and she paid the remaining INR 2,100/- (USD 25.26) For medicines and diagnostics- INR 10,000/- (USD 120.93)	Selling her ancestral property
7.	Philari	Private Hospital in Shillong	Acute Kidney Failure and is on dialysis	INR 44,000/- (USD 530.40) (latest hospitalization) (Thirteen days)	Selling of ancestral property
8.	Nini	Designated COVID-19 hospital in the district	Tested positive for COVID-19	INR 5,000/- (USD 60.27) for diagnostic tests at a private hospital (Thirteen Days)	Paid from her wage and her husband's wage
9.	Rimika	Public Hospital in the District	Burning sensation from feet up to her head, restlessness, profuse sweating	INR 50,000/- (USD 601.24) (forgot to take the smart card to the hospital)	Sold her land
10.	Ristina	Public Hospital in the District	Unconscious	INR 10,000/- (USD 120.93) (Six days)	Children's wage
11.	Darilin	Private Eye Care, Shillong	Blurring of Vision	INR 3,000/- (USD 36.16) (One day)	Financial support of a husband who worked as an agricultural laborer
12.	Rimonmi	Private Eye Hospital, Shillong	Blurring of vision	INR 17,000/- (USD 204.48)	Arranged from children's daily wage

The history of hospitalization and expenditure for treatment of diabetes, its comorbidity, and complications is described briefly in Table 7.5. Patients reported spending a minimum of INR 10,000/- to 70,000/- (USD 120.93-844.95) per hospitalization, depending on their health condition and the number of days they were hospitalized. The detailed findings are presented thematically.

7.4.5.3 Barriers to Enrollment in the MHIS Scheme:

At the village level, the operators face many challenges that deter enrolling all the target beneficiaries. These include data mismatch, socio-cultural issues, infrastructure and weather conditions, accessibility to villages, and irregular electricity supply. The other challenge in registration is the people's knowledge regarding the possibility of registering during the admission process. Misconceptions or beliefs about generating identification numbers for the smart card are another barrier to enrolment. In rural areas, people linked the number with that of the beast, “666,” as mentioned in the Bible,⁷³ which Christianity follows as the Holy Book. Given that a large proportion of the population in Meghalaya follows Christianity, this belief is rooted in them. However, this belief is stronger in rural areas and almost absent in urban areas where educated people mostly reside and understand the necessity of enrolling for an Aadhar card.

For instance, Queency, aged 51, a woman dependent on her children and suffering from a diabetic foot, did not enroll for the MHIS until she got admitted and had to incur huge out-of-pocket expenditures. Her son-in-law, Jerry, aged 30, shared how he availed the smart card for Queency while she was admitted to the hospital. He said:

I only started applying for the smart card after realizing the high treatment expenditure. We thought it was only diabetes; hence we did not have to spend much money. However, after three to four days, we realized the expenditure was very high, so we consulted the nurse, who suggested using the smart card. I visited the Block Development Officer's office to apply for a smart card for her, which is the fastest way to get it. The smart card was issued to us in November 2020.

Her youngest daughter, Heini aged 18, said she used the smart card only while purchasing medicines from private pharmacies outside the hospital empaneled with MHIS. They must pay from their own pocket for any diagnostic tests at private hospitals or medicines purchased from

⁷³ In Meghalaya, the belief about 666 stems from the Bible, where in the book of “Revelation” chapter 13:17-18, it was mentioned that in the last days, it will be the times of trial and tribulation as the beast will come. The Bible verse says, “And that no man might buy or sell, save he that had the mark, or the name of the beast, or the number of his name. Here is wisdom. Let him that hath understanding count the number of the beast: for it is the number of a man; and his number is Six hundred threescore and six (The Bible, King James Version).

private pharmacies that are not empaneled with MHIS. Concerning the cash memos, she shared that she had thrown them away as nobody explained to her that the money spent by them would be reimbursed. Nevertheless, reimbursement is impossible as Queency does not have a bank account. Her daughter shared:

Since we were young, my mother did not have a bank account. She feared using the Aadhar card as people in the village considered the number 666 as a bad omen. Those times people in our village were discussing that unless you have an Aadhar card, you will not be able to make any banking transactions. Since then, she has withdrawn all her money from the bank and closed her account. For her, closing her bank account is better than enrolling for an Aadhar card.

7.4.5.4 Economic condition as a factor that determines the type of hospital for seeking treatment:

Almost all of the twelve above-mentioned women belonged to below-poverty-line households or a low-income group. The daily survival and struggle to earn a livelihood made it extremely difficult for them to pay for hospitalization. Therefore, visiting a hospital is challenging for them unless they became seriously ill. Seven women reported that their last hospitalization was in a public hospital, but they visited private hospitals when they had money. Mimi mentioned earlier, shared her different experiences of hospitalization at public and private hospitals. As narrated:

When I had money, I used to go to Edwin, but I go to civil when I do not have the money. Edwin, I spent around (INR) 20,000-30,000/- (USD 240.55-360.75) in one admission episode, even after the hospital deducted from my card. Even if we spent that much at Civil (government hospital), they will pay for it or return it to us. Like the previous year (2020), when I got admitted to Civil (Jowai), I did get the reimbursement. Even if I do not get the whole amount, at least I got half of it, and they deduct the cost of medicine too. I was admitted thrice at Edwin when they said the smart card was not working anymore as it was time for a policy break, so they did not deduct. She was not able to recollect the year. During those times, I had to pay everything from my pocket- the medicine and the admission charges. Later on, when I got admitted twice (the new phase in which the MHIS was implemented), they (at Edwin Hospital) deducted from the smart card, but most of the amount was from my pocket. They were not willing to deduct the whole amount. After each hospitalization, I recovered and felt better. I got some help from the smart card, about one-fourth, which is fine...even with that much amount, and I feel light.

Given Mimi's social position, she could not undertake regular follow-ups for diabetes and hypertension until she became seriously ill and had no other option but to visit the public or private hospital depending on her financial status. She also lives about 40km from Jowai, the District Head Quarter, where all the hospitals are located. Frequent hospitalization makes

her more vulnerable to poverty due to healthcare expenditures. Her situation represents the case of all eleven other women in the study, who also faced numerous barriers to regular follow-up.

For Tipsngi, aged 38, a daily wage labourer, the decision to go to a public district hospital was its easy accessibility. She shared:

Because of the chills, my daughter and my husband took me to the District Hospital as it is near and it was at night. I was taken to the Emergency Room, and after the nurse checked my BP and sugar and the doctor examined me, they shifted me to the ward. As I was admitted through the Emergency Room, we did not register for the smart card during that time, but the nurse told me to collect all the medicine and test slip and submit it to them when I got discharged. They also asked for my passbook details so that they could reimburse the money. But I did not understand anything they were doing.

Thus, because of the perception that public hospital is free of cost and due to the easy accessibility, women opt for public hospitals unless they suffer from severe complications and are referred to Shillong. Although public health facilities are meant to provide services free of cost to patients due to the lack of diagnostic tests and medicines in public hospitals, women are forced to purchase them from private hospitals while being admitted to public hospitals. The cost incurred on medicines and expenditures is supposed to be reimbursed upon discharge from the hospital. Still, in most cases, women reported not getting or delayed reimbursement.

7.4.5.5 Limited knowledge about the MHIS-PMJAY Packages:

It became clear from the fieldwork that women had limited knowledge about the services provided under the MHIS-PMJAY package. For instance, Mimi mentioned, “Edwin Hospital did not deduct the whole amount,” indicating her limited knowledge about the MHIS scheme that functions on a package basis for each disease. Like all other respondents, Mimi did not know the amount of money deducted from their card or the balance. Nevertheless, her anticipation that the hospital should deduct the whole amount was not wrong, as she is categorized as Below Poverty Line (BPL). Therefore, she was entitled to totally cashless treatment. To ease herself, she said she is happy with the state paying at least one-fourth of the expenditure for hospitalization.

The concept of “packages” under the MHIS-PMJAY is beyond the understanding of women, given their low educational level. This is reflected in their concern which came out constantly: “We are illiterate; we don't understand anything that they are doing.” According to health officials, patients with diabetes are usually allotted under the General Ward Unspecified Package, whereas other NCDs, such as cancer, have different specified packages. Given the

low knowledge about the packages amongst women, it appears that healthcare providers associated with implementing the scheme did not attempt to explain to the women how they are charged under the insurance scheme.

Understanding the complexities surrounding MHIS is challenging for women, given their low level of education. The lack of education among women further lowers the position of women as educational attainment is considered a marker of socioeconomic position (Coeli et al., 2009). People with higher education perceived the benefits of preventive care and treatment as higher, but the rest of the population might not have the same perception (Sundar & Sharma 2002). As my study shows, women believed they were poor and illiterate, so they did not know anything about the scheme. Poor knowledge among women can also be attributed to information asymmetry, an inherent characteristic of markets in healthcare. More than a professional healthcare transaction, the market transaction is the most predominant mode of interaction between patients and providers (Nandi & Schneider, 2019). The power relations between patients and providers also prevent them from asking more about their problems (George, 2010) and seeking full information about the care package.

7.4.5.6 Fragmentation of Healthcare Services Leading and Out-of-Pocket Expenditure:

All women admitted at JCH Ialong, shared that they were referred to do most of their blood tests and diagnostics investigations in private health facilities such as Lifeline Hospital, or the nearby private diagnostic centres. Moreover, they were advised to purchase most medicines from private pharmacies outside JCH, Ialong. Jerry, the son-in-law of Queency and in charge of her treatment expenditure, shared:

We used to spend (INR) 3,000/- (USD 36.16) per day only on medicines. We have to pay up to (INR) 5,000/- (USD 60.27) for blood tests as they told us to do four to five types of tests. Once you have to take her for the test, then “*ngak ngak ne*” (an expression referring to the extreme cost of the test). I gave my sister-in-law (INR) 5,000- 6,000/- (USD 60.27-72.33) for 4-5 days. We spent around (INR) 70,000/- (USD 844.95) for the two months of hospitalization (November- December 2020). The smart card is not helping. Even the gloves they told us to buy... only for the bed we did not have to pay.

Queency was financially dependent and had no social security. She had to depend on her son-in-law, a truck driver earning approximately INR 10,000/- (USD 120.93) monthly, for her medical expenditure. This was the case with almost all the respondents admitted to JCH, a public hospital in the block, who shared that they must first pay from their pocket, and the money will get reimbursed in their bank account. When women are admitted at JCH, Ialong is

referred to Lifeline Private Hospital. They can no longer use the smart card as they had already registered in JCH, Ialong with the public hospital. This is one of the factors leading to high out-of-pocket expenditure by women living with diabetes in the study area.

7.4.5.7 Delayed reimbursement process: “*Reimbursements depend on luck*”

The main objective of the MHIS-PMJAY Scheme is to provide free hospitalization for the poor and to make the scheme cashless. However, the lack of adequate diagnostic tests and medicines at the public health facilities forced women to spend money from their pocket first and wait for reimbursement. The respondents reported the reimbursement process to be cumbersome; sometimes, it was delayed for many months. Further, the amount reimbursed is usually lesser compared to the amount spent. Chiang aged 55, narrated her dissatisfaction with the scheme as follows:

I was hospitalized for four nights, costing almost (INR) 10 000/- (USD 120.93). Now and then, I have to go and do the tests at private health facilities, but they never deducted from the smart card, not even one rupee. The doctors prescribed the medicine, and we purchased them from private pharmacies. I used to spend (INR) 600-700/- (USD 7.23-8.42) daily for medicines from my pocket. I do not understand it. No matter how much the cost is, it is all from us. What is the point of wasting my time registering for this smart card? The people at Lifeline Hospital told me, “Here, it is not working”? Why is the card working only in Edwin Private Hospital? They told me I would get the reimbursement within 3-5 months. My friends told me that if they spent (INR) 5,000/- (USD 60.27), they would only get (INR) 2,000-3,000/- (USD 24.11-36.16) as reimbursement. Those who are lucky get the reimbursement. Those who are unlucky do not get it. Sometimes, they give half, and we must spend half from our pocket. We are illiterate. We do not understand it. However, others share their stories of not getting the reimbursement even after one year. We must sacrifice day and night and take all the pain to avail of the card, but it is useless. I do not understand how they are doing the reimbursement process. If it is like this, if we have to spend about (INR) 10,000/- (USD 120.93) from our pocket, what is the use of the smart card...it did not help us at all.

The high out-of-pocket expenditure and the delay in the reimbursement process stressed Chiang, given that she has to take care of a large family and her husband is working as a cowherd on a daily wage basis.

Like Chiang, Ristina, aged 67, elderly widow, who was admitted to JCH, Ialong for six days in December 2021, shared a similar story:

We used to collect all the bills, and before I got a discharge, I gave it to them (referring to the Arogya Mitra at JCH, Ialong). They told me I could update the passbook in May 2022. They said the reimbursement amount was credited to my account in May 2022. The money that entered my account was (INR) 5,000/- (USD 60.27), but we spent (INR) 10,000/- (USD 120.93), so I got half of it. I went to Lifeline twice for some tests, and

they told me I had gallbladder stones. I spent (INR) 3,800/- (USD 45.68) on the tests. That one was from our pocket, but we were not reimbursed. I do not remember them asking for a smart card at Lifeline. About (INR) 5,000/- (USD 60.27) credited to my account was only for the medicine we purchased from a private pharmacy. We have calculated the total amount we spent.

Like other women, the case of Ristina reveals that even if they are admitted to a public hospital, they are still forced to go to a private hospital for diagnostic tests. The costs of these tests are not reimbursed under the scheme. Women reported delays in the reimbursement process. The money spent during hospitalization was credited to their bank account after one to three months and, in many cases, even after three months.

7.4.5.8 Complications of Diabetes Leading to Huge Treatment Cost:

Women suffering from chronic kidney disease (CKD) and requiring regular dialysis must visit Shillong to get treatment from private hospitals, similar to women who need eye surgery. Thus, they have to incur huge treatment cost, both for transportation and treatment. For instance, Philari, aged 68, widow, was diagnosed with diabetes in 2017-18. Since 2019, she suffered from chronic kidney diseases (CKD) and she had to undergo hemodialysis every alternate day at Newlife Hospital, Shillong, located 90 km from her village. She has to reserve a vehicle for INR 2,000/- to 5,000/- (USD 24.11-60.27) per visit to Shillong back and forth. Regarding other expenditures, she said:

Only for dialysis, costs more than (INR) 3,000/- (USD 36.16), but we also have to do blood tests every month. The cost of the blood tests varies from one month to the other. Sometimes, they charge INR 2,000/- (USD 24.11), and at other times INR 5,000/- (USD 60.27). I have to also undergo a blood transfusion every time I go for dialysis. It costs INR 1,500/- (INR 18.08) per injection. The smart card is not helping much. For example, dialysis costs around INR 3, 700/- (USD 44.49), but they deduct INR 2,775/- (USD 33.37), and we have to pay the remaining INR 925/-(USD 11.12). They only deduct the cost of the dialysis every time we go. They did not deduct the cost of the injection or the blood tests...

Another woman, Rimonmi, aged 65, a widow, was unfortunately diagnosed with diabetes before her second eye surgery at Meghdoot Eye Centre, Shillong. Her first eye surgery was conducted in 2020 at Amory Hospital, a private hospital in Shillong. She narrated the amount she had spent on her eye surgery as follows:

The first surgery was for my left eye in Amory Hospital, costing around (INR) 3000/- (USD 36.16). They also advised me to buy medicines that cost (INR)1000/- (USD 12.05). We went to Meghdoot to get my right eye operated on in 2021. My children spent almost (INR) 10,000/- (USD 120.93) for the operation despite the smart card, of which Rs. 7,000/- was for the equipment they needed for the surgery. My daughter only purchased

the simple equipment they used to stitch my eyes. They deduct some from the smart card, but we only have to pay for the equipment. Regarding medicine, I do not know how much, but it was not so costly. They took the smart card from us, but we do not know how much they are deducting or not deducting that we do not know. I am sure we spent (INR) 3000/- (USD 36.16) at Amory Hospital and (INR) 7000/- (84.38) at Meghdoot for the equipment. Other than that, they used to take (INR) 1000/- or more after the doctor examined me.

The case of Rimonmi also shows that women were not intimidated regarding the amount deducted from their cards. They were unaware of the procedure for booking their illness package from their smart card.

7.4.5.9 Source for Medical Treatment Expenditure:

Since all women work in the informal sector or are financially dependent on their children, getting money to pay the hospital bill is challenging. Women, however, managed to get the money through some means- by borrowing, selling properties, and by the little earning they made or through the daily wage of their children. Tipsngi, aged 38, daily wage laborer, who spent around INR 17,000/- (USD 204.48) for seven days of hospitalization at JCH, Ialong shared her source of medical expenditure as follows:

My husband borrowed from the *Malik* (owner) of the sawmill, where he works as a daily wage laborer. Then we pay the money back to him on an installment basis. His *Malik* deducted the money we borrowed from my husband's wages. Sometimes he deducts (INR) 500/- (USD 6.03), and sometimes (INR) 1000/- (USD 12.05). It is hard for poor people. What we earn today, we have to spend today on our food.

For Philari, the source of money for her treatment was from selling off her assets, such as pine trees (commonly sold in the community to be used as wood), from the land where she and her late husband had purchased. She cannot estimate the amount of land she has sold or the trees. She shared:

It was because of the ancestral property. For now, we can still sell our land. I wasted everything on myself, and my children and grandchildren will not get any more. Poor them, they are unlucky because of me getting an illness like this. They did not explain to me since the beginning that we always have to do it like this once we start doing the dialysis. Had they explained to me that I would have to do dialysis until the day I die, I would not do it. I could have told them to let me die. However, they did not explain it to me. I thought they would only treat me once, so I considered tolerating it. My children do not have the money to give me, so they did not grumble even if I sold the property. I regret selling them, but I have no choice. I have sold the land and the trees. If only their father had not died, we could have saved money, but he died and left me alone.

Having many grandchildren who are supposed to inherit her property, Philari feels guilty that she had to sell the property for her treatment instead. She even felt guilty for starting the dialysis

and expressed her desire to die instead of wasting money on herself. For her, spending on her treatment is a waste of resources. Thus, this has affected her mental health as well as she kept blaming herself. She was anxious and stressed about her grandchildren's future.

The Government of Meghalaya claims it is progressing toward UHC as more than 50 percent of the eligible beneficiaries have been enrolled in the MHIS-PMJAY (Dutta et al., 2022). However, findings from the present study highlight the implementation process of MHIS and its failures in providing financial protection to women suffering from diabetes complications. Narratives of women show that the scheme seems to have failed to improve healthcare access for the poor and ease the burden of people hospitalized due to chronic illnesses. One of the objectives of the MHIS-PMJAY is “to strengthen citizen’s voice and empower patients by influencing their health-seeking behavior.”⁷⁴ Women in the study considered themselves “poor” and “illiterate,” making them passive rather than active participants in health care. Rather than questioning the health authority and exercising their agency, women passively accepted whatever is offered to them owing to their limited knowledge that they are entitled to free and cashless treatment. My study shows that women suffered from multiple illnesses that required immediate medical and surgical intervention. Yet, fearing out-of-pocket expenditure, they preferred to stay at home instead of seeking care. Moreover, the cost of transportation acts as a hindrance to seeking treatment. In consonant with the study conducted by Oosterhoff et al. (2021) in Meghalaya, women were hesitant to visit the hospital despite having a smart card. What held them back, and they stayed at home despite having complications, was the fear of huge out-of-pocket expenditures. The fact that a large section of the population from lower-socioeconomic strata in need of services are forced to forego treatment due to financial constraints is well-documented (Coeli et al., 2009; Verma et al., 2018). The advice given by doctors to patients admitted at public hospitals to do the diagnostic tests at private health facilities exposed patients to financial risk due to the unavailability of these tests. People are drawn to public hospitals, as they expect free or affordable services. However, the actual situation is different where even while being admitted at public hospitals, they have to incur expenditure because they still visit private hospitals for diagnostics procedures or medicines (Nandi & Schneider, 2019).

⁷⁴ Available at [Our Mission, Vision & Objectives | Megha Health Insurance Scheme \(mhis.org.in\)](https://mhis.org.in) accessed on 10th June 2021.

In Meghalaya's matrilineal society, women are largely engaged in agriculture and work long hours in the field (Mukhim, 2005). The fact that they are also responsible for their children further increases the responsibility of women to become economically productive so that they can raise their children, especially when she is widowed or abandoned by their husband (Nongbri, 2008). Women are more likely to suffer from various health problems, such as chronic illnesses, because of the multiple works they are engaged in (Lewis & Kieffer, 1994; Vlassoff, 2007). The narratives reveal the plight of poor tribal women who suffer from chronic illnesses and are hospitalized. Gender interacts with other axes of social division, such as age, education, occupation, and place of residence, to shape women's experiences. The narratives of the twelve women indicate they suffer from multiple disadvantages that shape their experiences while using smart cards during hospitalization or while undergoing tests. Poor Pnar women who lack education, a source of secured income, and are widowed suffered from multiple axes of social discrimination, thereby acting as barriers to seeking diabetes care. Therefore, there is a need for the assessment of resources available for health promotion and treatment of illnesses (Lewis & Kieffer, 1994). Knowing what resources are available and the ones controlling them and deciding for whose benefits are also necessary (ibid). Findings from my study show that the number of claims made by women was higher than by men, indicating that health insurance coverage is higher among women than men. Health insurance coverage is considered a marker of potential healthcare access (Coeli et al., 2009). However, women's narratives indicate that having an insurance card is insufficient without providing adequate information on how to utilize it and without providing financial protection.

In the next section, I make an attempt to discuss the barriers in accessing healthcare services during the COVID-19 pandemic.

7.5 Barriers to Utilization of Healthcare Services for Diabetes During the COVID-19 Pandemic:⁷⁵

People with diabetes can never forget that they suffer from diabetes, even for an hour (Weaver, 2018). Thus, they must take extensive care of themselves, affecting them psychologically and financially (Verma et al., 2021; Pardhan et al., 2021). Along with self-management, people living with diabetes need to have continuous face-to-face interaction with different healthcare providers, such as general physicians, diabetes counselors, dietitians,

⁷⁵ This section of the chapter has been published as a paper.

endocrinologists, and podiatrists. These different healthcare providers and specialists' doctors function together to achieve the desired blood glucose level and prevent further patient complications (Mohseni et al., 2021). With the outbreak of COVID-19, the vulnerabilities of people with co-morbidity, such as diabetes, increased. They were at a higher risk of getting infected, falling severely sick once infected, and facing difficulties in accessing healthcare services for managing diabetes (Ateino, 2020; Beck, 2020; Hartmann-Boyce et al., 2020; World Health Organization (WHO), 2020). This was intensified by the restrictions imposed on the mobility of people as a result of lockdowns introduced by most countries. The lockdown has led to a sudden change in daily routine, reduced physical activity, and difficulty accessing basic needs (Nachimuthu et al., 2020; Pal & Bhadada, 2020; Gamble et al., 2020). The disruptions caused by the raging pandemic and the conversion of existing health facilities into designated COVID-19 centers hampered the delivery of essential health services and have also led to the delay in the treatment of chronic illnesses (WHO, 2020; Hartmann-Boyce et al., 2020). It is well-documented that COVID-19 increases the risk of developing complications among people with diabetes. Therefore, patients, especially those with a chronic disease like diabetes, were advised not to visit the hospital (Joshi et al., 2020 & Nachimuthu et al., 2020). As discussed in chapter four, self-management of diabetes varies across individuals belonging to different social groups. The social and economic factors also determined the ability to self-manage diabetes during the lockdown. It is important to note that lockdown and its implications are felt differently depending on the socioeconomic context (Al-Moteri et al., 2021). The pandemic severely impacted the already marginalized social groups and intensified their vulnerabilities.

7.5.1 How COVID-19 and the subsequent lockdown was Perceived in the Study Villages:

To contextualize the study, I will briefly explain how most people in the villages perceived COVID-19. They said COVID-19 was “just a new name” for “common cold and cough”. The perception of COVID-19 was the same in both waves, i.e., in 2020 and 2021. There was a strong denial of COVID-19, and it was considered a “political issue.” Most elderly men⁷⁶ and women with whom I interacted in the study villages commented:

The state wants to increase the number of COVID-19 cases to get more funds from the Center, and people who tested positive for COVID-19 do not get the required medical

⁷⁶ The present study focuses on women with diabetes. However, during fieldwork, I also conducted focus group discussions and interactions with other community members, both men and women.

care. This is “*kjut politik*” (*kjut* is a Pnar word for disease or illness, and *politik* means politic).

According to the people in villages, the symptoms of COVID-19, such as fever, cough, and shortness of breath, were normal, and by going to the hospital, they will be tested, and the result will be positive. This perception that seems very strong in the community also shaped the cognitive process of people living with diabetes, as they live within the same environment. For instance, Hannah, aged 60, a widow, who studied up to Class III financially dependent on her children, and lived with diabetes since 2017, shared:

We do not understand this disease; this *synrum* (sneezing) *wadat* (headache) has always been there. Our elders said that whenever this season (winter) arrives, this *synrum* and *wadat* will also come. It is these symptoms only that the government considered Corona. It is just that, earlier, they did not know how to name it, so elders called it *choh synrum* (sneezing) *wadat* (headache), and *khykyoh* (cough). However, now I am amazed at how they gave names to these conventional symptoms. It is crazy.

In 2021, when the second wave began, COVID-19 cases increased and became more serious. Based on the data collected from the official Twitter account of the Government of Meghalaya (@MeghalayaGov),⁷⁷ the number of deaths reported in the district increased from 10 deaths on 18th May 2021 to 34 deaths on 26th May 2021. Majority of the people were neither convinced nor believed in the COVID-19 pandemic. They still attributed the symptoms of COVID-19 to a common cold and cough. During the second wave, the COVID-19 pandemic also affected the rural areas of West Jaintia Hills. At the national level, it had been acknowledged that the rural areas were also affected during the second wave. This was evident even in the West Jaintia Hills district, where most of the population resides in rural areas.

As there was a spread of COVID-19 in villages during the second wave in 2021, healthcare providers from public health facilities conducted active surveillance to detect COVID-19 cases. Nonetheless, people even refused to get the Rapid Antigen Test (RAT) for COVID-19 done. The reason for refusal of the test was because of stigma and denial of the diseases. However, more than stigma, it was the denial of the existence of the disease. In both the COVID-19 pandemic waves, i.e., 2020 and 2021, people in villages were skeptical about the disease when they had a fever or cough. They preferred to stay at home or visit private clinics. The other argument that the people in the community made was the absence of medical

⁷⁷ <https://twitter.com/MeghalayaT>

care for people who tested positive. This was because those who tested positive were just advised for home isolation.

During the first and second waves of the COVID-19 pandemic lockdown in 2020 and 2021, people in remote villages did not strictly follow the COVID-19 protocol. For instance, in Mynsngat village, it was observed that all the shops were open, and people in the market who were engaged in trade businesses, such as selling meat, groceries, and other household items, mostly women, were not wearing masks. This happened during the second wave despite the spread of COVID-19 in rural areas. Iaineh, aged 45, farmer, denied COVID-19 when I interviewed during the second wave. He shared:

In our village, there was no restriction; there was no Corona. Recently (in 2021), there were six deaths in our village. The health department said they died due to COVID-19, but it was not like that. The people who died were the ones who had been sick for more than ten years. In some of them, their hearts were rotten already.

Thus, even during the second wave, there was a denial of COVID-19 in the study villages. The other incident Iaineh shared was a clash between the people living in the villages and the village headman. He said:

How can he stop us from earning our livelihood? He will not come and give us food when we are deprived. That is why people in the village did not obey the order and still opened their shops.

Given the poverty and marginalization of people, the struggle to earn livelihoods and daily survival was more important than the COVID-19 pandemic.

7.5.4 Challenges in Accessing Healthcare Services During the COVID-19 Pandemic Lockdown:

7.5.4.1 Increased travel costs and its impact on women from different socio-economic groups:

The geographical location of the respondent's residence and economic status also influence their access to health facilities. Respondents living in rural and remote areas faced numerous challenges in accessing care for diabetes. One of the challenges is the lack of transportation services and also its cost. For instance, Mimi, aged 58, shared that she had stopped treatment for two months (April to June 2021) due to the lockdown. There are no local vehicles available. Given her poor economic status, reserving a car is also costly. She said:

Every time I go, the drivers used to charge (INR) 1,000-1,200/- (USD 12.05-14.47) because while going, it is difficult to get a cab, and while coming back, if I get the exact car, then I don't need to pay. But if I get the medicine late and the cab I reserved earlier has gone, I must again book a different taxi for (INR)1000/ (USD 12.05).

Although Mimi did not explicitly mention that high transportation costs are the reason that prevents her from routine follow-up, she shared that she is still saving money to go to the hospital. Only when she has money can she go for a follow-up? Even before the COVID-19 outbreak, transportation was a major problem for people living in rural and remote villages. During the lockdown, people must reserve a vehicle in an emergency, which is very expensive. During the unlock phase, the drivers charged a huge fare as they had to transport fewer passengers than the number, they used to take to maintain the COVID-19 protocol. This impact is not felt by respondents with better socioeconomic status who shared that they could visit the health facility for follow-up of diabetes care. What enables them is that they have a vehicle at home and can afford to pay for the treatment expenditures.

For instance, Treki, aged 55, Lower Division Clerk in the Jaintia Hills Autonomous District Council (JHADC) office, was able to visit a private hospital in Shillong, about 62.7 km from her village, for a follow-up. She said: “I used to go for follow-up using our vehicle during the lockdown, so it was not a problem. After showing the prescription slip, the police permitted us to go.”

Findings from the present study reveal that the impact of lockdown on people living with diabetes varies across respondents depending on their socioeconomic context. While it is necessary to empower the community with knowledge and skills about diabetes self-management, understanding the challenges beyond the individual level is also crucial. These challenges are the socioeconomic factors, for instance, the ability to access health care services, types of facilities accessed, social support and social networks, and financial status. Accessibility to health services is one factor determining the utilization of healthcare (Jeermison, 2012). The difficulty in accessing healthcare services was further exaggerated by the COVID-19 pandemic lockdown (Nunez, 2021), especially among poor people living with diabetes in rural areas. This is due to the absence of public transport and increased travel fares. This made it hard for patients to reach the health facilities (Mohseni et al., 2021) unless they have a vehicle, which is not a privilege for many respondents in the present study.

7.5.4.2 Fear of Visiting Healthcare Facilities During the COVID-19 Pandemic:

The mandatory RAT at public health facilities scared away people, and they, instead, resorted to home remedies or visiting private clinics. People were suspicious of the health system and considered the test unimportant. A group of middle-aged men that I interacted, shared:

We always used to suffer from *khairih* (fever), *indoh* (common cold) *khaikyoh* (cough). *kani ka kjut toh kawa juh em hi cha I, mynchwa leh* (It was also there earlier). It is better not to go to the hospital when they do the test; they will say it is the corona.

This fear thus prevents even people living with diabetes from visiting public health facilities unless they become seriously ill. Nonetheless, few respondents were scared to visit the hospital not for the mandatory test but due to the fear of contracting the virus. For instance, Emma, aged 66, a widow and a retired government employee, shared:

I had to visit the doctor, but I was scared, as my daughter working at a private hospital in Shillong as a nurse, is not letting me visit the hospital physically. My daughter is afraid that I will get infected with COVID-19 infection. She said she would get the sugar medicine for me. She said there are around 20 COVID-19 patients in the hospital.

7.5.4.3 Economic constraints due to the outbreak of the COVID-19 Pandemic:

Public health facilities are the first choice for seeking care by about 30 women out of the 71, regardless of the poor quality of services available at these facilities. Chiang, aged 56, visited the hospital on October 30, 2020, for a follow-up. During her visit, she was advised to do many tests such as HbA1c, Kidney Function Tests (KFT), and serum lipid profile in a private hospital because these tests were unavailable at the district hospital. She said: “They told me to do these tests at a private hospital in Jowai, but I do not have enough money to go there. I will go home.”

Given her financial condition that was weakened due to the outbreak of the COVID-19 pandemic, Chiang could not comply with the advice to do the tests and instead return home. She cannot afford to visit the private health facilities as she or her children could not earn during the lockdown period. Thus, even when she could access the health facility, given its proximity to her village, she did not receive comprehensive services for diabetes care.

In Meghalaya, although some public health facilities are accessible to patients, the fact that they were asked to do laboratory tests at private laboratories and had to purchase drugs from private pharmacies led to high out-of-pocket expenditure (Oosterhoff et al., 2021). In the

present study, respondents reported that they could not visit any doctor unless they had a minimum of INR 1000/- (USD 12.05) in their bag/purse. The outbreak of the pandemic and its impact on their financial status act as a barrier to routine care for diabetes. The lack of adequate health facilities within the district forced people to visit Shillong, thereby incurring huge travel expenditures. The failure of India's public health system has been widely documented (Sahu & Kumar, 2014), and its weaknesses have been exposed even more during the COVID-19 pandemic. While the public health facilities were struggling to prevent and control the pandemic, people living with NCDs, such as diabetes, were left on their own.

7.5.4.4 Disruptions in the supply of antidiabetic drugs at public health facilities during the lockdown:

Another challenge faced by respondents who depended on public health facilities for diabetes care was the disruption in the supply of antidiabetic drugs during the lockdown. For instance, Syntiew, aged 55, a widow who worked as a stone crusher, shared:

I could not get any medicine from the dispensary⁷⁸. If it did not happen like that, I would have only taken medicine from the dispensary. The doctor told me, "This medicine we do not get anymore. Please do not mind. You have to purchase it." For one entire month, I had a fear of taking medicine randomly from anywhere. I was just unable to get the medicine. From that time, I was told to take *mahajon*⁷⁹ medicine, but I do not have the money to purchase it.

Syntiew could not afford to purchase antidiabetic medicine from a private pharmacy, so she shifted to ayurvedic medicine. She could do this only because her son aged 17, worked as a helper in her village's Ayurvedic doctor's house, giving her medicines and treatment in exchange for her son's wages.

In Meghalaya, public health facilities in rural areas still struggle to ensure a regular supply of antidiabetic medicine, diagnostic tests for diabetes, and even counselling services. This is reflected in the present study. As reported by WHO (2020b), there was a disruption in the supply of antidiabetic drugs in public health facilities during the pandemic. Nevertheless, the lack of medicine and diagnostic tests is an inherent problem in public health centers (Bhojani et al., 2013). Unless efforts are made to improve the quality of diabetes care at public

⁷⁸ Referring to Nartiang PHC. In the study village, PHC is called a dispensary.

⁷⁹ In the Pnar language, *mahajon* means rich. Here by *mahajon* medicine, she means the branded drugs sold at private pharmacies and are only affordable to the rich.

health facilities, the poor will suffer the most. Chaufan & Weitz (2009) argue that although in medical literature, “affluence” is considered one of the factors that had led to the diabetes epidemic, it has also been documented that it is poverty that causes diabetes and its complications resulting from poorly controlled blood sugar.

7.5.7 COVID-19 Vaccines as Preventive Measures from COVID-19 Infection:

7.5.7.1 The Attitude of the Community Towards Vaccination:

With the coming of COVID-19 vaccines, the community’s perception of COVID-19 became much more complex. There were many challenges faced by healthcare providers in motivating people to come forward for the vaccination, especially those who belong to the age group of 45 years and above. For instance, Blossom, aged 45, a senior nurse, shared:

During January-May 2021, when only those in the age groups of 45 years and above were advised to take the vaccination, hardly four to five people came in a day. However, with the new order to vaccinate the target group, those in the age group of 18 years and above, the number of people coming forward for the vaccination increased.

The information regarding population groups prioritized for vaccination was shared through the announcement made by the village administration. In the Ummulong village, Meena aged 48, a small trader selling clothes, shared: “The village administration had warned us that if we do not take the vaccine, we will not be allowed to carry on with our work.”

Meena, also diagnosed with diabetes in 2020, shared that had it not been because of the certificate, she would not have taken the vaccine. Her rationale for not taking the vaccine was that she has hypertension and diabetes; therefore, she was scared that the vaccine would result in complications. According to the protocol, people with comorbidities were prioritized for vaccination. However, in most cases, people living with hypertension and diabetes were the ones who were scared to take the vaccine as, according to them, it would complicate their existing illness.

7.5.7.2 Fear of death post COVID-19 Vaccination:

The community’s attitude towards vaccination became more complex when two people in Nartiang village infected with COVID-19 died. There was fear that people seemed to have believed the dreadfulness of the disease now. At the same time, the fear of getting vaccinated also became more pronounced. This was because the people knew that the ones who died had already been vaccinated. In a village, information usually spreads very rapidly as people easily know each other, and with the coming of mobile phones, it became easier for information to

spread. For instance, while we were conducting the disease surveillance at the ASHA's house in Nartiang village, one man from the community who was at their house commented- “the people who died in our village have been vaccinated. I have not been vaccinated”. His expressions show a sense of fear and doubt about the vaccine, for which the disease surveillance worker told him, “We are still alive.”

People in the villages shared, “Even vaccinated people still got corona and still die of the disease.” They also argue that “people even die after taking the vaccination.” Also, based on the District Administration’s order, people at a higher risk of getting the disease should get vaccinated. Otherwise, they will not be allowed to conduct business, whether driving local vehicles, trading, etc. This surprisingly made the people more suspicious, and they said – “what kind of vaccines is it that they have to force us to take? There must be something beyond”. Their arguments revealed fear of death even post-vaccination.

The local news channels streamed on YouTube were flooded with news about the refusal of COVID-19 vaccines by people across the State. In one video, the *Rangbah Shnong* (village headmen) of one of the localities in Shillong argue that although they believe in vaccination, the State should not force its residents to take the vaccine by denying their rights to earn their livelihoods. He said the people should inform him if they are denied opening their shop so that he will talk to the administration. He further stated that they are ready to file the Public Interest Litigation (PIL) if their concerns are unheard of. He said that people should not be intimidated nor threatened directly or indirectly if they refuse to take the vaccine. The question he raised was who would take responsibility if there is any untoward incident post-vaccination- he said that people are ready to get themselves vaccinated if the State promised to give INR 10 crores for deaths post-vaccination.

The doubt and fear of COVID-19 vaccines increase with deaths reported following vaccination and the fact that people vaccinated still succumbed to COVID-19. People in the community interpreted the order to take the vaccine as a forceful act of the State and also coercive as it denied them entry to work and access to groceries.

7.5.7.3 COVID-19 Vaccine and the Perception of People Living with Diabetes:

As part of the community, people with diabetes also developed their views concerning COVID-19 vaccines. Out of the 71 respondents, 40 were interviewed in 2021 after the COVID-19 vaccine was introduced. Almost 50 percent (n=21) did not take the vaccine. There was a mixed response from them, both positive and negative, but most of the respondents living with

diabetes shared that they were weak and were afraid to take the vaccine. The other fear was the fact that they were old and had hypertension. In this case, they fear that the vaccine will worsen their condition. For instance, Lanalang, aged 68, a widow, did not receive any formal education and was financially dependent on her children shared:

When my daughter told me to take the vaccine, I said *chi* (an expression when one does not like something). I am already old enough. That is the reason I do not take it. I was thinking that since I am growing old and sit at home, if my power is gone, I will die anyway. I only feel like that, so I don't take the vaccine.

The response was similar even with educated respondents who work in the government sector.

For instance, Emma, aged 66, a retired public sector bank employee, shared:

I thought as I am already old and I cannot eat properly, if I take the vaccine, I will become weak, then the vaccine will overpower me. I was only sitting at home and did not go anywhere. Imagine if they told me I got it, then they would keep me in a place where I have to sit alone. What would happen? I did not go anywhere. I am afraid I will meet different kinds of people.

Their perception was contrary to the government protocol, where according to the protocol, elderly individuals with comorbidities should be prioritized for the vaccine. Another contrary response was- why do we need to vaccinate ourselves when we are healthy? This shows that people were yet to fully understand the importance of the vaccine in preventing COVID-19. The narrative about people who died post-vaccination in the village and the magnetic effect of the vaccine spread in the community through word of mouth and social media, such as WhatsApp, further scared people of the COVID-19 vaccine. The perception of the COVID-19 vaccine was shaped not only by education but also by their worldviews. For instance, Syntiew shared:

Out of everyone from my locality, I am the only one who has taken the COVID-19 vaccination. They are still afraid. They said if we take this *kynjek* (inject), we will die after two to three years. Then I said even if I die, it is all right as I am already old. It is not like I am young; I would regret the world if I died. Now we are so old, so it is okay even if we die, I am not afraid.

Narratives of women in particular, indicate the complexities in the uptake of the COVID-19 vaccine, a preventive service provided by public health facilities. While most women refused to take the vaccine, few consider themselves “brave enough to take the risk” and take the vaccines.

7.6 Summary:

The diagnosis of diabetes was made accidentally among almost all women in different types and levels of healthcare facilities. While diagnosis was largely made in the professional sector, for treatment, women also utilize the services provided by traditional tribal healers and unqualified medical practitioners. Private clinics and hospitals were found to be the major source for treatment follow-up of diabetes, even among the low-income group. While for women from high-income groups visiting private clinics or hospitals is their first choice of treatment source, for the poor, it is “out of choice.” The poorest section of women continues to seek care from public health facilities despite the poor quality of services for diabetes in these facilities.

Several factors determine the utilization of healthcare services for the treatment of diabetes. The major factors influencing the utilization of health care services at the individual level based on women’s narratives include the severity of illness, past experiences, knowledge about the disease, and proximity to treatment sources. Gender roles and responsibilities, economic status, and health insurance are the other factors shared by women.

During both waves of the COVID-19 pandemic, i.e., in 2020 and 2021, women who belong to low-income groups shared that they stopped visiting health facilities as there were no local vehicles during the lockdown. Even when the lockdown was relaxed, the high cost of travel expenditure prevented them from going for treatment follow-up. This is, however, not the case for women from high-income groups who have the means to visit their doctors, traveling for long distances from their village to Shillong in their care. The fact that they also have secured income sources enables them to pay for the treatment expenditure even during a job crisis due to the COVID-19 pandemic lockdown.

Only a few women were privileged to have a glucometer at home, which helps monitor their blood sugar regularly during the lockdown. Moreover, having professionally qualified children or relatives as doctors or nurses is one of the social capitals that enabled the management of diabetes during the COVID-19 pandemic. The absence of regular follow-up increases the risk of women’s hospitalization due to complications leading to OOPE. The main objective of the publicly funded health insurance scheme is to provide financial protection to the poor during hospitalization. Unfortunately, women in the present study shared that despite having insurance cards, they still have to pay an exorbitant amount to the hospitals. This is due to the health system factor discussed in the previous chapter. Health system-level factors such

as the availability and distribution of health facilities between rural and urban areas, availability of human resources in health also shape people's access to and utilization of health care.

Chapter Five and Chapter Seven discussed the challenges women face in managing diabetes in the household and their interaction with the health facilities, respectively. The three pillars of self-management of diabetes- diet, exercise, and medication are largely seen as a biomedical and individualistic approach where the onus of care rests only on the individual. Mendenhall (2019), in her work on “Rethinking Diabetes,” argues that these biomedical model components of diabetes control- diet and exercise are “terribly difficult to accomplish.” Therefore, unpacking the risk environment on what makes these essential components challenging to accomplish is crucial. The “risk environment” or the underlying determinants of self-management and development of diabetes is discussed in detail in Chapter Eight.



Chapter Eight

Syndemic Suffering in Matrilineal Society: Poverty, Stress, and Diabetes

“Diabetes is a Disease of Poverty”

- Prof. Emily Mendenhall (2019:135)

Introduction:

The present chapter attempts to understand the lived experiences of women with diabetes in a tribal society. It draws on the concept of syndemic coined by Merrill Singer in the mid-1990s and used by Emily Mendenhall in her book “Rethinking Diabetes: Entanglements with Trauma, Poverty, and HIV” (2019). Mendenhall applies the notion of “syndemic suffering” in her discussion of the life experiences of women with diabetes across different socio-cultural contexts. The chapter also uses the concepts of intersectionality, the life course approach, and the social determinants of health frameworks to analyze and discuss the data and findings presented in this chapter.

Chapter Five discussed the constraints of the biomedical approach to diabetes management, focusing on the “three pillars of diabetes management,” namely, diet, exercise, and medication. The present chapter investigates the reasons and causes of the development of diabetes in Pnar women from West Jaintia Hills District of Meghalaya and the difficulties they face in following the advice of healthcare professionals in diabetes management. I offer a structural analysis of the cause and management of diabetes in Pnar women, the most disadvantaged group in these areas. The structural determinants include childhood experiences, education, occupation, income, and working conditions (Mendenhall, 2019:120).

My study is furthered by using the approach of narrative inquiry. I use testimony and anecdotal evidence to understand how social suffering leads to diabetes. Narratives of five selected women is enclosed as Annexure 16. My study includes the perspectives of health officials associated with implementing the health programs and policies of the State so that I will be to understand the health system's role in providing financial protection to this marginalized group. In addition to the narrative inquiry of women and interviews with health officials, I also draw from interviews conducted with an activist and scholar of the civil society from Meghalaya. Moreover, the perspective of officials working with the International Development Organization and officials of the State Health Directorate are also included.

The present chapter is divided into seven sections: Section 8.1 discusses the narratives of women related to adverse childhood experiences. Section 8.2 explains how poverty is link with diabetes based on women's experiences; Section 8.3 discusses the gender relations and women's status in the community; Section 8.4 focusses on food insecurity, diet management and diabetes; Section 8.5 explains the co-morbidities, multimorbidity and complications of diabetes; Section 8.6 provides the view of officials from the health system and representatives from civil society and other international development organizations; finally, Section 8.7 presents a summary of the chapter.

8.1 Adverse Childhood Experiences:

Ravindran et al. (2022) argue that the longer an individual is exposed to unfavorable conditions, the higher the risk of them suffering deleterious health conditions. Information about the early life of those suffering from diabetes was elicited through women's narratives of their life stories for the present study. On the question of education and occupation, most women from the study narrated their childhood history. It is evident from their living contexts that most of these women were deprived of education and suffered hard physical labor since childhood. This hard physical labor increased during their reproductive years with the addition of child care to already existing economic activity. Wanda, aged 55, a farmer said: "When we are healthy, and during our reproductive years, we were doing all the hard work without realizing that it will affect us as we grow older."

The impact of structural impediments during childhood in older age may be understood through the life history of Chiang, aged 55, a daily wage laborer. Chiang started working when she was 14 years old at the coal mining site at Lad Rymbai village of East Jaintia Hills, Meghalaya. This region is a coal mining hub in the district (Dutta, 2022). She worked as a daily wage laborer, carrying coal boxes weighing approximately 20-25 kgs from the mining to the storage site. Chiang explained:

During those years (1980s), the daily wage I used to get was (INR) 5/- (USD 0.06) per box. However, to earn more, I carried five boxes daily. I used to go to the site early morning, around 6 am, and then return at sunset when it became dark. You can imagine how much hard work I did during my childhood, even when my health condition was not good, as I had no choice.

When she turned 19, she got married, and her first child was conceived. This prevented her from working at the coal mine site. However, to sustain herself and her eleven children, she started working as a wage labourer subject to the type and amount of work available to her.

Her husband works as a cowherd. The lockdown imposed for the COVID-19 pandemic stressed the opportunities for manual work, so Chiang was unable to find work. The stresses of earning were further compounded by the fact that she was unwell during this period and could not work. Chiang was not able to link diabetes with her disadvantages during her childhood and also her everyday stress at work and financial challenges when it comes to raising her children. She did not know when and how she contracted diabetes. She was told that she had diabetes when she visited the public hospital as part of her regular check-up for hypertension in 2017. Expectations of falling ill as one grows older are natural for her. She explained:

I have been sick for so long; I do not understand it. Since childhood, I used to get sick frequently, and now it is expected as I am getting older. People said those 50 years and above are considered old, and those 60 years and above are approaching death.

On several occasions during our interactions, Chiang claimed that she was suffering from three illnesses: hypertension, diabetes, and gastritis. Chiang's story demonstrated most of the significant themes shared by the women interviewed for this study. The themes include "structural impediments," such as illiteracy, childhood labor, job insecurity, and poor working conditions (Mendenhall 2019: 120), which are largely due to poverty. The next section therefore discusses the linkages of poverty and diabetes.

8.2 Poverty and Diabetes:

Mendenhall (2019:135) argues that diabetes is a disease of poverty, and women's experiences of diabetes significantly differ from that of men due to social obligations and the other forms of personal sacrifice accrued by women. Mendenhall further argues that the definition of diabetes "as a product of modernization overlooks the complex cultural, social, and biological dimensions that drive and situates the epidemic differently across contexts." (2019:5). The present study confirms this view in its findings. Most women with diabetes interviewed for this study came from socio-economically impoverished backgrounds and worked either as agricultural labourers or in the informal sector. As discussed previously, there is rising inequality in Meghalaya. While a few sections of the population are accumulating wealth, a large proportion of the population living in rural areas are getting further marginalized. A majority of the women in this study were engaged in the informal sector, where there is little to no consideration regarding workers' health neither any social security. Employment opportunities, which is a critical indicator of economic development, are very low in Meghalaya. (Nayak & Thomas, 2007). The primary economic activity for a majority of the

population in rural areas is agriculture. Crucial stages in agricultural production, like sowing, weeding, and harvesting, are done primarily by women. The duration of time spent in the fields increases the health risks faced by women. “These risks include environmental pathogens, extreme temperatures, toxic agricultural chemicals, and carrying heavy weight” (Lewis & Kieffer, 1994:131). In addition, men are now moving out of villages and agricultural work towards mining projects, so household and agricultural responsibility now falls on the women. Women must further care for the men who return from harmful workplaces outside the city. (Lewis & Kieffer, 1994:132). Lewis and Kieffer (1994) argue that unemployment is one of the most crucial factors that could harm health outcomes. Job insecurity as a chronic stressor can also significantly affect an individual's physical and mental health and well-being (Benach & Muntaner, 2007). This brings us to the next section which is on everyday struggles and diabetes.

8.2.1 Everyday Struggles and Diabetes:

In Meghalaya, many households are headed by single mothers (GoM, 2022). In the present study, about 38.03 percent (n=27) of women were widows, and 7.0 percent (n=5) were abandoned by their husbands. Thus, 32 women, or 45.07 percent of women, are poor single mothers and face economic hardships to meet their daily ends. These underlying factors act as barriers to self-management of diabetes among the poor, both in following the treatment advised by the doctor and in dietary management. Most women and their caregivers reported that daily stress due to poverty could cause diabetes and hinder its management. For instance, Wanda, aged 60, small trader, sells traditional snacks and cooked pulses such as horse gram in the village markets. She was diagnosed with diabetes in 2017. Wanda herself did not know about the perceived cause of diabetes. Wanda's daughter and primary caregiver, Turin aged 32, reported that:

I observed that she did not get proper sleep or rest because of staying late at night. She could not even eat food on time, and her work demanded that she stay awake the whole night when she has to go to the market early the next day. If she does not cook at night, how will she get to sell? So, when her energy is drained, it (her sugar) will increase. On top of that, she cannot even take proper food, and she drinks lots of tea with sugar.

Wanda used to sleep late at night because she had to prepare food for selling in the market the next day. She would cook *chana* (horse gram) and prepare local snacks like *tpu sain* (a round flat snack made out of rice) and *tpu phniang* (another traditional snack which is also round, made of rice flour but deep fried in oil), etc. The preparation of these snacks is laborious and

time-consuming. Rice is mixed with ingredients such as mustard oil, turmeric, sugar, and jaggery. The rice-flour batter is cooked in different ways to make a variety of snacks. For instance, *tpu sain* is made by pouring one cup of the batter into a pre-heated earthen dish. The batter will be poured while ensuring it is round and then covered with the earthen cover. The snack is mainly prepared on fire. Known in the Pnar community as *bam dih cha pnar* (tea snack), these snacks are sold on the village's market day. The struggle to make a living impacts Wanda's health by predisposing her to diabetes, and the demands of work prevent her from necessary self-care. Wanda explained:

My work, no doubt, is hard. My sleep is not proper, and when I have to make a snack for sale the next day, I have to wake up around 2:30-3:00 am. I do not understand my sleeping pattern. When I feel sleepy, I use to sleep, and when I do not, I stay awake with my eyes open. When I reached the market, I used to eat little in people's food stalls, and in the daytime, I only used to drink red tea."

Wanda repeatedly commented on the sacrifices she makes as a mother and grandmother and how this self-sacrifice affects her. Her husband's migration outside the district makes her more vulnerable to stress due to poverty, as she has to manage the household alone. She shared:

I know we cannot stop working, but there is no night nor day, no darkness, meaning my sleeping time is less, and there is no proper timing for food. If only I could choose easy work and I could choose which food to eat, but I could not. I eat *lum sum* (anything) whatever I get. I cannot stop thinking also. I also have too many children and grandchildren, and I cannot go to work- it is unfortunate that I led a poor life. If I have sufficient money, then I do not have to think, but due to this poverty, I cannot pay attention to myself. When my children and grandchildren became sick, I only had to care for them, so I could not drink or eat the foods I wanted. Whatever little money I have, I have to spend on my grandchildren. I cannot take care of myself; I have to forget the care I need for myself. My poor grandchildren, I have to take care of them only. I have to sacrifice for myself because I want them to survive. I only think about that, and I do not think about myself. I wish that at least my children and grandchildren survived.

Financial hardship required to meet her children's and grandchildren's needs compels Wanda to ignore her health. In addition to her children, Wanda is also responsible for the care of her youngest daughters' children. Her daughter's husband has deserted her. Pnar custom dictates that Wanda's youngest daughter and children come live with her. However, in case the youngest daughter is unemployed, her mother will have to work hard to earn their livelihood. In most cases, as women works in informal sector, therefore there is no job security which makes it difficult for them not only to earn for their livelihoods but also even for follow-up and treatment of diabetes.

8.2.2 Barriers to Accessing Diabetes Care:

Chiang's poverty through childhood left her with no opportunities other than hard physical labour and early marriage and motherhood. Care and education of her eleven children necessitated further hard labour as a daily wage labourer where she was required to work in people's homes to weed grass and wash clothes. Explaining her struggle for financial support, she said:

With us, who are bad luck even after registering for cooking gas, we did not get it, we registered for rice card (ration card) also we did not get it. Earlier even when my 11 children stayed with me still, we did not get that card. Even when I have many children and grandchildren, even now when they are living separately, they still did not get the ration card.

The cycle of poverty and limited schooling is seen even in her eleven children. She explained:

It is useless for the poor like us even if we study. I have two children who completed their Bachelors in Arts (BA), but they are still unemployed. We are poor no matter which level of education we reached. We will not get a job unless we have the wealth. Unlike people in *poh dkhar* (mainland India), who usually got a job after studying, here it is different. Although there has been an increased number of educated people yet, it is of no use.

She expressed her stress:

Now there is hardly any job available for us, but still, I have to spend (INR) 200/- (USD 2.41) every day as taxi fare for my children, who are still studying. I have to think about how to get the money every day. I have to take care of everything, it is very hard. If only I had parents who could support me, then it would not be a burden on me. I have to manage everything, but it is difficult without money, right? I unconsciously kept thinking of all these everyday struggles and became sick.

The outbreak of the COVID-19 pandemic further increased her vulnerability. Due to job insecurities, both she and her children could not earn. This impacted her follow-up care for diabetes. The doctors at the public hospital referred her to a private diagnostic centre for blood tests to rule out any complications of diabetes. But limited finances prevented her from taking these tests. Her life represents the experiences of poor tribal women living in West Jaintia Hills District villages. Health equity is significantly influenced by employment and working conditions. A secured job and favourable working conditions impart “financial security, social status, personal development, social relations, self-esteem, and protection from physical and psychosocial hazards” (WHO, 2008:8). Poverty, accompanied by adverse working conditions, exposes individuals to various physical health hazards that are much more pronounced among lower-status occupations (Ibid).

Women suffer not only from diabetes but from other illnesses as discussed in Chapter Five. However, high treatment expenditure and transportation charges are barriers to further treatment. Darilin, aged 60, woman with multiple illnesses, was diagnosed with diabetes and vision problems in 2022. However, she cannot mention the exact diagnosis as she has misplaced her medical records. She was admitted to Gupta Eye Centre, Shillong, for eye surgery. However, the surgery could not be conducted as her blood sugar had increased before the surgery. She has no independent means of income and is financially dependent on her children. Her financial difficulties compromise her medical treatment. She said:

We spent a lot on everything we have to spend. When you got admitted even for one night, you also have to spend food, travel, and medicine. You have to spend all of this for two people. But last time (May 2022), we came back empty-handed. They did not do the surgery. It is just a waste right when it doesn't work at all. Hence, I will not go anymore. It seems some people say that when this sugar is there, it will affect the eyes anyway, so I will not go and waste money anymore. They told me to come back again, but I will not go anymore, they told me to come a few days ago, but I will not go as I only waste money whenever I went there. I will be content with whatever decision the one above makes [referring to God].

Another woman, Rimonmi, who is 65 years old, suffered from cataracts and was advised of surgery. She narrates an experience similar to Darilin's:

Dr. Mark⁸⁰ had advised us to go and remove this white thing from my eyes. He said they would give me the black one instead, but how can I afford it? We do not have money anymore. My children work as daily wage laborers, so where will we get them? Even that time (2020) we went, it was because I really wanted my eyesight again, but now, I sit like this. Earlier, they used to make announcements in the village regarding free eye operations, but now they do not. Since (2020), my eyes became like they made no more announcements for free eye surgery. We are scared to go because Dr. Mark told us to take some money- even if we take the smart card with us, we will still have to pay. My brother, who had gone to Gupta (Eye care center) to do an eye operation, said that even when he had already been given the smart card, he still had to pay (INR) 16,000/- (USD 191.91) more.

Ristina, who has gallbladder stones. Her story is similar to Darilin and Rimonmi where medical treatment and surgery are compromised due to the lack of money. Dashisha has kidney and gallbladder stones and is waiting for a miracle to happen so that the stones disappear.

Few women expressed that they have no other choice but to cope with poverty and stress. These different ways of coping are discussed in the following sub-section.

⁸⁰ Senior Medical Officer also has a private clinic where she visited him.

8.2.4 Coping with Poverty and Stress:

Even among poor women, the ability to respond to poverty varies depending on their worldviews and coping mechanisms. A few women said: *kat da juh duh hi ka chi rta te e re tip ka u pyrkhat ia ite I duh* (since we are used to being poor forever, we do not even realize that we should think about that poverty). For instance, Bhaki, aged 67, a widow, previously a farmer, is now dependent on her children, remarking on her poverty, she said:

As I used to be poor since I was born so I never worry about poverty till now. I am only worried about not getting enough food and sleep. It is only about that.

Stories like Bhaki's evidence the fact of women's resignation. Women's testimonies reveal that women accept their fate and believe that poverty is given rather than being a function of inequality. This has an important implication for diabetes. As discussed earlier, chronic stress can increase the blood sugar level, thereby worsening the condition of diabetes. The women's narratives recorded for this study show that stress could trigger symptoms of diabetes. Along with this, there is also a sense of acceptance of everyday stress. For instance, Linda, aged 53, a farmer was diagnosed with diabetes in 2019. Reporting on her illness, she said:

Whenever I am thinking too much, then my sugar became serious. When I feel sad, then also, but I do not have anything to feel sad about except my children when they disobey and when they are bad; that is what I get to think about- otherwise, there is nothing I think about, sometimes when my children are bad, I feel my head is spinning and if I do not sleep it will not be all right, when I sleep I get the energy, it seems this sugar when you think too much also it increases. We have to think. Ahh... no person will not think about life in this world. When I do not think and when my heart feels good, and when my children are good at home, they make me happy, then I feel light, and I am feeling like that. When I feel sad, my head becomes heavy *ngun* (an expression of heaviness) my head will also become weak.

In addition to worrying about her children, Linda also has to think about her husband, who has been ill since 2016. Before starting her farming work for the day, Linda would travel 35km each (70 km both ways) by public transport to Jowai to sell food in the market so that she could supplement her income. She did this for eleven years, stopping only when she was diagnosed with diabetes. Linda explained that her way of coping with uncontrolled blood sugar is by not monitoring her blood sugar. She said:

I do not go for sugar testing because I feel troubled with the result. After the MLHP or the ANM did the test, they will tell me my sugar is that much high, so I feel scared and angry and then stopped it, but I am still taking the sugar medicine from the sub-center. When I take the sugar medicine out of the strip, they crush and break into pieces, but I

still take them. I cannot look at the year (expiry date), but I am still taking it. There are some which are not crushed, but many are crushed.

Rather than managing her diabetes through regular blood sugar testing, Linda has chosen not to monitor her sugar at all. Her reasoning is that the results of the tests cause her more stress. Due to her economic condition, Linda has no choice but to continue taking medicine from the HWC despite the tablets being broken into pieces and probably nearing expiry.

As mentioned earlier, a majority of the women in the study villages are poor. Their funding for diabetes treatment comes primarily through the sale of their property, borrowings from friends and relatives, children's wages, and insurance. However, women such as Darilin shared that God's providence enables her to pay for her costly medical treatment. As she narrated:

I used to go for a check-up for my illness once a month in Shillong. If I do not have at least (INR) 7,000-8,000/- (USD 84.38-95.98) -in my pocket, it is not possible for me to go as the overall expenditure for travel, medicine, and diagnostic tests is very high. If the doctor gave me medicine for one month, it would cost me more than (INR) 7000/- (USD 84.38). I do not know how to say this, but I used to think- how is it possible that the Lord gave me sickness and money also? Wherever our friends advised us to seek treatment, we went there without creating any shortages to purchase food daily at home. We can eat rice, beef, how much ever we want. Ahh, the blessings of God for me, you know, child. I used to think alone that God's abundant love for me is more than the sand in the ocean. If only the Lord heal me, I could see his blessing and even the one beyond which I have not seen yet. Even when I cannot serve him, I can witness his abundant love and blessings.

The above narrative shows that religion acts as a source of solace for women going through suffering. Women with financial hardship have faith in God. They believed that God will provide what they need will ease their suffering.

The percentage of women in the present study who work in the organized sector is relatively less (16.9%). Being educated and having a secure job have an impact on the self-management of diabetes. For instance, Mary, aged 58, completed her matriculation and worked as a primary school teacher in a government school. Her husband also has secure employment in the government sector. She reported that her family members, including her mother and sister, had passed away due to diabetes. She knew that diabetes was hereditary and controlled her diet even before her diagnosis at Lifeline Private Hospital in Shillong. Regarding self-management of diabetes, she said:

I regularly went for a morning walk every morning at 5 am. I used to wake up at 4:30 am. A morning walk was a great medicine and refreshing the whole day. It is very

beneficial for health. Even before the diagnosis, I am a person who likes to go for a morning walk. After returning from a morning walk, I first drink water, aloe vera juice, and sometimes *amla* juice. It is not because the doctor advised me, but because it is my thinking. Then after 10-15 minutes, I will take the diabetes medicine. After 30 minutes, I will have breakfast, I used to drink milk, white oats, bread, and biscuits, like cream crackers. Earlier, for dinner, I used to have *atta*, but now I do not feel I have the time to prepare *atta*, and also because I do not feel like having it otherwise, I could have made time for it. I prefer to eat little *basmati* rice with three tablespoons of *tohja* (pulses). *Tohja* is very good to eat, but only a little and not much. However, if my sugar is high, I will have *atta* during dinner and vegetables fried in less oil or boiled, such as cabbage, brinjal, beans...

Mary reported that she follows the dietary recommendations of the dietician at the private hospital and consumes *valencia* (citrus fruit), apples, and watermelon. She recommended the benefits of cucumber and listed the fruit she avoids, such as orange, pineapple, and mango, on account of their high sugar content. She does not believe that diabetes has a negative effect on her life. She said:

It is not affecting me that much, and many people do not even know I am having sugar disease because I have no slight change in my physical appearance. People used to say those with sugar; their looks also change and look gloomy. So, it will be known that they are having sugar. For me, people said they did not see any change. They do not know that I have sugar. I do not feel any change; it does not affect me much. When it became serious, it usually affects my eyes...but I can still read because I have my glasses. I used to go to school regularly...I never missed even a day...

For women with the economic means and resources to comply with the advice of health professionals, self-management of diabetes is not a challenge. Women such as Mary shared that they can live well even with diabetes. Moreover, most of Mary's family members also suffered from diabetes. Therefore, she is aware of the preventive measures to be adopted, given her knowledge that the disease is also hereditary. She shared:

Because our family has a history of sugar, so I have tried controlling my sugar even before the diagnosis. That is why my sugar is not manifesting because I tried to control it through diet as I am growing older. But after the injection (for arthritis), my sugar shoots up. I tried controlling it a long time ago. I have got the experience of dietary management from my sister, who was diagnosed with diabetes in the past. Therefore, my sugar is under control now. I used to wake up at 4:30 am and go for a morning walk at 5 am regularly. The morning walk was a great medicine and refreshing the whole day. It is very beneficial for health.

Only a few women in the study, like Mary, could live well with diabetes, given their socioeconomic condition. This case clearly shows the impact of inequality on the self-management of diabetes.

8.3 Gender Relations and Women's Status:

As stated earlier, “the rule of property inheritance is purely matrilineal in organization, and the property is of two types - inalienable and alienable” (Gassah, 1994: 76). Inalienable refers to “*Yongrim* or *Nongtymmen*” or ancestral and alienable refers to “*Yutran* or *Nongkhynraw*,” or personal. Ancestral land and houses are customarily passed from the mother to the youngest daughter (*ka khad duh* or *ka khynruit* or *ka yangyung*) (ibid:76). In case of the demise of the youngest daughter, the property is inherited by the second youngest daughter. In the absence of a successor from the family (*ka yung* or *ka kur* or *ka kpoh*), the youngest daughter of the nearest family branch will be the successor (ibid: 76). If the family does not have a daughter, the youngest son succeeds. Although the youngest daughter inherits the ancestral property, she cannot manage it according to her will. Any transactions of property happen through the consent of her brothers or the mother. She is thus effectively merely the custodian of the property where real control is exercised by her maternal uncles (ibid). All possible heirs in the family need to be acknowledged and consented in case there is any transaction of ancestral property. The custodial owner has the right to dispose of the self-acquired alienable property or the *Yutran* according to her will (*pynkam*) (ibid:76). Being a matrilineal society, the status of women in the Jaintia society is distinct from that of the other societies. Both men and women are treated equally except in political matters. Despite being owners of property and keepers of the family purse and other valuable movable and immovable property, women are not considered or expected to be superior to men (ibid:76).

Women play an important role in domestic and household affairs in Jaintia society. They must fulfill their duty and responsibility of caring for their children. As per indigenous religion and tradition, the husband is not supposed to stay with his wife and children (Gassah, 1994:76). The entire responsibility to look after the overall development and upbringing of the children thus rests with their mother. Besides the right to inherit properties, descent, and residence also favors women. The Pnar culture gives women the right over their children. In case the marriage ends through death or separation, the children automatically belong to her (Gassah, 1994:77). The Pnars follow a matrilineal culture. Therefore, the burden placed on women is much heavier than women in patrilineal societies. Nonetheless, few elderly women from the community consider the culture to be advantageous to the women. For instance, Lang, aged 65, widow and retired primary school teacher in a government school, shared:

For us, everything is done by women, but the ones who manage things are men. In our case, women do all the works, but when it comes to managing, it is the men. Selling and purchasing, women hold it, and the power rest with women. It is in our names, so they (men) cannot sell anything if it is not as per our will. We have to have a mutual understanding with each other.

However, for women from lower socio-economic group matrilineal culture do not appears to keep them in advantageous position.

8.3.1 Inequality in access to property rights:

According to the customs of a matrilineal society in Meghalaya, the youngest daughter has the right over ancestral property and is responsible for caring for her aging parents. But the implementation of the custom is dependent on the mother, who has absolute authority over the property. If a mother finds that her youngest daughter has committed a moral offense, such as marrying outside the community or a man who is disagreeable to the mother, the mother can deny her daughter the rights over the house and property (Mukhim, 2019). In such cases, the mother will choose the daughter she favours the most and sign over the property to her. In the case of a landless family, however, the youngest daughter might not have such privileges. Dashisha, aged 35, daily wage labourer, was diagnosed with diabetes when she was 32 years old. She is the youngest daughter of a household and the rightful heir to her mother's property. But she shared that her mother does not allow her to stay in the house as her mother favour's her older sister. Dashisha said: "Even the land where I had made my house is not mine, my maternal aunt gave it to me, but someday she will take it away as she also has many children and grandchildren." She commented that people had advised her to fight for her property rights as she is the youngest daughter. But she responds to this advice by saying:

I do not want to fight; we are all our mother's children. She had given birth to all of us, it depends on her will. As long as she is happy, let it be, it is not like we will live forever here. We are going to die someday. So, what is the need for arguing and fighting? I want to be a good person.

Dashisha's desire to be a good person comes with a cost. She had to internalize her suffering as her two sons are too young to understand her problems, and her husband deserted her. Although she does not have to care for her parents, being a single mother in a new house without a secured income while also suffering from diabetes at a young age makes her condition more vulnerable. The intersection of these multiple axes of discrimination makes it difficult for her to manage her chronic illness.

I learnt of the transitions taking place in Meghalaya's social and economic structures in an interview with Sarah, aged 69, renowned social activist from Meghalaya. She explained:

There is a huge disparity in wealth ranking in Meghalaya, with few families owning so much land, but the rest are forced into poverty. According to the 2011 Socio-Economic Census Data, about 76 percent of Meghalaya's population is landless, but this has not shocked us. I fear that people from the city, the elite tribal, are buying up lands everywhere in the villages for contract farming, cash crop farming, and water catchments for selling water and buying forests, and there is nobody to control them. There is also much land grabbing for coal mines. Due to this, the sense of community is eroding in Meghalaya's tribal society. Earlier, there was more joint ownership of resources. About 37 percent of people in Meghalaya live below the poverty line, but we do not seem concerned. At least, the government does not seem concerned.

Dashisha and many other women are victims of poverty and inequality that has widened in the state. The moral responsibility of caring for one's parents is not only an obligation for the rich or the landed but for women across socio-economic groups. This has taken a toll on a women's health, especially when they belong to a low-income household and where their husband does not provide her with much economic support. The vulnerability of such women is increased when she has aging parents with chronic illnesses.

Recent years have seen a widening of inequality in tribal society. The creation of a land-owning propertied class has further stratified an already stratified social order (Xaxa, 1999; Karlson, 2011). The widening of inequality is well understood in the Pnar community. People in the Pnar community say colloquially: *ki wa ioh nang ioh, ki wa duh nang duh* (the rich are becoming richer, and the poorer are getting poorer). The experience of syndemic suffering was also expressed by Pnar tribal women: *wei duh wei kjut wei jynjar, da pyllang lut* (along with poverty, we also have illnesses, then lots of suffering, all of these are affecting us together).

A major part of the fieldwork required for this study was conducted during the lockdown for COVID-19 Pandemic in 2020 and 2021. This period saw an aggravation of syndemic suffering as daily wage laborers in Meghalaya faced extreme hardship in finding work (War & Kharkongor: 2021). Women's experience with diabetes is shaped by social conditions. This explains the interaction between social and health conditions such as diabetes and how this impedes "good sugar" control. Along with stress, poverty, and diabetes, women also suffer from illnesses that affect their mental health, hypertension, eye problems, and even kidney and gallbladder stones. This is largely attributed to multiple responsibilities that women in the present study have to undertake.

8.3.2 Triple Burden of Reproductive, Productive and Caregiving Role:

The story of another woman named Nora, aged 40, agricultural labourer, represents the impact of such vulnerabilities on women in the district. Nora was diagnosed with diabetes at the age of 39. She supplements her income through a small shop that sells betel nut, betel leaf, lime, and dried fish to supplement her income. Nora lives in a semi-*pukka* house in Iongthma village, one of the remotest villages in the district, along with her aging mother, husband, and nine children. Her youngest daughter is one and a half years old. Nora is now on Oral Contraceptive pills. Concerning her reproductive history, she said:

I cannot give birth anymore as I have already given birth to too many children. I do not have any more strength. Last time the nurses at the sub-center gave me an injection (Injectable Contraceptive) but later on, they said it is not good as I have so many other illnesses. They told me I should insert things (Copper-T), but I am uncomfortable with it, so I opted for Oral Contraceptive Pill.

Her medical records of 2020 from Amory, a private hospital in Shillong, show a diagnosis of Generalized Anxiety Disorder and Hepatitis B. She related the stresses in her life:

I used to feel sad and anxious every time, then I lose my sleep. I used to wake up every time in the middle of the night. I used to think a lot about getting rice, but God forbid we should not die out of hunger. I think because of those thoughts, I am having all these illnesses. I also used to think about how to make money, where and all I should work to earn a daily wage so that I can buy enough rice for my children, clothes for them, and medicines for myself. Even my mother is in her sick bed for almost four months now, and I alone have to take care of her. I am her only daughter and have four brothers, but they all live away from our village at their wife's place.

In the course of my interview with Nora, I observed her mother lying on a plain sheet on the house floor and unable to eat. Nora explained how she had cared for her mother at home and in the hospital. Linking her own illnesses with the caregiving role, she said:

I did not even have my father now; my mother is also ill like this, that is why I told you from *pyrkhat* (overthinking/stress) only I became ill (in between the interview, she told her children-go and cook rice for tea time and said- we only ate rice; we villagers are only eating rice always). My mother was not able to eat for two weeks. She does not even like taking Oral Rehydration Solution (ORS)...last night, her illness was very serious that I and my daughter had to wait for her. She doesn't even want to eat rice. Last time in June 2021, I think before the rice sowing season, we took her to JCH, Ialong, for treatment, but I was the only one taking care of her. I requested the health workers to allow my brothers to take care of my mother, but the nurses did not allow them because they are males. Even our relatives are only jealous of me and will not help. They used to say, "Let them look after their own family." However, she is not improving, her condition is always the same. My mother is always serious, and I alone have to take care of her, so I requested the doctor to discharge her so we can go home. The doctor said- as she is

old already, you can go. Although my health is not good either, I have to stay awake the whole night, and I cannot sit or sleep because I have to take care of my mother. From this only, I became sick. Most of the time, I used to think, how do I keep up with this.”

She continued to share her suffering:

You know we were having a hard time last night (11th July 2021). My mother did not sleep the whole night, and it had been two weeks since she did not eat anything. She became very weak, shivering, and her eyes were not clear. I thought, now it is over. So, my third daughter and I sat the whole night. She is a little older, so she helped me the whole night, and later on, around 2 am, we could sleep. With this condition also, I cannot quit going to work. If I do not go to work, what will we cook and eat? Before my father passed away in 2019, I took care of him the same way as I did for my mother.

Nora is alone in her caregiving and work. Her husband is unable to support her as he works as a truck driver and is away from home most of the time. Economic transitions, through processes such as the advent of mining, have led to an increase in male migration for daily wage, thereby drawing men away from the agricultural field (Lewis & Kieffer 1994:132). The migration of men away from the fields has contributed to the increase of single woman-headed households (ibid). Correlatively, it has also led to an increase in rural women’s workload as even typically male-oriented work, such as agricultural labour, production of food for trade, and domestic use, now falls on them. Women in developing countries (such as India and especially in rural areas such as the district under study) are responsible for childcare and household labor such as collecting water or firewood. The double burden of domestic and agricultural work as part of economic activity further compromises the health and well-being of tribal women.

Concerning welfare schemes such as the Public Distribution System (PDS), Nora maintains that she was denied a ration under the scheme as she did not have a ration card. She said that when the ration cards were renewed in her village, the village authority did not renew her card, along with some 15-20 households. According to her, this is due to her “bad luck.” Nora’s narratives reflect the suffering of poor tribal women who bear the onus of taking care of their sick parents as well as their children. As argued by many medical anthropologists, these social sufferings get reflected in clinical outcomes or in the form of different diseases (Farmer, 2004; Mendenhall, 2019). In the absence of social and psychological support, Nora’s mental health also got affected, evidenced by her diagnosis of Generalized Anxiety Disorder (GAD).

Similarly, Daphi, aged 55, schoolteacher, is another example of a youngest daughter with diabetes. She attributes the cause of her diabetes to the stress of taking care of her

paralyzed mother. This has also severely impacted her mental health. Her case and narrative history are discussed in detail in the following sub-section.

Daphi, is a primary school teacher at a private school and was diagnosed with diabetes in 2006. She is a single mother of six children, and her husband deserted her in 1998 when her mother passed away. She is educated and is a graduate. Her education might be the reason that she could relate her diabetes to tension and stress. Tension as a perceived cause of diabetes was discussed in Chapter Five. Daphi explained:

I think it is because my stress was very high when I was taking care of my mother. My mother was like a baby, she was bedridden, and she used to urinate seventeen to eighteen times a day, and I had to change her clothes. It was stressful. That is why I got this sugar. I am thinking like that. Who can carry their mother for seven to eight years, and that too three to four times a day. I had to carry her always when she wanted the sun, when she wanted to take a bath, I had to carry her. I think the years before she died, my sugar started. I have been sleeping for just four hours every night for eight years. I am thinking like that for eight years and four months. I used to carry her even during my pregnancy. Had her death been delayed, I would have died because I was not getting the chance to care for myself as I was caring for my mother. Now that my poor mother has died so I can take care of myself. My children were also very small in the year my mother died.

Her husband's desertion soon after her mother's death exacerbated her stress. She explained how this was reflected in her behavior three weeks before her mother died. Daphi said:

My friends told me I used to talk to myself and was about to go crazy then. I have lots of problems, you see. Three weeks after my mother died, my house was snatched away by our relative and her sisters. It was during this time that my children's father also deserted me. He left me alone to take care of the children. I cannot explain all the difficulties. I think it is because I was so stressed that I am getting the disease.

Divorce or "abandonment" is not uncommon in the matrilineal society of Meghalaya. Women are usually left with their children. As it is a matrilineal society, the onus of raising children is on the women. Given that most men in the state are engaged in the informal sector, getting them to abide by the law to ensure the maintenance of their wives and children is challenging (Mukhim, 2021:5). A socialist activist, Sarah, explained the reason for higher rates of desertion in Meghalaya in an interview conducted on 12th August 2022. She explained:

We were a society that was very liberal, and there is a saying in the society for men – *shynrang 12 bor 12 lama* (men having 12 strengths, 12 flags), which means he can go and keep on giving children to women and in the Khasi mindset, the man is there only to procreate. To care for children is only the responsibility of a woman and her clan. In the case of educated and more forward-looking men, they do take their responsibilities very seriously. However, those who are not very educated and do not want to take up the responsibility of fatherhood will blame matriliney and get into alcoholism. This is the reason for the high separation rate, I would say abandonment. It is very difficult to change

a societal mindset that has continued for 100 years. Nonetheless, it can happen, but it is a very slow process.

Daphi claims that she has other illnesses besides diabetes that have affected her mental health. She explained:

As I have so many illnesses, I do not even know how to explain them. I have a Sinus problem; my cholesterol is also very high, then diabetes. If I am overthinking, my chest will be paining a lot, but I have not yet checked it. If I can stop feeling sad and depressed, then I will not have chest pain. When I am feeling very depressed, it became severe. Every time I feel depressed in my life, my chest pains. I tried to make myself happy amid difficulties.

Daphi faced family difficulties after her mother passed away, when her relative took possession of her house, and when her husband abandoned her. According to her, these stresses add to her vulnerability to diabetes. Daphi claims to be a responsible mother. Thus, despite her illnesses, she continues to work hard. She supplements her income by doing a tailoring job so that she may educate her children. She also cultivates rice and vegetables for household consumption to avoid expenditure on food. Tradition assured strong bonds within family groups so that relatives could share the responsibility of caregiving to children. The subsequent weakening of social ties in recent times leaves women as the sole bearers of this responsibility. Being a poor woman in a matrilineal society provides no assurance of good health. Rather, she is responsible for additional duties that further affect her physical and mental health. Besides her job as a teacher, Daphi also has multiple household responsibilities. Vlassoff (2007) argues that women facing extreme hardship due to unemployment, as well as working women with multiple family and care responsibilities, are more prone to depression compared to men. This is due mainly to the impact of economic stress on women's mental health. Nonetheless, even women who have access to property and a secure income are not resistant to anxiety and depression (ibid).

The narratives discussed above show that diabetes in women cannot be explained without considering their structural conditions. Economic activity and access to healthcare for aging parents compel women to travel in poor public transport or on foot for long distances. Addressing women's health beyond maternal and child health does not imply a devaluation of their reproductive needs (Lewis & Kieffer, 1994). Many women are in various stages of pregnancy and breastfeeding while performing their productive and social reproductive roles (ibid). Women perform multiple roles and must fulfill various responsibilities while bearing the physiological effects of child-rearing (ibid). This exposes them to numerous risks that may

affect their health (ibid). It is thus crucial to note the socio-cultural and environmental context of women's lived realities in order to identify their health risks correctly.

8.3.3 Aging and Diabetes:

The multiple axes of discrimination are faced differently by different groups of women. In this case, I will explain how poor, elderly tribal women experience diabetes, other illnesses, and social suffering. Women live longer than men. However, they experience many chronic illnesses as they age, threatening their lives and leading to poor health and disabilities. This significantly impacts the quality of women's lives (Vlassoff, 2007). As women age, they become more vulnerable and face difficulties accessing treatment and managing their illnesses (Piang et al., 2010).

About 40.84 percent (n=29) of women in the present study belong to the age group of 60 years and above. Besides diabetes, they suffer from illnesses such as vision problems that requires surgeries, hypertension, and musculoskeletal disorders. Internalizing their old age, these women consider accessing available care for their illnesses as unnecessary. Arkini, aged 63, suffers from many problems. A hip fracture in 2020, worsened her condition as she was now unable to walk. She has stopped taking treatment for diabetes. She also believes that she has been rid of diabetes. She has not sought treatment for her hip or diabetes for over a year because of poverty. Her husband abandoned her after selling all her property and jewellery. She has no formal education and has worked as a daily wage labourer at the coal mining site at Ladrymbai in East Jaintia Hills. She returned to her village after her illness and lives with her youngest sister. Her only son is married and lives far from the district. Lewis & Kieffer (1994:134) have pointed out that migration has become a female phenomenon as women have also started looking for jobs outside due to the dearth of employment opportunities in their own villages. Places of migration such as the coal mining site have poor living conditions: crowded spaces, poor access to water and sanitation, and stressful working conditions. These spaces also lack traditional family support and social networks. The cumulative effects of these stresses on women's mental health, especially on the mental health of elderly women, receive next to no attention.

Arkini is left at the mercy of her relatives taking care of her. She complains that they are "rude to her." The intersection of age, gender, place of residence, disability, abandonment, and illnesses like hypertension and diabetes is a challenging situation for Arkini. She is deprived of social welfare schemes, including health care services, as she cannot even walk to

the nearest public health facility. Even the public health facility workers are reluctant to provide care to Arkini as she is staying up in the hills, which is very far from the location of the HWC.

Arkini used to live alone in a very small hut in her village. Her son took her to her youngest sister's house after the hip fractured. But she asked her son to take her back to her house after being mistreated and verbally abused by her sister. Though her son took her back to her village, he had no option but to leave her at his other maternal aunt's house given her physical condition. Falling very sick one day Arkini's brother-in-law took her to the private clinic in Ummulong. A nurse in the clinic gave her medicines for her kidney along with other Ayurvedic drugs but she wasn't given a prescription. Seeing no improvement in her condition, her brother-in-law carried her on his back through the hilly terrain to a nearby PHC. She was tested and her RBS and BP were found to be very high. The doctor immediately started her on treatment. Suffering from pain in her hip due to the earlier fracture, she was assessed by a doctor who recommended surgery. However, her socio-economic condition and, according to her, "who will take care of me if I get admitted to the hospital" stopped her from undergoing further treatment. Arkini's case is representative of other elderly women with diabetes who live alone and in poverty in the study villages. This is discussed in detail through the narrative of Janai.

Melinda, an ASHA worker, reports that her mother has been living with diabetes for the past year. Janai, aged 77, is a widow. Her husband passed away in 1996 due to asthma. Janai related that she was deprived of education as a young girl. The demands of the household required her to graze the cows instead. But she had a strong desire to learn. She and her friends used to write on the ground using pebbles and even arranged maize according to the alphabet, such as A or B, when they were children. These games and exercises taught her to write her name and form a signature. Janai lives with her youngest daughter, the sister to the ASHA, Melinda. When asked about her health status, she shared:

I am healthy, but I cannot see properly anymore *nger nger* (an expression of how her vision is). I am taking treatment from Esther,⁸¹ so I am healthy and have a good appetite. I used to swell, and blood came out of my nose twice daily. But now it is not there anymore because I am taking medicine from Esther. I do not know about sugar, but this year (2022) made it more difficult for me to see. Esther told me I had sugar last year (2021). I do not remember if she had given me the prescription slip or if she had kept it with her.

⁸¹ Esther is a nurse who practices at Ummulong village and uses her father's pharmacist license. I tried contacting her, but the respondents shared that she is not in the village. This is because since she got married in 2019 her visit to the village and pharmacy became irregular. Her husband is a soldier so she has to go where he gets the posting.

It is difficult to determine the dates for Janai's last check-up and RBS without a prescription slip. This is because Janai visited a pharmacy instead of a hospital or clinic. Treatment for patients is provided by a nurse at the pharmacy who does not provide a prescription slip. When asked about the expenditure for her treatment, Janai replied: "At the beginning, I spent (INR) 15,000/- (USD 179.98), but now I do not have any more money to seek treatment as now it is only my son-in-law who is working." She showed me her medicines which cost more than INR 1200/- (USD 14.47) each. The medicines cost her INR 15,000/- (USD 179.98) and were all prescribed by the nurse. Janai expressed that: "Even if the medicine is costly, it is helping me, but it is only my eyes that are still having problems, but I am scared to go and get the operation done." Though she could not find the nurse's prescription slip, Janai explained the what, how, and when of her medicine consumption. She also suffers from hypertension and seeks treatment from the private clinics of different doctors at Ummulong. She said, "My daughter told me that if we take too many medicines, we will die." She explained how she was diagnosed with diabetes when she visited a nurse's clinic:

I do not know what she was doing with me, but she made me stand at the wall, measured, and then wrote something. She also took my blood from here by pricking my finger, and then blood came out, and again she wrote something. After she had written it, she explained that I am having sugar, BP was also big, and acid is also big. My children once took to the hospital for an operation. I am tired, my daughter also took me to either (Dr.) Mark or (Dr.) John (allopathic doctor). I used to seek treatment from John as well, I do not know how many times I have visited him, but I used to spend (INR) 600-700/- (USD 7.23-8.40) whenever I go to him. During those olden times, I sought treatment from Dr. Manjait (homeopathic doctor), who told me not to eat meat and potato. He also told me not to eat too much salt as well. That time I visited him because I was having a fever. Then I told him how we can afford to eat meat when we are poor. We only eat once a week during dinner on market day. Even to Dr. Manjait, I went once or twice, and after that, I did not go anymore because I became better. It has been very long since I last tested my sugar. Someone suggested I go to Dr. Kular at Amory Hospital there in Shillong, but they told me I need to take around (INR) 6000/- (USD 72.33) but where will I get that amount of money as I cannot go and work anymore? My children also think I am all right as I could still walk in and around the house. That is why they did not take me to the doctor.

She shared that her vision has started to blur. "No, my children did not take me to the doctor, but it is all right as long as I can go to the washroom. When the Sun is too bright, I cannot see at all. If it is because of my age, my vision is still good, but it is because someone did it to me. That is why I am having this vision problem." She shared how her sister-in-law tried to harm her and other family members through black magic due to a property dispute.

The intersection of age, gender, ethnicity, class, and widowhood increases the vulnerability of Janai. Because of poverty, her children cannot afford to take her for regular medical check-ups, and given her age, it is difficult for her to go alone. She has to continue suffering with her vision problem and is helpless as there seems to be no support from the health care systems to address the health problems faced by poor elderly women, especially widows. Treatment by a nurse at a pharmacy was her only feasible access to health care, but it incurred a huge expenditure and was met with less than adequate success. She had visited the nurse given the accessibility as the nurse clinic is within her village, and visiting well-equipped private hospitals in Shillong would mean high travel costs and huge medical expenditures. In spite of suffering from diabetes, Janai's sugar levels had not been tested for at least a year (2021). Her daughter is the ASHA of Ummulong village and had received training on NCDs. She does not, however, follow the recommended advice on monitoring her mother's RBS or dietary management. It is worth noting that when the ASHA worker was asked about population enumeration and population-based screening of NCDs, she responded: "We are so busy we do not have the time to do that NCD work."

8.3.4 Access to Social Support: Role of Primary Caregivers:

Social support from Non-Government Organizations (NGOs) working on health and education was absent in all study villages. Even peer support groups for people with diabetes seem to be absent. The only support women get or are expected to get is from their families. Family or *chi yung* is the smallest unit in the Jaintia social organization. This unit called the "Pnar domestic group," consists of the "grandmother, mother, sisters, brothers, maternal uncles, aunts, nephews, and nieces" (Gassah, 1994:75). The grandfather and the father may reside in their wife's family. The traditional system of the Jaintia family resembles that of the Hindu joint family, where the maternal uncle, rather than the father, manages family affairs and social and religious matters. The social transformation has, however, seen a decline in the role of the maternal uncle. Jaintia society is naturally matrilineal (Gassah, 1994). But this is true only in the case of the youngest daughter. For women other than the youngest daughter, the Jaintia family is invariably a nuclear family, with the father as the head of the household. This is mainly seen in Christian families due to the influence of the preaching of the Bible, in which fathers are seen as the head of the family and are held responsible for raising children (ibid). Class and caste divisions are absent in the Jaintia society, and social hierarchy regarding

subordination and superiority did not exist until recently. Without a rigid caste or class system, social relationships among the Jaintia have a greater cohesion within the society (ibid).

Women with diabetes reported that they received some support from family members, either from their husbands or from other family members. Family disputes, however, have increased over the years for issues of land grabbing so that societal and family bonds are weakening, and women have to rely primarily on their children. A few women reported family conflict over land but mentioned how they refused to engage in property fights. They mostly rely only on their children's daily wages for the treatment of illnesses, including diabetes. Syntiew lost her husband in 2003 when her twins were seven months old. She shared her experiences of having to raise six children on her own. Her life has been difficult and full of suffering. On being asked about family support from her siblings, Syntiew said: *ma ioh kite na nga se u khloh ki* (given a chance, they will forcefully take away everything I have). She received support from her in-laws only when her twins were very young. They also introduced her to work as a stone crusher. Syntiew has been struggling for the past 17 years - raising her children alone, labouring at the stone quarry, and working as a domestic labourer washing and cleaning other people's homes. The only land she owns is the land and house in which she currently lives. She said- *ini leh dei thied na iong ki Dr. Mario wa io ryai ki I da ka poisa wa li khih mylla ki khon o wa nga* (this one also I bought it from Dr. Mario's family as they were feeling bad for me, I bought it with the daily wages of my children). Though she is the youngest daughter and one of four siblings, her mother disinherited her and gave the family property to an older sister. She was forced to visit an ayurvedic physician who works with her son during COVID-19 when the supply of anti-diabetic drugs was disrupted at the PHC. The ayurvedic physician treated her in exchange for her son's wages.

Due to poverty, women's children have to drop out of school to earn a living. These wages are important financial support to parents, particularly when they are ill. This process seems to have continued throughout generations in most families in the villages. The case of Syntiew represents the situation of other women whose children have to drop out of school to support their parents. Mukhim (2021) argues that in divorce, women are usually assisted by their children to meet daily living needs by engaging themselves in labour. The findings from the present study reinforce her argument, as most women interviewed shared that medical expenditure for their diabetes treatment is usually made through their children's wages.

8.4 Food Insecurity, Diet Management, and Diabetes:

The nutritional status of tribal populations, especially women and children, is considered poor (Ravindran et al., 2022). According to (NFHS-5) (2019-21), the percentage of ever-married women in Meghalaya in the age group of 15-49 years suffering from anemia is 54.4 percent. The percentage of ever-married women in the same age group with a body mass index below normal is 10.8 percent. In West Jaintia Hills, about 9.6 percent of women have body mass index (BMI) below normal, and 55.9 percent are anemic. Interaction and observation at women's homes, especially among those from the lowest income, reveal the lack of diet diversity in their households.

Food is a basic human need, and “food security is an important social determinant of health” (Gucciardi et al., 2014:324). Food insecurity in disadvantaged populations has been reported as an international public health concern (ibid). Food insecurity among socio-economically poor populations leads to low consumption of diverse foods, fruit, and vegetables, a lower quality diet, reduced micronutrient intake, and increased rates of iron deficiency anemia (ibid).

Poverty restricts women from taking care of themselves in terms of eating a balanced diet, eating on time, exercising, and using services that enable a healthy life. The death of a spouse pushes women further into poverty. Women like Nora, who are the most marginalized, do not possess a ration card by which they would receive subsidized grains, etc. They have to pay full price and buy rice from the market. They supplement their basic diet of rice with seasonal vegetables collected from the wild and dried fish. Thus, tribal women in villages largely depend on wild forests for vegetables. The foods usually advised by dietitians for diabetes management include brown rice, milk, pulses, oats, fruits, and other green leafy vegetables largely inaccessible to most tribal women. Syntiew, aged 55, widow and a stone crusher was diagnosed with diabetes in 2020. She learnt from a neighbor that brown rice was healthy for people with diabetes. Though keen to eat it, she could not afford its costs. She was lucky when a voluntary organization mistakenly distributed brown rice to some households during the COVID-19 lockdown. While the ASHA of the village reported that “People were also confused about why they were given the brown rice,” Syntiew was happy. She had learnt from her neighbour that people with diabetes eat brown rice. Fortunately for Syntiew, her neighbour disliked the brown rice, calling it bland and smelly, and exchanged it with Syntiew's white rice given as ration. It was only for a few months that Syntiew could eat *kho snar* (brown rice) because it was given to her free of cost by the voluntary organization

accidentally. She could not afford to buy the brown rice as it is sold whole and not loose where each gunny bag of 25kgs costs INR 2000/- (USD 24.11). She continues to eat the white rice given through the PDS. Syntiew explained:

It is quite costly, and they are selling it in a gunny bag...I do not know the price as I do not even have the money to buy it...25kilo cost (INR) 2000/- (USD 24.11), so how can I afford that much, right.

Syntiew's impoverished economic condition allows her to purchase only *atta* (wheat flour). She explained how she prepared the *atta* "Sometimes when I do not have the time to prepare *atta*, I used to mix the wheat flour with water and salt and then fry the batter as a pancake. Her dinner consists of red tea without sugar, while breakfast is made of red tea with cold rice. She eats rice and dried fish at noon.⁸² Syntiew explained:

Apart from rice, I did not get anything else to eat. I used to pack rice and dried fish after crushing it. I am poor, so how can I afford to eat those strange foods? Even now that I have sugar, I used to eat only those bitter vegetables such as bitter gourd. They said it is good for sugar.

Other women like Nora, discussed earlier, find it difficult to adhere to dietary recommendations. It is difficult to sustain oneself for hard physical labour by eating small and frequent meals in the fields. Rhetorically they ask: "How will we work if we eat rice in small quantities?" Doctors advise the eating of fruits for patients with diabetes. But Nora asks an important question:

Shall I buy fruits or medicine?

People's health is affected not only by their access to nutritious food but also by their capacity to manage their health condition, such as that of a strict dietary regimen for diabetes management. It is difficult for these women to access sufficient food for diabetes. It becomes all the more difficult to tailor their diet in accordance with a diabetic diet (Gucciardi et al., 2014).

Women in the present study also shared that they do not have the time to prepare *atta* as they have to leave home early morning and come back home late at night. There is no one to take care of them. Ioobiang, aged 57, a small trader selling dried fish to various markets, cried while telling her story:

⁸² Commonly eaten by people who belong to low-socioeconomic groups in the Pnar community and are commonly sold in the market.

No one is taking care of me. I also have to go to work in the morning and return late at night. I have to eat anything. There is no time to prepare *atta* as it is already late when I return home from the market.

These narratives demonstrate that work, time constraints, and the struggle for basic needs prevent women with diabetes from altering their food choices toward a more diabetic-friendly diet. However, the situation is different for women belonging to a better socio-economic class.

For instance, Mary, aged 58, a teacher in a government primary school, is secure in her occupation and earns a stable income. She is able to afford the food she desires as well as control her blood sugar levels. Her economic condition allows her the luxury to manage her diabetes better. She said: “I do not like eating brown rice; it has no taste. Imagine if we eat food, which does not taste good and eat only a small amount, it will be difficult to work, right?”

Mary’s economic condition gives her access to dieticians at private hospitals so that she has access to knowledge. She is also able to afford various food items. For instance, she can afford to eat basmati rice (known to have a low glycaemic index) but also knows that she has to eat it in small quantities and supplement it with other food items. She knows other food alternatives, so she is not compelled to prepare and eat *atta*, which she “does not have the will to make.” She can also afford to regularly eat and drink other food items required by a diabetic diet, such as milk, fruit, vegetables, and fish.

8.5 Co-morbidities, Multi-morbidities, and Complications of Diabetes:

Poor awareness and limited knowledge about the symptoms of diabetes in villages have led to delays in its diagnosis and treatment among women in the study villages. Most women were also not aware of the risk factors of diabetes. People have a dominant understanding that the main cause of diabetes is high sugar consumption in tea. Thus, they believe that it is only due to the consumption of tea that diabetes is caused. Women used to say, “I never took tea, so I assumed it is not there.” Due to this assumption, they consider it unnecessary to check their blood sugar even during the screening. In the Pnar language, diabetes is known as *kjut chini* where *kjut* means disease, and *chini* means sugar. Due to this reason, people perceive that diabetes is caused due to drinking tea with sugar (Little et al., 2016). This assumption could also be due to a lack of effort from the health system side to provide health literacy to the people. Leki, aged 68, a farmer, who visited the HWC to check her BP, stated: “I am not aware of the NCD program.” She further opined about the state of diabetes in her village, maintaining that it is free of diabetes because their main occupation is hard agricultural labour. She said, “People in our village do not suffer from diabetes as we do hard work.” A combination of all

these factors has led to delays in seeking medical treatment. The delay leads to cases becoming serious and women suffering from multiple illnesses. Most women in this study sought care for diabetes with complaints of neuropathy, one of the complications of diabetes. Three women, however, reported major complications such as chronic kidney disease, diabetic foot, and diabetic retinopathy.

The experience of complications associated with diabetes may be described through the narrative of Philari Shadap, aged 68, widow. Philari was widowed in 2008 and was diagnosed with diabetes in 2018 at the Urban Primary Health Center, Ladthadlaboh Jowai. In 2019, she was diagnosed with acute kidney failure at Super Care Hospital in Shillong and has been undergoing dialysis ever since. Before she was diagnosed with diabetes, she was taking treatment for knee joint pain for 8-9 years. She lives in Takhniang village, located approximately 90 km from Shillong. Given her illnesses and her husband's monthly pension of INR 10,000/- (USD 120.93), she is financially dependent on her children. She has birthed fifteen children, of which four sons and seven daughters have survived. She lives in a semi-*pukka* house with her daughter Nishan, aged 30, who also takes care of her. She believes that she contracted diabetes from medication that she was taking for arthritis. She complains of having to undergo regular dialysis as she had believed that it was a one-time procedure. As she narrated:

Since 2009, I always took that knee joint medicine, I do not even go for sugar testing. Because of that knee joint medicine, I did not even visit the hospital. I only went to a private doctor who examined me and did not even know I have sugar. In 2018, when I visited the UPHC at Ladthadlaboh, Jowai, along with my daughter, who also took her children for a check-up, the doctor tested my sugar and found that I have sugar. It was 800 at that time. So, he immediately referred me to Dr. Banker's (medicine specialist) private clinic at Jowai, and since then, I started seeking treatment for diabetes from him. But in 2019, I became serious, and my children took me to Newlife Hospital in Shillong, where they told me that my kidney was damaged and I need to do dialysis thrice a week. My children did not tell me that once I started dialysis, I have to do it until I die. Had I known, I would not have consented to the dialysis. I could have told them just let me die. The expenditure for my treatment is so high that I have to sell my ancestral property. We have to pay for the medicines, blood tests, and other equipment every time I go for dialysis. In addition, we have to reserve a car to go to Newlife Hospital. Just for the car, I used to spend (INR) 2,000/- (USD 24.11) for every visit to get the dialysis done. I used to be hospitalized frequently when I became serious when it was not the day for dialysis. In that case, I have to be admitted to ICU. For now, I can still sell our land, I had wasted all the money on myself. My poor children and grandchildren will not be able to inherit anything anymore. Poor them, it is all because of me getting an illness like this. I have tried my best to access dialysis services in the hospital within the district or government hospital, such as NEIGRIMS so that I don't have to incur much expenditure. However, my relative, who works at NEIGRIMS told me it is difficult to get a bed there. It is

difficult in the Civil Hospital Jowai as my condition can become critical at any moment. Hence, I need to be shifted to ICU, but that hospital does not have an ICU, so I have no choice but to continue in Newlife Hospital.

While explaining her suffering from regular dialysis and the expenditure involved, she expressed extreme sadness and guilt at having to sell her ancestral property instead of bequeathing it to her children and grandchildren. Women who suffered from complications such as chronic kidney disease or eye problems have to travel to Shillong City for haemodialysis or eye operation due to the lack of advanced treatment within their district. In Meghalaya, almost 90% of the private health facilities that provide specialized care services are located in Shillong City, the State capital (Dutta et al., 2022). Thus, traveling to these health facilities in Shillong is a major challenge to women seeking treatment, as more than 80% of the population resides in rural areas. The inequitable distribution of health infrastructure in the State acts as a barrier to achieving universal health coverage (Dutta et al., 2022). Both in India and globally, physical distance significantly impacts the utilization of health care services (Sundar & Sharma 2002). Delays in seeking treatment attributed to gender barriers and its association with physical distance led to complications of NCDs such as diabetes (Shalev et al., 2004; Smith, 2001). A low socio-economic position is also associated with a worse diabetes prognosis (Coeli, 2009). Burdened with domestic responsibilities, women seek medical treatment only when their condition becomes serious (Buor, 2004). Poor attention to women's health within the family and the traditional stereotypes about their roles and gender norms also hinder their decision-making and access to resources (Srivastava, 2010; WHO, 2020c).

Vulnerabilities of Women living with Diabetes to COVID-19:

It is well-documented that people with diabetes became severely ill when infected with COVID-19. Three out of the 71 women interviewed for this study had contracted COVID-19 in the second wave of the pandemic in 2021. Naphi, aged 53, schoolteacher, was diagnosed with diabetes on 11th January 2021. She succumbed to COVID-19 on 3rd June 2021. On 21st May, 2021, when active surveillance for COVID-19 was conducted in her village, one of her close friends tested positive for COVID-19. According to the ASHA, Naphi became very scared and tried to avoid taking the COVID-19 test. However, on 23rd May 2021, Naphi started developing symptoms. She agreed to go to a private hospital in Jowai, located approximately 27 km from her village, on 1st June 1, 2021. She tested positive for COVID-19, and within one night of admission to the hospital's Intensive Care Unit (ICU), she succumbed to COVID-19.

People in the community where she lives said- “it was because she also has sugar, and that is why she died.”

The chance of getting admitted into the ICU is higher among people with diabetes infected with COVID-19 (Tiwari et al., 2021). This is true in the case of the present study; Naphi died during the second wave due to her excessive fear, which prevented her from seeking immediate treatment.

Poor Outcomes of Diabetes:

The structural factors discussed above affect women’s lives and make it difficult to attain the ideal HbA1c level that biomedical doctors consider “good sugar control.” Medical anthropologists such as Lesley Jo Weaver (2018) and Emily Mendenhall (2019), working on the social dimensions of diabetes, also measure the Glycated Hemoglobin Level (GHL). The present study draws on their scholarship but does not measure GHL. Medical records of the respondents were used to note only the level of HbA1c of women with diabetes. The drawback of this approach is that a lot of the women respondents did not have their HbA1c level checked. In particular, the women treated at the public health facilities in the district and private clinics do not get their HbA1c tested. A further challenge associated with sociological analysis based on laboratory tests was that even those women who did have these tests did not always keep them and were unable to explain the content of the tests. Therefore, the HbA1c of only six women has been documented. Table 8.1 shows that the HbA1c level of all six women was higher than normal. The latter indicates poor control of blood sugar levels.

Table 8.1 HbA1c as a measure of treatment outcome for diabetes

Sl. No.	Name	Source of treatment	HbA1c	Any complications	Outcome
1.	Queency	JCH, Ialong (admitted)	13.4	Diabetic foot	Died
2.	Mary	Civil Hospital, Shillong	8.7	No	Under control
3.	Iba	Private Clinic	10.68	No	Resumed treatment after one year
4.	Ristina	JCH, Ialong (admitted)	14	Complain of tingling or burning feeling in the hands and feet	Resumed treatment after four months due to COVID-19 pandemic lockdown second wave
6.	Cynthia	JCH, Ialong	7.4	No	Diagnosed with diabetes in 2021

Source: Data compiled from fieldnotes

The present study found that most women from low socio-economic groups could not afford regular visits to a private hospital. The main reason was physical distance and financial constraint to seek care. It was found that women visit private hospitals in Shillong for treatment only when their symptoms become serious. Otherwise, women relied primarily on private clinics or public health facilities within or outside their village for regular check-ups. Though these facilities lack the service of dieticians, even when the women are given diet charts, they are unable to follow their advice. Poor women reported not having the time and means to follow through with their diet charts. Moreover, the socio-economic context of women also determines their ability to self-manage diabetes. Nonetheless, in most cases, women were found to lose hope in their ability to control blood sugar due to structural impediments. They seemed convinced that their death would be caused by diabetes. About 18 out of 71 women in the study expressed anguish that they could not manage diabetes as their blood sugar kept fluctuating. They expressed sadness that their deaths would be caused by diabetes. The women in this study associated diabetes primarily with food without realizing the role of other factors such as stress, delayed diagnosis, poor access to health services, and poor blood sugar control. Wulcy aged 53, shares her experience with diabetes:

No, diabetes will not disappear. The doctors told me it will not disappear. It will lead us to death. We are taking treatment only for our body to get relief from its symptoms. If we can follow a strict diet, we feel relieved, but if we eat the food we are supposed to avoid, it will increase. We have to take care of it by ourselves- but still, we would crave the food we used to eat. I crave that food almost every time, but I did try to avoid it. Had I not avoided those foods, I would have died by now. I could understand how this sugar affects me.

Similarly, Wani, aged 49, a small trader selling vegetables, stated: “I feel like diabetes will lead me to death. This is my understanding. Because whatever I did is not helping me at all. Even if I restrict my diet, I do not feel like my sugar is clean. It will increase even if I eat the slightest of what I like, so I think it lasts throughout.” Women also blamed themselves when they could not follow and adhere to the dietary restrictions suggested by their doctors. This further increased their blood sugar levels. For instance, Dashisha, while thinking diabetes as a short-term illness, commented:

It was my mistake of eating yam, potato, and pumpkin during the lockdown (first wave in 2020) that my sugar illness started again, and till now, it has not yet been cured. It was my fault for making a mistake in eating, I thought my sugar has disappeared. I do not know it; it is only now that I knew about sugar that once it catches us, we cannot eat those kinds of food anymore. I came to know only now. Earlier, I used to think it is like many other diseases. How will I know this sugar disease is so *khor* (tough)? From now on, I

will not eat the food the doctor advised me not to eat. If I am going to be healthy, let me be deprived of that food. I am fine with eating other food they advised me to eat.

Dashisha's knowledge about the long-term nature of diabetes is poor, and she stopped following the dietary advice given by the doctor. She thought that her diabetes, like other minor ailments, was cured. But the symptoms reappeared, and she visited the doctors again. Only then did she learn that diabetes is a chronic disease that requires long-term dietary management. Dashisha is largely dependent on public health systems that lack proper nutrition counseling or dietitians to advise patients on dietary restrictions.

Poverty forces women to work hard within the household through the care of their children and outside through engagement in economic activity. Along with domestic responsibilities such as child and parent care, most women in the present study were employed either as agricultural labour or domestic labour in other people's homes or owned small establishments to sell traditional snacks, vegetables, and fish in the market. Different groups of women do, however, exhibit some resilience towards their lived experiences.

While a majority of the women experience social suffering, other privileged women like Lang consider themselves to be precious. This clearly shows that women in the tribal society are not a homogeneous group. Lang could not recall when and where she was diagnosed with diabetes. She said she used to seek treatment for diabetes from an Ayurvedic physician within her village of Nartiang as and when she experienced symptoms. Lang had a friend visiting her during this interview. When asked whether women were precious and why all the village heads were men, Lang's friend, Wan aged 78, replied:

In our case, women never become the *rangbah chnong* (village headmen). It has been like this forever. We have never heard of it since time immemorial. Our elders never taught us this. We considered women precious. Even family members considered women as precious. The customary law considered women precious. Looking at it, we feel it is better this way like our elders have arranged it.

Matrilineal culture impacts women's lives differently. It is a privilege for women to access resources such as land. Land ownership is a symbol of social status in society. Land ownership and control prove to be one form of resilience available to Pnar women. The other kind of resilience among poor women is the acceptance of poverty.

8.6 Views from the Health System, Representatives from Civil Society and International Development Organizations:

The former sections of this chapter attempted to understand the lived experience of women suffering from diabetes through case narratives. This section tries to integrate and understand the larger policy response to the problems associated with the health system in Meghalaya in general and diabetes care in particular in order to have a detailed explanation of the way in which the health system provides care within the larger context of Meghalaya society and economy. It takes into account perspectives of the key officials working with the health system, as well as a scholar and activist and a key representative from an international organization working in the area of gender and health in Meghalaya.

Chapter Seven discussed the perspectives of the health workers, medical officers, and other specialist doctors with respect to the provision of diabetes care in the state. This section is largely based on the narratives of key officials associated with the formulation and implementation of various programs and policies in health care at the state level. It also provides insights from the government, civil society, and the international development organization.

8.6.1 Views from the Health System:

8.6.1.1 State Health Officials Perspectives Regarding Knowledge about Diabetes in the Community:

One important finding that emerged from fieldwork and the narratives of women in the study villages concerned public knowledge about diabetes. It was found that knowledge and awareness about diabetes were limited regarding its chronic nature and symptoms and that care was fragmented regarding prevention and treatment. According to Dr. Silva, aged 51, a senior official working at the State level said:

People in the villages of Meghalaya are extremely hard to deal with. They will not tell you the truth about their health conditions when you visit the field. It is extremely difficult for medical officers at the community level to deal with people. Even if we make them aware, they will get other information from the traditional healers so that they will believe the traditional healer instead of you. It leads to a clash of information.

She spoke in detail about the low level of awareness about illness in general and about diabetes in particular. According to Dr. Silva, people refuse to disclose the truth of their

illness to anybody, particularly not to outsiders trying to understand the health situation. She said:

They will not tell even if they know you are from outside the health system. If you go and ask questions, they will give all the negative answers. That is the thing. The villagers are always like that. But if you had gone with the health person, then they will tell the people- you knew already, right and then they will say, ohh yes, it is like this like that. But if you go alone, you will interview them they do not like that so they will give all negative answers. Sometimes, they also would not want to disclose the information they know as they see you as an outsider. It is because they know you are not from the health department, so they will think, why tell? We will not tell. Their responses are always like that. It is the same even with other diseases- if we tell them, you know what to do when you have a fever, they will say we do not know. Imagine they say that even after the ASHAs had explained it to them. Awareness is going on from the MLHPs, and also the ASHAs, especially ANMs. They are doing home visits and all of that. The thing is that anyone who comes from outside, they will share all the negative information. They are also like that; I do not know why they are like this. Before also, they were like this. When someone from outside came to interview them, they are like this. It is as if, in that facility, they are not doing anything. Then the officials will look at us and say we have not given the awareness, although we already did.

Given the various myths, misinformation, and beliefs about diabetes in the study villages, Dr. Silva opined:

The myths or misconceptions regarding diabetes might have developed based on the discussions they must have had with other people in the community. Maybe the ASHA and the MLHPs might have told them not to walk barefoot, but their family members will tell them to walk barefoot when they go home. Women will listen to them more. They do not have much trust in us. By default, they like to listen to others more than us. That is the problem when we talk with villagers. However, this is not with urban people. *Ki nongkyndong* (the villagers) are simple. If you share some health information, people in the village will discuss it with others in their village. They will not believe us; they will believe and accept what the other person from the community is telling them. The MLHPs are addressing these problems, of course, at the community level.

Interviews with state and district-level health officials revealed that they find it very difficult to communicate with people from villages. Already existing beliefs and myths about illness and disease in the community make it difficult for medical officers to communicate the causes and complications of the disease. It is also evident that people do not trust the health system. The dominant understanding amongst the top officials is that people do not tell the truth about their health problems. Most importantly, even after seeking care from the health system, they seek advice from traditional healers resulting in contradictory information about illness and treatment mechanisms. To support that people in villages can lie, another male official, Mike, aged 35, said: “Even our staff lie about the training we had already

given to them just to get away from work.” According to Mike, the staff lies about their training as they do not want to do extra work.

The narratives of long-serving state health officials working in the health systems and communities of Meghalaya reveal various stereotypes, biases, and prejudices against the poor tribal communities in the villages of Meghalaya. This is clearly reflected in statements such as “people are hard to deal with” and “people will not tell the truth.” Rather than understanding the difficulties and suffering that people, and women in particular, face in accessing medical care, the officials conveniently blame the people and their behavior and reluctance to listen to health workers and medical doctors. Thus, it is observed that despite the fact that the officials were from the community, there was a disjuncture in their understanding of the social realities and lives of the people in remote villages. Thus, rather than understanding the structural impediments that restrict people’s awareness and access to health care, the officials blamed the victims for not adhering to or complying with the norms of good health. This, in the words of medical anthropologist Farmer (2004), is known as “victim blaming” (Farmer, 2004:317).

It is interesting to note that despite being a resident of the district, I was considered a “stranger to the people” by the health officials. In contrast, as discussed in the “Self-Reflexivity” section in Chapter Three, I was viewed by the village community as “*pra I hi*,” meaning “you are one of our own.” Women called out to me even when I was far away from the field at my Institute working on my thesis. They just wanted to talk to me and give an update about their health status after undergoing a blood sugar test or after hospitalization for complications due to diabetes. The bond that developed between me and the women in the study villages over two years of fieldwork was long-lasting and full of trust, whereby I was considered a part of their community and was one of them.

Another major finding emerging from the field is related to the functioning of the MHIS-PMJAY. While it has enabled people to access medical care at the secondary and tertiary levels in the hospital, people still incur huge expenditures despite being covered under the insurance scheme. Therefore, I attempted to understand the problems associated with running this insurance scheme from the perspective of various officials associated with the scheme.

8.6.1.2 Perspectives of the State Health Officials on MHIS:

a) Limited Knowledge about MHIS-PMJAY in the Community:

Field narratives from this study revealed limited knowledge and awareness amongst women respondents about various packages and insurance schemes. Information regarding MHIS-PMJAY was gathered through in-depth interviews with officials associated with it. Their background characteristics is enclosed as Annexure 17. With respect to awareness generation about the packages under MHIS-PMJAY, Reema, aged 37, key official at MHIS, said:

The experiences among people vary depending on the type of treatment they undergo. Sometimes our package can cover everything, and sometimes there will be out-of-pocket expenses. We have written many times to the hospital to explain this to the people, but then they are so overburdened that they do not seem to make an effort. Over the years, different people have had different experiences. For instance, there will be someone who says no, you will not get benefit from the package, but then they do not know that your treatment package is different from theirs. It is challenging to make people aware of the package rates. However, we tried giving IEC at the hospital level, but it is impossible to advertise a list of 2-3 thousand packages.

b) Reasons for the Absence of a Separate package for Diabetes Treatment in MHIS:

It was also observed from the field that no separate package was available for diabetes care as a part of the MHIS-PMJAY. All health workers and officials working with the scheme highlighted this. They also shared that patients with diabetes are usually allotted the “general ward unspecified package” instead of the diabetes package. The diabetes package is divided into two: insulin-dependent and non-insulin-dependent. Dr. Sam, aged 32, a medical officer, has in-depth knowledge of how the scheme functions in the state. He explained:

See, when patients come to the hospital, they do not come only with diabetes. They will come with other comorbidities, for example, hypertension with diabetes, diarrhea, fever, and also stroke. In this case, if we only block (or allot) the package for diabetes, then what about the treatment for other illnesses? This is why the general ward unspecified package is used instead of the diabetes package, as the general ward unspecified package covers the treatment for all the diseases. The other reason is that, per the state guidelines, only one package can be blocked, either hypertension or diabetes, and not both. Multiple packages cannot be blocked for one patient. For example, if the patients suffer from three conditions, the package with the highest amount will be blocked. The amount for the diabetes package is also less, and it is sufficient just for diabetes and not for other comorbidities that patients suffer. For instance, the package rate for insulin-dependent diabetes is (INR) 9,635/- (USD 115.60) for the entire stay at the hospital, which in most cases is unpredictable. If we block this package and the patient has to stay for many days at the hospital, then the amount will be insufficient. Whereas the rate for the general ward

unspecified package is (INR) 1,200/- (USD 14.47) per day, so in this case, if the number of days of stay is extended due to some reasons, the package rate also will increase.

Another finding from the field concerned increased out-of-pocket expenditure paid by patients despite the MHIS-PMJAY. Dr. Sam explained as follows:

The reason is that the hospitals will advise extra investigations beyond what is covered in the package. The package rate we created is based on the amount we calculated for the cost of mandatory investigations for particular diseases based on the standard treatment guidelines. Again, if the hospital has not advised all the tests, the patients will be unhappy, right?

However, other health officials at the district level associated with the MHIS-PMJAY often blamed the patients for not knowing how to use the health card. They shared that patients still needed to pay from their pocket despite the scheme because “they do not know how to use the card.” Dr. Anvi, aged 56, a senior health official, said:

The MHIS is helping NCD patients, but most people do not know how to utilize it. They did not know about the package. They thought they could use the whole 5 lakh rupees (USD 5999.05). When they seek treatment from a private hospital, some people admit themselves in a room, which is beyond the package, so they must pay an additional amount.

Reema, aged 37, a key official at the MHIS-PMJAY office, stated that although it was not intended to be a reimbursement scheme, the lack of availability of comprehensive services at public health facilities has made MHIS-PMJAY a reimbursement scheme. She said:

When you go to the hospital, you show your card, and your money is deducted. It has become a reimbursement scheme in many cases, especially in public health facilities, because sometimes there are no medicines or consumables, and the diagnostic tests are unavailable within that facility, whether it is a PHC, a CHC, or District Hospital. Then the hospital makes people buy the medicines or do the tests outside in private pharmacies or private diagnostic centers, and they have to reimburse from the scheme.

c) Absence of Coordination between the NPCDCS and MHIS:

This study also observed no coordination between different offices and schemes working towards the prevention and treatment of chronic illness in the state. For instance, the MHIS-PMJAY officials seemed completely unaware of the National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases, and Stroke (NPCDCS) implemented by the state government. Pratul, aged 37, official of the MHIS, said:

No, we are not aware of the NPCDCS program. It is related to prevention and screening, but we only deal with the “treatment.” I think there is no integration of MHIS with the NPCDCS program.

Similarly, even Dr. Silva shared:

We will not know what they are doing, we are doing our work, and they are doing their own. It is better if you ask directly from them how the MHIS is helping people living with NCDs.

There is an absence of proper referrals for treatment for people with complications of NCDs.

Similarly, Tom, aged 31, a key state health official, said:

We are not following it up, as our role is to ensure screening to prevent and control NCDs and to ensure the supply of logistics such as diagnostics and drugs. We are not following up on cases that need advanced treatment as that is beyond the program's scope. Concerning management, we are trying to streamline this program at each level of the health facilities. However, our role is limited to the designated facilities' district hospitals.

Regarding expenditure on travel and facilitating referrals for people suffering from complications of diabetes, Tom said:

The National Ambulance Service (NAS) is available in the state, but it is up to the district to utilize it. Ambulance services are also available under the Chief Minister's Motherhood Scheme (CM-SMS). They can use even that. Although it is for the RCH program, they can also use it for NCDs.

d) Complications of Diabetes are Beyond the Reach of the Program:

One of the program's key objectives is to facilitate early screening and diagnosis of people suffering from chronic illness. However, given the fact that there is limited information about the causes and determinants of chronic illness, many women were diagnosed with diabetes only when they developed other serious symptoms and illnesses. Thus, when asked about how they are addressing the problems of complications due to diabetes, Tom said:

These are all beyond the reach of the program. However, there are new projects in the state, for instance, the Indian Hypertension Control Initiative (IHCI) to prevent complications due to hypertension and the Pradhan Mantri National Dialysis Program (PMNDP) to provide free dialysis service for patients. All these are available at Civil Hospital Shillong. Yes, I agree that for people from your district, it will be quite far for them, whereas it is easier for those in Shillong. However, we have the CPHC to address the problems in the rural areas as the program is rural-centric. Because most serious patients always come to Shillong, as they are hardly going to the district hospital given the lack of resources and absence of equipment at the DH. If their condition became serious, they would always go to a private hospital or Civil Hospital in Shillong. Concerning the Coronary Care Unit, we plan to have it at the Civil Hospital Shillong, in Jowai, also, but it depends on the availability of the space. We planned to have the geriatric ward at Jowai, but we cannot due to space constraints. Only after we went there many times, we finally have found the space.

It becomes clear from the above narratives that there are serious challenges in implementing various important schemes and programs that aim to provide universal health coverage and comprehensive care to people suffering from chronic illness. There is no inter-sectoral coordination between important programs to ensure a continuum of care and health promotion, prevention, and curative care. Various systemic issues restrict the implementation of cashless insurance schemes, which then fail to achieve their objective of ensuring financial protection for poor and vulnerable households. One of the major problems that can be identified from the response of the officials working with the NPCDCS program or the MHIS-PMJAY officers is the complete disconnect from the lives of people and their living conditions. Given the rude behavior of health workers and officers and the absence of drugs and diagnostics, patients become discouraged from seeking treatment at public health facilities. It has reduced people's trust in public health facilities.

8.6.2 Perspectives from Civil Society Representatives and Official International Development Organizations:

Apart from the state officials, this section attempts to understand the perspectives of a scholar and activist working in the area of gender and health in Meghalaya as well as the views of an official working in public health with an international development organization in Meghalaya. The objective is to understand critically from different actors about the initiatives and efforts undertaken by the state to provide comprehensive health care to women in Meghalaya. One of the important findings from the field has been the poor outreach of health services for chronic illness. Since the implementation of the Ayushman Bharat Program (ABP), under which the SCs were transformed into HWCs to provide comprehensive health services, there were some efforts directed to ensure that care is provided even for different health problems such as communicable diseases, chronic illness, injuries as well as reproductive and child care services. On enquiring about the initiatives undertaken by the government to provide comprehensive health care, Rinjin, aged 38, official from the international development organization working in collaboration with the MoHFW, shared:

During the NHM period from 2005 till about 2018, it was a very women and child health focus program. Only after 2018, we are talking about comprehensive primary health care. So, it is still very early to talk about NCD. We are still at the stage of understanding and building the facilities and infrastructure. You cannot bring an overnight change in health facilities. With respect to screening, people in villages are yet to be made aware. ASHAs are yet to mobilize the males to come forward for screening in the community.

Discussions with officials revealed that the community's dominant perception is that public health facilities are only for women and children, as only services for reproduction and childcare are provided at the primary level. This is one reason men avoid visiting the sub-centers. Given the effort to provide comprehensive healthcare, ensuring that awareness is generated about the different services provided for other health problems is also important. Apart from this, it is also important to note that the larger focus within which the health system implements health programs and interventions has often remained gender-blind to the health problems women suffer beyond reproductive morbidities.

It was observed that there was a dominant understanding amongst the health workers and officials about the low level of awareness about health issues and delays in seeking medical care. They presume that the effort undertaken by the state towards increasing information, education, and communication among the people fails because village people are hard to deal with or prefer to follow the advice of traditional healers and their friends and community members. Sarah, aged 69, scholar and an activist in the area of gender rights and health in Meghalaya, offers a different reason. She highlighted why the IEC efforts have a limited impact on the community. She shared that one of the most important reasons is the difference in the social status of the people and the officials, which also results in "psychological distance." She said:

In these government-run facilities, doctors and nurses generally talk down to women, especially the poor and illiterate women, so this exists even today. Women do not listen to them even when they give awareness camps. There is already a psychological distance between those who come to give them awareness programs and those who listen. Unless and until you come down to the level of the village women, we cannot do anything with them. We have to understand the difficult lives of the women in the village.

On inquiring with the activist if women from villages face discrimination in health facilities. She shared:

We do not face caste-based discrimination like in mainland India, but it is mainly poverty here. Poverty is replicated again and again in the family. If you are poor and your socio-economic status is weak, everywhere you go, you will not get the best treatment, that is for sure. This is because our nurses or doctors perhaps have not been trained to be more empathetic, sensitive, and understanding of people.

Thus, it is evident from the field narratives of officials and key informants that there are significant changes that are recently being implemented with respect to comprehensive health services, insurances schemes, as well as policies and programs to improve state capacity and capability to improve the nature of care provided in health facilities. However, at the same

time, it is also evident that there exist differentiations within the tribal society of Meghalaya based particularly on the differences in rural-urban, land ownership, education, and occupation. Thus, most people living in the city or towns who own land are educated and work in government jobs, are often considered distinct and higher than those living in the villages. For instance, field interviews revealed that most people from urban areas consider people from the village as *nongkyndong* (those from remote places) in Khasi or *palatchnong* (strangers to their town, usually meant to refer to people from the village) in Pnar. Those who are educated and employed in the health systems perceive “villagers” as “illiterate,” “difficult to communicate with,” and “dirty people.” Thus, discrimination is largely based on gender and class, even when there is no caste system.

8.7 Summary:

The present chapter attempts to discuss the health status of Pnar women in the context of chronic illnesses like diabetes. The tribal society, is undergoing transitions in various aspects. The chapter also offers an understanding of diabetes beyond the biomedical explanation that diabetes is caused due to “risk factors” such as genes, unhealthy dietary practices, obesity, and physical inactivity. Under the biomedical approach, the onus of managing diabetes falls solely on the patient and their adherence to the three pillars of management: diet, exercise, and medications. However, the cause and complications of diabetes in an individual have multiple factors. This is especially so in the case of poor women who cannot afford to follow strict dietary advice, take regular medication, or avoid their work to exercise.

The chapter discusses the lived experiences of women with diabetes in Meghalaya’s matrilineal society, which is undergoing transition given urbanization, the introduction of mining, and the epidemiological transition. Fieldwork through observation and interviews revealed that women in the study villages were deprived of education and were compelled towards hard physical labor since childhood. Most of them were engaged in agricultural activity, such as working in the rice field as farmers, cultivating vegetables for sale in the village markets, and producing and selling rice-based traditional snacks. With the advent of coal and stone mining, women also started working as stone crushers in the stone quarry site and as daily wage laborers there. Thus, women with diabetes in the study were, at the time of the interviews actively engaged in different kinds of economic activities. Almost all women narrated that they had difficult and stressful childhoods. Almost all of them shared that their

difficulties and stresses continued after marriage. This could be one of the factors that led to the development of diabetes among these women. Moreover, due to poverty, they also suffered from food insecurity in instances where there was a lack of diversity in their diet or when they were deprived of essential nutrients because their main consumption was rice and potato. The preconceived notion by the health system that diabetes is a disease of the rich and not of the poor is reflected in the limited knowledge about the symptoms of diabetes among women. This limited knowledge about the symptoms of diabetes, coupled with poverty, has led to delays in seeking care among women with diabetes. These delays have called for advanced treatment, and women thereby enormous treatment costs, making them poorer. To pay for their hospital expenditure, women who have land have had to sell their property, whereas those who do not have land had to borrow or exhaust their savings or even have had to suffer from disabilities caused by complications of diabetes.

The study shows that women suffer from multiple axes of discrimination. Poor elderly women were abandoned by their families, which could be due to poverty as family members also have to earn a living. Social support for women suffering from multiple axes of discrimination is almost absent in the study villages. This has further increased the vulnerability of elderly women, especially when they suffer from musculoskeletal and vision problems and demanding illnesses like diabetes. Few elderly women in the study who migrated to coal mining sites ultimately returned to their villages, having no social support and having to depend on the mercy of their relatives. In most cases, their family members ignored their basic needs in providing a nutritious diet, let alone care for diabetes. Even in a matrilineal society where women are considered “precious,” the quality of their life is compromised to a large extent.

In the Pnar culture, women, especially the youngest daughter, are assumed to be of higher status due to property rights and rights to control resources. This is, however, not true in a landless family. Instead, a woman from a landless family has the added burden of having to care for her aging parents, herself, and her children. The condition of these women worsens if their husbands migrate to mining sites or get employment as truck drivers because the women become the sole bearers of all household and economic responsibilities. Women with these sufferings also suffered from illnesses such as hypertension, mental health problems, kidney stones, gall bladder stones, and even Hepatitis B. Overall, the chapter explains the entanglement of social suffering experienced by women with diabetes and the lack of empathy from the health system toward their suffering. These together produce what Mendenhall (2019)

called “syndemic suffering.” Further, the chapter also provided insights into the challenges faced by women in seeking health care for diabetes by reflecting on the discussions and opinions shared by the various health officials working at the state and district levels as well as representatives from international development organizations and academicians and activists closely associated and working on gender and health in the state of Meghalaya. It becomes evident from their narratives that there is a tendency to blame people for limited awareness about health problems. Their behaviors were considered a major hindrance where they do not listen to health workers but instead listen to friends and traditional healers. Moreover, it also became clear that there exists, to some extent, certain discriminatory practices and stereotyping of women belonging to rural areas and who are illiterate. This is apparent in how health officials and workers often view the tribal women as ignorant, less educated, and difficult to deal with in case of matters related to health and illness.



Chapter Nine

Summary and Conclusion

The present qualitative study attempted to explore the lived experiences of women with diabetes in the matrilineal society of Meghalaya. The study also explored the implementation of the national program related to the prevention and control of diabetes and the interaction of women with the health system in seeking care for diabetes. Doing so, the study addressed a knowledge gap concerning women and diabetes in the matrilineal tribal community of Pnar. A comprehensive understanding of the problems associated with health, particularly of socially excluded groups such as tribal women, necessitates an interdisciplinary approach that integrates discussions in the social sciences, specifically in sociology, anthropology, and gender studies (GoI, 2018a). The present study finds analytical resources in medical anthropology, syndemic analysis, intersectionality, and the notion of the life course in order to understand the social determinants of health and to situate diabetes within a socio-cultural context. It also uses the qualitative research methods of ethnography, case studies, and narrative inquiry to collect empirical data from multiple levels of the health systems as well as from the community. It also relies on material taken from official reports, notices, and registers, as well as records collected from the NHM and DHS office. Published literature such as books, monographs, journal articles, and newspaper clippings on matrilineity, women's health, health systems, and COVID-19 in the context of Meghalaya was also accessed from different libraries in Meghalaya, Assam, and New Delhi. Information collected from various sources was eventually triangulated to ensure the credibility of the findings.

My study also attempted to understand and explore the experiences of women living with diabetes and their interaction with different health systems at various levels. For instance, at the micro-level, which is at the individual and household, women's perceptions, beliefs, health-seeking behaviour, and everyday experiences with diabetes were explored. At the community level, women's interaction with healthcare providers in seeking diabetes care was studied. At the level of health institution, services available for diabetes care and women's interaction was examined by exploring the perspectives of a range of health providers at the village, block, district, and state level. This last level encompasses the administrative, managerial, and policy aspects of diabetes prevention and control programs as well. The

contribution of the MHIS to ensuring access to care in case of chronic illness and financial security was also explored.

Diabetes, to a large extent, was predominantly understood to be a lifestyle disease that inflicts wealthy people living in urban areas. My study also aimed to understand the experiences of women with chronic illnesses such as diabetes in tribal and rural contexts. Findings from this study highlights the burden of diabetes in people from low-income backgrounds who also suffer from problems associated with malnutrition. My study also assesses the response of the health system in addressing the problem of diabetes. Given the weak capacity and shortage of health workers to provide comprehensive diabetes care, the study further highlights the challenges faced by women in accessing health care. Some of the broad findings of this study are: everyday stress caused by poverty and marginalization is a determining factor in the development of diabetes among women with diabetes; various socio-cultural determinants of health influence the outcome of diabetes among women with diabetes; and women in Meghalaya's matrilineal society are overburdened with multiple responsibilities that then affects their health and health-seeking behaviour.

The present chapter is organized into three sections. Section 8.1 is a summary of the findings. It presents an analysis of the empirical work done in previous chapters. Section 8.2 advances policy recommendations based on the findings of the foregoing study and draws out a scope for further research. Section 8.3 concludes the study.

9.1 Summary of Findings from Analysis Chapters:

9.1.1 Chapter Five: “*Diabetes in a Matrilineal Society: Experiences of Pnar Women*”:

Diabetes as a chronic illness is caused due to multiple risk factors. The nature of the illness necessitates regular self-management, diet control, and continuous access to health care. Chapter Four discusses women's experiences regarding their knowledge of diabetes and its management. It further discusses the cultural beliefs and practices related to diabetes and barriers to self-management of diabetes.

My study reveals that most women I interviewed were, at the outset, unaware of the cause or risk factors involved with diabetes. However, on probing, they reflected on their experiences and shared various explanations for the cause and risks of diabetes. While elderly women considered diabetes to be a “new disease,” other women with friends or relatives

suffering and dying of diabetes were aware of the prevalence of diabetes in other study villages. The study revealed that women's information and knowledge about the risk factors, symptoms, management, and treatment of diabetes were insufficient and inaccurate. For example, they held that the cause of diabetes was the excessive consumption of sugar with their tea or the consumption of red meat such as beef and pork. They were unaware of the fact that carbohydrate-rich foods, such as rice-based traditional snacks, increases blood sugar levels as well.

Most women who have lived with diabetes for years have learned the long-term nature of diabetes based on their experiences. However, women newly diagnosed with diabetes considered diabetes to be a short-term and episodic illness like a fever or a cough that requires a one-time treatment. Consequently, they resume eating foods such as rice, potato, red meat, and tea with sugar which their doctors prohibit. This aggravated their condition further. In some cases, it even led to complications associated with diabetes, such as neuropathy, blurring of vision, unhealed wounds, and chronic kidney diseases.

Findings showed that even women educated to the level of higher secondary were unaware of the symptoms of diabetes before being diagnosed with the disease. The classic symptoms of diabetes, such as increased thirst, hunger, and urination, were considered normal by women in the study villages. They explain increased thirst by saying that it is a result of their heavy work, so they need to drink water. They associate increased urination with drinking too much water, so it is obvious to urinate frequently. They consider increased hunger to be a factor in a good appetite. This has led to delays in seeking treatments for diabetes. Most women in the study were diagnosed with diabetes only accidentally when they visited a doctor for other serious symptoms. As shared by one doctor, women with diabetes usually seek care when they have complications such as neuropathy. The study found corroboration with this fact in women's narratives of their symptoms. Most women said that they experienced tingling sensations in their hands, feet, and whole body. They also shared that they experienced numbness and other symptoms.

The absence of health information with respect to diseases and health problems among the people in the community is well-documented. Although the Reproductive and Child Health Program (RCHP) has been in implementation for more than two decades, Oosterhoff et al. (2021) found in their study that women lack knowledge about sexual and reproductive health. This could be because of the limited information provided by the health workers about the

importance of ante-natal care, institutional deliveries, or family planning. For illnesses like diabetes, considered a “new disease” by the community, knowledge is limited amongst the women about its risk factors, signs and symptoms, and complications, as well as the fact that it is a chronic or long-term disease.

Women in tribal society, as argued by Xaxa (2007), are not a homogeneous group which is also evident in the present study. There is internal differentiation and stratification among women based on education, occupation and income, access to property and land, residence, and strong social support and networks. Thus, there is also a stark inequality in the management of diabetes across women from different socio-economic groups. Women with secure occupations and income, some level of education, and access to property were able to go for regular check-ups for diabetes, take anti-diabetic medicines regularly and adhere to the dietary advice of their doctors. Some women are also able to monitor their blood sugar and blood pressure regularly at home as they have the means to purchase glucometers and sphygmomanometers. Social support, crucial in reducing stress levels and thereby good for managing blood glucose, is present among women from better income groups. For instance, they have children or relatives working as doctors or nurses who provide them with proper information related to diabetes. For these few women, diabetes has become a part of their life, and the three pillars of management related to diet, exercise, and medication has become a part of their daily routine leading to a good outcome of diabetes which is good glucose control. For the majority of women in the present study who are poor and working in the informal sector, the management of diabetes is complicated. The intersection of their class, place of residence in remote villages, and gender of being a woman endowed with many household responsibilities as they cannot afford external domestic help has led to poor experiences with diabetes. Due to the demands of their occupation, financial constraints, and lack of access to adequate healthcare facilities, they are unable to comply with the demands of diabetes care. These demands include consuming nutritious food, such as increased fruit and vegetable, regular blood sugar and medication monitoring, and physical activity. Walker et al. (2020) conducted a study in the United States using secondary datasets “to understand the longitudinal relationship between financial, psychosocial, and neighbourhood social determinants and glycaemic control (HbA1c) in older adults with diabetes” (Walker et al., 2020:760). Their study found that “difficulty paying bills, medication cost and non-adherence, food insecurity, depression, negative social support, and loneliness” are significant barriers to reasonable sugar control among older adults with diabetes (Walker et al., 2020:762). Similarly, in the present

study, most women find it challenging to adhere to self-management of diabetes. This is because they belong to low-income households. Structural determinants such as poverty, low education, and unemployment are barriers to managing diabetes (Mendenhall, 2019). For instance, adhering to or tailoring the diet required for good diabetes outcomes among low-income households suffering from food insecurity is elusive (Gucciardi et al., 2014). Nevertheless, to prevent complications associated with diabetes, such as neuropathy, retinopathy, and nephropathy, there is a need for optimal control of blood glucose levels (Chentli et al., 2015).

Numerous misconceptions related to diabetes emerging from study villages also act as barriers to managing diabetes effectively in the community. These include the myth that walking barefoot is good for diabetes and that consuming highly sugary drinks such as Horlick is also good for people with diabetes. Other misconceptions include that herbal medicine provided by traditional tribal healers can cure diabetes and that consuming antidiabetic drugs for long durations affects the eyes and kidneys. All these misconceptions may be attributed to limited knowledge and low awareness regarding diabetes in the community. Misconceptions regarding diabetes are common in every culture. In consonance with the study conducted by Lai et al. (2004) in Taiwan, the present study also found that participants fear that their kidneys will be damaged if they take allopathic antidiabetic drugs for a long period. Few participants also believed that diabetes could be cured through herbal remedies and that home remedies could help reduce blood glucose levels. The use of vegetables as home remedies to reduce blood glucose levels and relieve symptoms has also been reported in the study conducted by Wah Oo et al. (2020) in Myanmar as well. Misconceptions about diabetes among women or in other words, their partial understandings that may not be coherent or align with biomedical understandings have negative impact in the outcome of diabetes.

The outbreak of the COVID-19 pandemic and the resultant lockdown has further widened the inequality in the management of diabetes. Testimony and narrative experiences of women also provide evidence of the challenges faced in self-management and access to health facilities during the COVID-19 pandemic. As with other determinants, women with means such as a secure income and social support experienced diabetes differently during COVID-19. While women from better-income groups were able to visit their doctors even during the lockdown, women from low-income groups were forced to stay at home and switch to home remedies such as drinking the juice of passion-fruit leaves. There was a complete absence of

blood glucose monitoring among them as they were unable to afford expensive glucometers. Further, the lack of job opportunities during the lockdown weakened their financial state. Even when the lockdown was relaxed, the raised travel fare acted as a barrier to follow-up. Most women reside in rural and remote areas that lack regular transport. The resultant impact of poor follow-up during the COVID-19 pandemic lockdown, as found in the present study, was hospitalization due to complications and the seriousness of their condition. Few women reported being admitted to the hospital due to unconsciousness; some had very high blood glucose.

Individuals with diabetes, especially from marginalized and disadvantaged populations and the elderly, who are deprived of social support, found it difficult to practice self-care and adjust the doses of diabetes medicine. These populations largely need the support of health professionals for diabetes care (Sciberras et al., 2020). However, the lockdown prevented them from visiting health professionals. In times of crisis, it is difficult for them to reach out to health facilities. The outbreak of the COVID-19 pandemic, limited knowledge about the long-term nature of diabetes, and the lack of regular follow-ups made people with diabetes further vulnerable. Nonetheless, this impact was not seen across all social groups. The study revealed that educated respondents with secure jobs and income were able to follow self-management of diabetes even during the lockdown.

9.1.2. Chapter Six: “*Diabetes Care and Management: Availability of Services and Healthcare Providers’ Perspectives*”:

Chapter Six describes the existence of multiple systems of health for diabetes care and the perspectives of the health providers. Diabetes services are available across various systems of medicine —Allopathic, Ayurvedic, and even traditional medicine. Allopathic and Ayurvedic are available both at public and private health facilities. The public health system provides preventive, promotive, and curative services for diabetes through the NPCDCS program. The program is implemented at different levels of the health facilities – SHC/HWCs, PHCs, CHCs, and District Hospital. Different levels of these facilities provide different packages of diabetes service. At the HWCs, these services include health promotion, awareness generation through health education, population-based screening, opportunistic screening and referral of suspected cases of NCD. In addition, referral and follow-up services are carried out by the ASHAs at the village level. At the HWCs, diabetes care is also provided by the MLHPs and the ANMs. At the PHC level, services include health education, opportunistic screening, diagnosis, treatment,

follow-ups, and referral of complicated cases of NCDs, including diabetes. The services provided at the District Hospital are similar to those at the PHC. However, at the District Hospital, an NCD clinic is mandated to be established for ease of conducting NCD-related activities. To manage the program, there is a need for setting up NCD cells at the national, state, and district levels, as mandated by the operational guideline of the NPCDCS. Findings showed that while there was an adequate human resource at the state NCD cell as per the program guidelines, the district NCD cell has two vacant posts- program officer and program coordinator.

In the present study, I also identified numerous gaps in the implementation of the program at all levels of the health institution. These include space constraints for the NCD clinic at the District Hospital, vacant posts at the HWCs and District NCD clinic, shortages of human resources, lack of IEC materials, inadequate and poor staff training, and lack of orientation about the program for most categories of healthcare providers. The other gaps include the irregular supply of consumables required to screen for diabetes and antidiabetic drugs. My study also reveals a lack of specialists and dietitians at the District Hospital, affecting service delivery for NCDs, including diabetes. For instance, specialists to manage complicated diabetes cases, such as cardiologists, neurologists, and super-specialists, such as nephrologists, are unavailable in the hospital due to the lack of infrastructure, such as ICU.

Atre (2019), in his work on “The Burden of Diabetes in India,” argues that the NPCDCS program was initially implemented in select districts of India. This leaves many diabetic patients uncovered. The author also argues that even after many years, people still face problems in availing services, treatment, or antidiabetic medicines from public health facilities. Due to this, they are compelled to visit private practitioners. The long-term nature of diabetes has also led to high treatment costs, thus creating a huge burden to the patient and his or her family in the form of high out-of-pocket expenditure. Studies on the implementation of the NPCDCS program have been conducted in different districts of Karnataka, such as Belagavi and Udupi. Some of the major shortcomings conducted in the sub-centers of Belagavi districts by Kashyap & Shivaswamy (2019) were under recruitment of human resources, poor training for the staff, shortages of medicines, conflicting timing of screening and work, and inadequate IEC materials. Ainapure et al. (2018) have also identified multiple barriers to the implementation of NPCDCS in their study conducted in Udupi, Karnataka. Some of these barriers include vacant posts, fund constraints, and low levels of awareness in the community.

A common finding in both studies is the concern of the sub-centre staff that NPCDCS is another program added to the list of programs that need to be carried out at the sub-centre. The burden of too many programs could henceforth decrease the quality of care. Ainapure et al. (2018) also find that community perception may act as a barrier to utilizing the service given at health facilities. Their studies revealed that the local community was unaware of NCDs and that informal providers were encouraging members of the community to avoid using modern health facilities.

Findings from the study show that the quality of care provided for diabetes at public health facilities is poor, and screening for diabetes complications is almost absent. Diabetes clinics at private hospitals in Shillong provide comprehensive care for diabetes to some extent. Two major hospitals in Shillong have diabetes clinics, with one of them having a diabetes educator who registers people with diabetes and provides them with health education. At a private hospital, people with diabetes are provided with dietary counseling by dietitians and are also screened for complications such as neuropathy and foot complications. Although private healthcare facilities provide good quality services for diabetes, due to the cost involved, it is not accessible to most women in the study. Women from impoverished backgrounds who could not afford the services of private hospitals and were not satisfied with the services at public health facilities resorted to private allopathic or Ayurvedic clinics. Thus, the quality of care received for diabetes is not the same for all women, thereby creating inequality in the outcome of diabetes among women, given their socioeconomic status.

In the remotest villages of the study areas, most traditional tribal healers also consider diabetes a “new disease” and hence did not provide treatment for it. Traditional tribal healers do, however, play a critical role in providing care for diabetes in a few villages, which have seen a recent increase in the prevalence of diabetes. These healers gain the skills of providing care for diabetes based on their experiences with diabetes and experiments with treatment. Different modalities of treatment, such as herbs, prayers, and massage, were used by traditional tribal healers for the treatment of diabetes. Traditional tribal healers have different explanations regarding the causes and symptoms of diabetes. They believed diabetes could be cured after six months of treatment through herbs.

9.1.3 Chapter Seven: “Utilization of Healthcare Services for Diabetes: Narratives of Women from the Field”:

Chapter Seven discusses the various sources of healthcare facilities that women access for diabetes treatment. Findings showed that the initial diagnosis of diabetes for a majority of the women was made at private healthcare facilities such as private clinics-cum-pharmacy run by allopathic doctors and private hospitals. The follow-up sources for the treatment of diabetes among women vary. While women from better-income groups access private hospitals in Shillong, sources for treatment for women from low-income groups vary, depending on their financial status at the time of visit. Women from the lowest income group depend on the public health facilities such as the HWCs/PHCs and the District Hospital.

Women narrated different experiences regarding their engagement with healthcare services both at public and private health facilities. As reported by other studies, women have unfavourable experiences with public health facilities on account of the irregular supply of antidiabetic drugs at these facilities. The fact that subsequent consultations are not done by the same doctor makes these women anxious about the care they receive, and they question the quality of care. Low-income women, wholly dependent on public health facilities, reported that doctors from these facilities refer them to private health facilities because of the lack of adequate diagnostic tests at public facilities. Few women reported that they chose to go back home instead of going to these private health facilities. As a consequence, screening for complications of diabetes is not possible among women from low-income groups. The fragmented nature of healthcare services delivered at the District Hospital creates obstacles for women seeking treatment as they are expected to move from place to place to access medicine and tests from different private facilities. It also results in large out-of-pocket expenditures for women as they have to spend money on travel, doctor's fees, medicines, and diagnostic tests. They end up losing daily wages for a day or two as they are often required to make multiple trips in case a doctor is unavailable. The inconvenience of such a system encourages some women to seek an alternative at private facilities. The early hours of private clinics also prove to be more convenient. Because of the availability of antidiabetic drugs, women are saved from the run-around requirements of public health facilities. Gulliford et al. (2003) conducted a population-based study in Trinidad and Tobago, an island country in the Caribbean, to understand diabetes-related inequalities in health status and the financial barriers to accessing healthcare faced by diabetic and non-diabetic populations. The present study agrees with

Gulliford et al. (2003), as a majority of the women from higher-income groups used the services of private health facilities. Individuals from lower-income groups, however, tend to be regular users of public health facilities despite the poor quality of services available for diabetes.

Women, particularly from low-income groups, are constrained from accessing sufficient care. Fragmentation in health services at public health facilities enables only limited care as it caters to sections of care rather than recognizing the interrelatedness of the different aspects of treatment. Fragmentation of health care became more pronounced in the era of reform in the health sector in the early 1990s and continued to intensify with the advent of neoliberal economic policies. It was further legitimized with the introduction of various reforms brought in as part of the National Health Policy 2017 (George, 2020; Hooda, 2020). The phenomenon of reducing state intervention and boosting private players is influenced by neoliberal policies directed at minimizing regulation in financial and labor markets (Antoniello, 2020). Neoliberal policies have led to the privatization of medical care and decreased state accountability for the population's health (ibid). More strategically, individuals are held responsible for their poor health and are expected to improve through individual behavioural change. Minimum attention is given to social factors that negatively impact the population's health status (ibid).

My interviews with doctors revealed that most patients with diabetes are treated as Out Patient Department (OPD) cases. However, MHIS does not provide financial assistance to illnesses treated on an OPD basis. Doctor consultations constitute a large part of medical expenditure as the long-term nature of diabetes necessitates repeated consultations. The study confirms Gulliford et al. (2003) finding that individuals with diabetes are more likely to be excluded from insurance schemes as a large part of the total cost for treatment includes aspects such as doctor consultations, medicines, and travel as cases of OPD that are not covered by insurance. Further, women suffering from the complications of diabetes, such as chronic kidney disease, diabetic foot, and diabetic retinopathy, spoke of the added suffering of enlarged out-of-pocket expenditures not covered by insurance schemes. There is an absence of advanced treatment for diabetic complications in the District Hospital, so women are forced to incur additional expenses to travel long distances to the city of Shillong. This aggravates their poverty and levels of stress, and they are forced to sell assets such as land and jewelry for medical expenditures. The various schemes associated with health insurance fail to provide financial protection to patients from low-income groups, even for hospitalization. The failure

of the publicly-financed health insurance scheme to provide financial protection to population from the lowest income is well documented in previous studies (D’Cruze, 2020; Nandi & Schneider, 2020; RamPrakash & Lingam, 2021). Health insurance appears to benefit only the private players and not the patients (Hooda, 2020). In the present study, women reported incurring huge treatment expenditures for hospitalization despite deductions made through insurance cards provided under MHIS-PMJAY.

Popular opinion plays a major role in deciding where to seek treatment. In the village, women interact and discuss their experiences of illness. They advised their friends, families, neighbors, or relatives accordingly. Findings in the present study also show that numerous factors influence the utilization of healthcare services for diabetes among women. These include educational status, occupation, income, place of residence, gender roles and responsibilities, and health insurance. The study revealed that while women enjoy a degree of mobility in a matrilineal society (Oosterhoff et al., 2021), gender-based roles and responsibilities negatively impact healthcare service utilization. Women have subordinated their own health, often prioritizing the health needs of other family members. Gender norms and inequality prevent women from making decisions concerning their health, thereby limiting their access to health services (Oosterhoff et al., 2021:240). The dual responsibilities of women to perform domestic and wage labour disabled women from caring for their own health.

It is well-documented that women with high education levels are more likely to utilize health care services and comply with treatment. However, in the present study, it was found that few women with a low level of education also comply with the treatment advised by their doctors. This shows that factors other than education, such as experience and knowledge about the disease, motivate women to adhere to the treatment for diabetes. That education facilitates regular follow-up treatment is disproved by the evidence that some graduate women from the study believed that long-term medication for diabetes would affect the kidney. This belief is borne from women’s personal experience of knowing family members suffering from chronic kidney disease. Chronic kidney disease was believed to have been caused by long-term antidiabetic medication rather than as a complication of diabetes.

A few women reported that while taking allopathic treatment, they also visited the traditional tribal healers hoping to get the “cure” for diabetes. Regardless of their economic status, women also utilized traditional medicine and herbal remedies to treat diabetes. The study revealed that the socioeconomic position of women does not impact the influence of

traditional tribal healers for the treatment of diabetes. Religion, however, impacts this influence as most women practicing Christianity believe that services provided by traditional tribal healers, especially from the indigenous tribal religion, stand in opposition to their religious beliefs. Some Christian women, however, continue to seek treatment from traditional tribal healers. Thus, preference for utilization of traditional tribal medicine varies across women depending on their experiences and world views. While few women considered the treatment beneficial, others were apprehensive of traditional tribal healers as it made them more anxious. These women preferred allopathic medicine as they were satisfied by its diagnoses and trusted the treatment of antidiabetic drugs. Women choose their source of treatment based on their access to these sources and their ability to bargain with healthcare providers. They approach informal providers for treatment because they are more accessible. Better-equipped hospitals in Shillong invite high travel and medical expenditure.

9.1.4 Chapter Eight: “Syndemic Suffering in Matrilineal Society: Poverty, Stress and Diabetes”:

Chapter Eight discusses the underlying determinants that led to the development of diabetes among women from lower-income groups residing in the study villages. It explains how these structural factors act as barriers to the self-management of diabetes among women and their access to social support and social network. The study shows that matrilineity does not lead to good health among women. It enables disadvantages that affect tribal women more than others as they live in geographically isolated villages with difficult terrain. Most of the women in the present study have had a difficult childhood. Poverty and the lack of access to educational facilities have left them with little choice but to engage in hard physical labour since childhood. Most women interviewed for this study received no schooling and were compelled to earn a living by seeking employment in the informal sector. Pnar women can choose their occupations and work in different geographical spaces as it is a matrilineal society. But long-term exposure to physical spaces such as agricultural fields, coal mining sites, stone quarry sites, and marketplaces heightens women’s risk of poor health. Most women I interviewed endured poor living conditions at the coal mining site, noisy and unsanitary environments in the marketplace, and the risk of back and spinal problems owing to the long hours of working in the field. Ageing women, in particular, are impacted by these physical conditions and developed health problems such as hypertension, musculoskeletal problems, and diabetes.

Women's health and well-being further deteriorate with the death or desertion of their husbands. They lose financial and emotional support, and child care becomes the sole responsibility of women. Poverty and the absence of a father force children to discontinue their school education in order to support their mothers. Meghalaya's matrilineal society romanticizes the role of the youngest daughter as inheritor to the ancestral property. This romanticism is broken in low-income households where the youngest daughter becomes the sole caregiver of her ageing parents with almost no support from her brothers and other relatives. Some women from this group of interviewees attribute their diabetes to the stress of long-term caregiving to bedridden parents. There is strong evidence to suggest that diabetes is directly linked to stress. Fulfilling basic needs is challenging enough for these women, so diabetes management gets rendered as an unnecessary luxury. The constant stress of everyday life affects their mental health, so they are prone to depression and anxiety disorders. Various studies demonstrate the detrimental effects of depression on diabetes. A further cause of stress for most women in the study villages is the lack of social support other than children and husbands and the absence of social welfare in terms of rationed rice, gas, electricity, and pension. In the absence of social support, women in the present study find solace in religion to cope with their illness and suffering. While studies have shown that religiosity can help in reasonable sugar control, some show it can be counterproductive (Walker et al., 2020). In the case of the present study, women consider their illness as "God's will," and there is no need for intervention, such as taking active health promotion activity.

Stress, accumulated from a life of increasingly heavy work, has impacted the general health of elderly women who develop complex health problems. Poverty often creates challenges for children from taking their mothers for regular medical check-ups, and age prevented them from going on their own. Without aid from healthcare systems, women bore the problems of old age compounded by diabetes. Gulliford et al. (2003) found that diabetes was prevalent in low-income and low-education populations. Further, their study also reveals that individuals with diabetes suffer from the worst health status, loss of functioning capability, have a vision problem, and are more likely to be diagnosed with hypertension. In my study, I also found that most women with diabetes suffer from comorbidity, mainly with hypertension, multimorbidity, and even complications.

Walker et al. (2020) found that the primary reasons for financial stress with respect to diabetes are: complicated treatment (the range and quantity of medicines, exasperated with co-

and multi-morbidities); regular monitoring of blood sugar level; and nutritious food. They found that stress affects blood sugar levels and that the primary causes of stress include a struggle for daily existence, limited resources, absence of social support, lack of time to take care of oneself, and unemployment (Walker et al., 2020). The present study shows that these concerns obstruct women from necessary self-care. My study also confirms the findings of Weaver (2018) in Delhi that women inflicted with demanding diseases like diabetes sacrifice their own health and prioritize the needs of their husbands, children, and grandchildren. Nongbri (2008) shows that Meghalaya's matrilineal society burdens women further with the sole responsibility of child care. Oosterhoff et al. (2021) also argue that women in Meghalaya have internalized the notion of second-class citizens and do not even assert their rights. The scarcity of employment opportunities and financial insecurity during COVID-19 also increased levels of stress among women in Meghalaya (War & Kharkongor, 2021).

The public health system overlooks the social determinants of health, considering it outside their work domain. Their understanding is largely biomedical and individualistic, where the cause of diabetes and poor blood sugar levels are attributed to individual lifestyles. Misunderstandings and preconceived notions amongst public health workers neglect the needs of the rural poor. According to them, diabetes is a disease of the urban rich, and that hard physical labour by the rural poor precludes the development of diabetes. Studies have also found that genetic predisposition to diabetes accounts for a very small percentage of the cases (Whiting et al., 2010:79). The impact of diabetes is, therefore, significantly associated with socioeconomic status. Access to healthcare services and education about diabetes could lead to better outcomes (ibid).

9.2 Policy Recommendations and Scope for Further Research:

9.2.1. Policy Recommendations:

Oosterhoff et al. (2021) argued that poor design and implementation of health programs are attributed to limited research in the sociocultural context of Meghalaya. They also argue that the health programs implemented at the state are not context specific but are designed based on national priorities and do not align with the local needs of the population. Thus, for health programs to be effective, there is a need for local level evidence and data (ibid). The present study addresses these concerns by providing relevant information within the

sociocultural context of Meghalaya. Findings from the present study will contribute to improving diabetes care and management in Meghalaya.

The Government of Meghalaya announced a state-wide health reform through the declaration of the Meghalaya Health Policy in 2021. It is one of the first states to declare a state health policy during the COVID-19 pandemic. The health policy document outlined six visions that range from providing affordable, patient-centric universal healthcare to all its citizens to addressing gender inequality.

The policy calls for a special focus on women's health. Named MOTHER, the stated objective of the policy is to achieve Measurable Outcomes in Transforming the Health Sector through a holistic approach with a focus on women's Empowerment. According to the policy, "women's health is not a standalone issue and needs to be dealt with holistically to remove societal gender barriers" (GoM, 2021:4). The health policy adopts a three-pronged strategy and places equal focus on Preventive Care, Curative Care, and Enabling Dimension. Preventive healthcare services include nutrition, fitness, vaccination, early diagnosis, antenatal check-ups, and health education. Curative Care includes primary, secondary, and tertiary healthcare services, MHIS, telemedicine, and improvement of referral services. And the enabling dimension encompasses gender equality, early childhood development, public health, population management such as water, sanitation, etc., and social audit" (GoM, 2021:5). The State Health Capacity Enhancement Project (SCEP) in Meghalaya also aims to ensure Universal Health Coverage (UHC) (Kumar & Bhargava, 2023)⁸³ and to transform the "inverted pyramid model of healthcare in India, which focuses on tertiary healthcare and a quantum of primary care, into a more robust preventive healthcare and well-being model" (ibid). It stands on six pillars constitutive of local leadership through problem-solving, citizen-state relationships: responsive systems, effective use of data and research, accountability and agency, identifying and addressing systemic challenges, and political supportability (ibid).

In the following section, I will highlight the status of NCD services in Meghalaya to explain how the effort of providing comprehensive primary healthcare to the community is being addressed. This is based on my field observations and discussed below, followed by a few policy recommendations for improving the health status of people in Meghalaya.

⁸³ Available at <https://www.weforum.org/agenda/2023/03/integrated-approach-meghalaya-universal-health-coverage-india/> Accessed 22nd July 2023.

Comprehensive Primary Health Care Services through HWCs: A Ray of Hope

Comprehensive Primary Health Care (CPHC) was implemented in Meghalaya in 2018. The study found action at the grassroots level, with sub-centres being upgraded to HWCs to provide CPHC. Mid-Level Healthcare Providers (MLHPs) were at the forefront of providing healthcare service packages to people, including for NCDs at the village level. My observations find that the primary services provided by the MLHPs regarding NCDs include – screening and referral for suspected diabetes and hypertension cases and monitoring of blood pressure and blood glucose level of people visiting HWCs for follow-ups. MLHPs are assisted by ASHAs in listing individuals aged 30 years and above and in mobilization for screening.

MLHPs make the diagnosis of hypertension through teleconsultation with medicine specialists on call. However, medical officers make the diagnosis of diabetes at PHCs. Follow-ups and refills of antidiabetic medicines for patients with diabetes are made at HWCs each month. The NPCDCS program mandates that ASHAs arrange follow-ups for patients with hypertension and diabetes at the community level. Field observations reveal that ASHAs are not, however, fulfilling this task. In 2020, during fieldwork, they were occupied with COVID-19-related work. But they were also unaware of the incentives given for each case as a part of the NCD works. Analysis of the national program guidelines for NCDs shows that a system is in place to provide continuity of care for NCDs, including diabetes, at the community level. These efforts to some extents have benefited rural and remote village populations by increasing access to NCD care and management and reducing medical and travel expenditures. Based on these field observations, the study recommends strengthening PHC care services by providing health services that are accessible to rural populations with a focus on disease prevention, as envisioned in the health policy.

The Government of Meghalaya also developed various measures to provide CPHC to its population. In July 2022, the National Health Mission and the Department of Health & Family Welfare, Meghalaya, drafted the CPHC Guidelines.⁸⁴ The guidelines titled “Understanding Comprehensive Primary Health Care: The Meghalaya Way” was published in November 2022. CPHC is important to ensure universal health coverage, especially for NCDs, as it encompasses “preventive, promotive, curative, rehabilitative, and palliative care” (GoM, 2022:5).

⁸⁴Available at <https://theshillongtimes.com/2022/07/23/consultative-writeshop-to-healthcare-guidelines/> accessed on 10th December 2022.

Based on the findings from the field and analysis of the Government of Meghalaya's health policies and guidelines, the present study made the following recommendations:

1. Need for Health Literacy:

The present study shows that women have limited knowledge about the signs and symptoms of diabetes and the care and management required for diabetes. Limited knowledge is one determinant of the poor outcomes of diabetes among women. The present study thus emphasizes the need for providing health education to people by healthcare providers at all levels of health facilities. For example, healthcare providers such as ASHAs, ANMs, and MLHPs at HWCs could educate local populations on – the risk factors of diabetes, its signs and symptoms, the importance of regular blood glucose monitoring, and taking medicines. ASHAs could also inform the community about the long-term nature of the disease, the importance of wound care, and avoiding applying nail polish on wounds and walking barefoot.

It is argued that poor health literacy is strongly associated with low education and poor health status, and frequent hospitalization is associated with a lack of health literacy (Brown et al., 2004). Efforts can be made to raise functional health literacy in low socio-economic groups whereby patients learn to read and comprehend medical prescriptions, appointment slips, and other important health-related information materials. Regular health awareness and screening camps should be conducted in rural and remote villages to address misconceptions about illnesses, including diabetes. Awareness and screening camps may be organized in collaboration or convergence with other governmental development activities, thereby maximizing outcomes toward gender equality, better education, and improved health for the community (Nayak & Thomas, 2007).

Further, most study respondents were unaware of the NPCDCS program and its objectives. The role and objectives of HWCs are not properly understood by communities. This could be because the establishment of HWCs had been introduced very recently at the time of this field study in 2020, and it overlapped with the COVID-19 pandemic. Nonetheless, there is a need to create awareness about the services available at the HWCs for all population groups. There is a misunderstanding in the community that HWCs exist solely for mothers and children. The need for creating awareness about services available at the HWCs and other government services is also emphasized in the Meghalaya Health Policy 2021. The policy documents the need to “generate awareness on how to access various services provided by the State” (GoM, 2021:7).

There is also a need to strengthen the public health system for better use of its facilities and ensure effective service delivery. The following points discuss recommendations with respect to strengthening the public health system, especially at the primary health level. It focuses on the referral system established to provide quality care for diabetes and other chronic illnesses in rural tribal areas.

2. Strengthening of the Health System: Invest, Recruit, Train, and Retain:

In the present study, eight of the twelve HWCs catered to a population more than that recommended by the Indian Public Health Standard (IPHS) for hilly areas. Inadequate health facilities and shortages of human resources are major challenges to providing comprehensive primary healthcare to the people. Therefore, there is a need to increase the budget allocated for health in Meghalaya to create more health infrastructure and recruit frontline healthcare providers, medical officers, and specialists. Further, the District Hospital in West Jaintia Hills functions poorly in providing care for cases of chronic illness. Screening for diabetes complications is almost absent. The post of dietitian required to provide dietary counselling to patients with diabetes and other illnesses was vacant. Even investigational facilities to screen for complications of diabetes were absent. All aspects of the secondary level of health facilities must be strengthened to address the growing burden of NCDs in tribal areas. These include providing in-house testing facilities, a regular supply of medicines and counselling services, and abstaining from referring patients from public hospitals to private health facilities. Healthcare providers must be trained to provide care for chronic illnesses, and their skills must be assessed regularly. They also need to be sensitized regarding the needs of women. For instance, women need to check their blood glucose early morning, but the HWCs will open late, and even if the staff live in the residential quarter, they complain that women come to the HWCs too early. Thus, to provide NCD care at the village level, there is a need to revisit the operational timing of the HWCs, while considering women's health needs and economic activities. Similarly, other innovative ways need to come up to increase the participation of the community in NCD screening. This can be done through collaboration with village headmen, who will plan a day for this activity after making the community understand the benefits of screening.

Healthcare providers, especially those recruited on a contractual basis, need adequate compensation and a proper living environment to motivate them to serve the community better. Their skills need to be upgraded, providing them better career prospects within the public health

system. Efforts to retain staff in rural areas by providing attractive incentives are important to prevent workers from leaving the posts.

3. Ensuring Continuity of Care and Financial Protection:

Findings from the present study suggest a lack of referral linkages between primary and secondary levels of care. There is no mechanism to track patients coming for follow-up consultations for chronic illnesses. The present research emphasizes the need for continuity of care and financial protection for chronic illnesses such as diabetes. Women incurred large out-of-pocket expenditures despite having insurance cards. This finding runs counter to the Megha Health Insurance Scheme (MHIS) claim that they provide “cashless” financial protection. Without guidance from public health providers, women suffering from NCD complications were forced out of health care due to financial constraints. One of the focuses of the health policy is ensuring universal access without financial risks and hardships. Efforts must be directed to ensure health workers reach out to the people living in difficult terrain and remote villages by strengthening HWCs in villages. Secondly, those with complexities must be guided properly to ensure they receive treatment.

There is also a need for multiskilling, team building, and resolving health problems at the primary level rather than referring cases to high facilities. It was observed from the field narratives of women with diabetes that they are required to shuffle between public and private health facilities in order to get the diagnostics and blood tests done, purchase medicines, or make MHIS cards. Attempts should be made to ensure comprehensive health care services at single health facility. Further, the HWCs and PHCs should ensure the availability of medicines for chronic illnesses such as diabetes and hypertension. The follow-up of drugs should be available at the primary health facilities without disruptions in the supply.

I also observed in my fieldwork that women were diagnosed with diabetes at a very late stage when they already had various health complications. This leads to increased mortality at a young age. To counter that, there is a need to strengthen comprehensive health services at the primary level so that diabetes is detected at an early stage. Such a need has been introduced as a part of Ayushman Bharat, a flagship health programme in India. The primary health facilities will help in the early detection and diagnosis of diabetes and thus avoid complications. It will also reduce the expenditure on transportation and complicated tests for the patients. Apart from this primary facility, continuity of care should involve proper referral linkages for chronic illnesses.

Women in the present study are not homogeneous. The intersection of their age, gender, marital status, education, occupation, and disability status determines the extent of their vulnerability. For women from low-income groups, expenditure on medical treatment is seen as a waste of resources. They feel guilty if they use resources for the treatment of their illness, thereby affecting them. So, their choice is between using their resources for food and other basic needs or diverting them to treat their illness. This precarious situation affects their mental health deeply. Keeping the precarious situation of vulnerable women in view, the most marginalized section of society living with NCDs should receive free treatment services from public health facilities or under the MHIS. They also need support and guidance in learning about the benefits of the MHIS through health literacy. In short, their access to health facilities should be made easy. It can be done through the MLHPs and the HWCs in collaboration with officials working under the NPCDCS program and MHIS.

The CPHC guidelines underline the need to reach out to the most marginalized sections of the population in Meghalaya, as they often receive less health care. The guideline rightly points out the marginalization faced by people with disabilities across genders, and this is due to challenges related to accessibility and limited awareness regarding services available for treating their illnesses. In this context, the identification of the most marginalized groups by the Village Health Council and ASHAs is needed to ensure that they get access to treatment through affirmative action, such as the provisioning of transportation costs to access treatment and compensation of wage loss while seeking treatment (GoM, 2022:51)

4. Inclusive Healthcare Services:

To make access to healthcare services equitable and to ensure universal health coverage, there is a need to reach out to population groups who cannot access healthcare services independently. These include elderly women who suffer from disabilities such as vision problems and musculoskeletal disorders and who are bedridden. Frontline health workers must be sensitized that each life matters and that everyone has the right to seek healthcare.

The Meghalaya Health Policy 2021 focuses on a “Rights-based framework” to empower the residents of Meghalaya. It demands greater accountability from the state towards its residents (GoM, 2021:7). As per the Policy, all the residents of the state have the right to receive healthcare services for emergencies and all other diseases and also have the right to receive information related to healthcare services (ibid). Further, the Policy mentions that a

“lifecycle approach” will guide how services will be provided to individuals at different stages of their life- “at conception, neonatal, newborn, toddler, pre-schooler, school-age child, adolescent, and adulthood” (ibid:13).

Though healthcare is necessary across all ages, attention needs to be given to elderly care because they suffer from multiple diseases, and their number is increasing in the state. Such attention can be given by first strengthening the implementation of various components under the National Program for Healthcare of Elderly (NPHCE). Further, there is a need for greater involvement of ASHAs, ANMs, and MLHPs to provide home-based care to the elderly and individuals with disabilities.

5. Strong Monitoring and Supportive Supervision Mechanism:

There is a need for strong monitoring and supportive supervision mechanism to implement any programs or policy effectively. Healthcare providers also need to be supported on-site regarding translating policies into practice. Findings from the study suggested poor monitoring and supportive supervision at all levels of health facilities. Therefore, there is a need for regular monitoring and evaluation of healthcare providers’ skills to ensure they can deliver what the Meghalaya Health Policy 2021 envisioned.

6. Addressing Social Determinants of Health:

The present study shows that most women belong to the low-income group, have a low level of education, and are mostly engaged in the informal sector. Such conditions make their lives difficult as they also have to deal with poverty and illnesses. This poses major challenges for them. Similarly, widows and women abandoned by their husbands face difficulties because they are left alone to care for their children. Another group of women who suffer great responsibilities in Meghalaya’s matrilineal society is the youngest daughter, who must care for their parents and children.

Identifying these groups of women suffering from multiple levels of oppression by ASHAs or the Village Health Councils is needed. Accordingly, action must be taken to provide them with the benefits of existing social welfare schemes. The state can address this problem by working together with other departments of the government, such as the social welfare department, to provide welfare services to them.

Apart from the above, the poorest districts of Meghalaya should be identified, and funds should be allocated to such districts. As we know, around one-third of the population in Meghalaya is living below the poverty line, so there is a greater need to enhance fund allocation

to reduce poverty in Meghalaya (Nayak & Thomas, 2007). But while increasing fund allocation, greater weightage needs to be given to the poorest districts (ibid). In addition to reducing poverty through fund allocation, there should also be coordinated efforts to increase the literacy rate in the state by ensuring that every child gets the right to education.

Reducing poverty and ensuring universal education should go hand in hand with improving the health of the citizens of the state. In the last few years, a renewed political will and commitment has become visible with respect to improving the population's health status in the state. This can be seen from the number of initiatives undertaken by the Government of Meghalaya, from formulating the state health policy to the implementation of the various projects aimed at improving the state health capacities. It is envisioned that through these efforts, health care is made available for all and reaches out to the most vulnerable social groups in the community.

7. Community Participation:

Some experts argue that civilians do not participate in policymaking in Meghalaya. They do not have that capacity or are yet to evolve in gaining the skills and knowledge to get involved with the government (Oosterhoff et al., 2021). However, the enabling dimension of Meghalaya Health Policy 2021 addresses this scepticism by providing for social audits. It underlines that for effective implementation of national health programs and effective delivery of healthcare services, there needs to be greater involvement from the public such as NGOs or CSOs. However, the study finds that community participation in health promotion, including NCD prevention, is very low. My interactions with village headmen revealed that most were unaware of the NCD prevention and control program.

Collaboration with the traditional governance structure is one of the measures adopted by the Government of Meghalaya to implement CPHC successfully (GoM, 2022). As part of the SCEP, Meghalaya has also developed a “unique concept”- the creation of Village Health Councils (VHCs). VHCs are formed at the local level to encourage community participation (Kumar & Bhargava, 2023).⁸⁵ To address gender inequality, women are also made representatives at the VHCs. The village headmen, as leaders and members of the community, usually work with other members of the village councils for the welfare of the village. For instance, village members volunteered and worked together to prevent and control COVID-19

⁸⁵ Available at <https://www.weforum.org/agenda/2023/03/integrated-approach-meghalaya-universal-health-coverage-india/> accessed on 22nd July 2023.

transmission. By sharing information about the importance of health promotion through village leaders and engaging community members in health promotion activities, it is anticipated that the community as a whole can come together to promote the health of people in their villages. The main function of the VHCs is to identify the gaps and needs of the community and to make the public health system accountable for delivering healthcare services. The all-women community-based groups known as Self-Help Groups (SHGs) are also part of VHCs.⁸⁶ The implementation of VHCs is still in its initial stage. Therefore, it will require some time to understand its contribution to strengthening the public health system at the grassroots level.

All these efforts that the Government of Meghalaya has envisioned will contribute to achieving the global target of reducing overall mortality from cardiovascular diseases, cancer, diabetes, or chronic respiratory diseases to over 25 percent by 2025 (WHO, 2018; GoM, 2021). This global target is envisioned in the WHO Global NCD Action Plan (WHO, 2018).

9.2.2 Scope for Further Research:

It is important to reiterate that the increased burden of NCDs among tribal populations needs further exploration. The present qualitative study only focuses on diabetes and the challenges faced by tribal women in seeking treatment. However, there is greater scope for exploring the experiences of the tribal population with other NCDs, such as hypertension, cardiovascular disease, and cancer. The last is particularly relevant as Meghalaya is currently witnessing increased cases and burdens of cancer. Preliminary findings from the study also suggested poor health-seeking behavior among men. Therefore, it is important to understand the reasons for poor health-seeking through further research. Gender analysis of NCDs mortality and morbidity due to NCDs within the sociocultural context of Meghalaya is important in formulating gender-sensitive health interventions and programs.

9.3 Conclusions:

This is the first qualitative study conducted to understand the lived experiences of women living with diabetes in Meghalaya's matrilineal society, especially during the COVID-19 pandemic. The present study voiced the challenges faced by the most deprived section of the population of the state, which in this case are – the poor tribal women living in rural and remote areas of Meghalaya. This study attempts to bring to the forefront the voices of the unheard and invisible women by highlighting their concerns and health problems specific to

⁸⁶ Same as footnote number 84

the context. It also reveals the difficulties faced by Pnar women during the COVID-19 pandemic and how the lockdown exacerbated their vulnerabilities. The narratives discussed in various chapters highlight women's suffering, far from the reach of mainstream research. The study also discussed the cultural beliefs and practices related to diabetes behaviors among Pnar women. As the Pnars constitute the major proportion of the population in West Jaintia Hills, and their culture is like that of the other tribes and the Khasi, the study broadly represents the culture of people living in Meghalaya. The occurrence of diabetes varies across socio-economic and cultural contexts. Therefore, the present study provides insight to policymakers and health planners in tailoring prevention and control strategies specifically to the people of Meghalaya, particularly the vulnerable sections of the state.

The burden due to NCDs has been acknowledged in the state through the Meghalaya Health Policy 2021. The focus of the health system at the primary level should now encompass services related to chronic diseases. The implementation of the NPCDCS program is a positive step in diabetes management at the community level through its efforts of early detection, referral, and treatment. Nevertheless, as discussed in the present study, the implementation of population-based screening at the community level is accompanied by many challenges. Therefore, addressing these challenges is paramount for successful implementation in rural areas. The increased burden of NCDs, coupled with other persistent health problems such as increased maternal and child deaths, is a major challenge for the state due to shortages of human resources and weakened health system capacity. Like any other tribal-dominated region, Meghalaya suffers from a triple disease burden that needs immediate attention. Although the health policy and guidelines are now in place, they must get translated into practice in the field. The study shows the limited attention given to the NCD prevention and control program in the state. It also became clear from the study that even health workers and medical doctors have a poor understanding of diabetes in remote tribal areas of the district. The notion that “people in villages do not suffer from diabetes” has led to a neglect in providing preventive and curative health services to people in rural areas. This is evident from the present study, where people had limited knowledge about the signs, symptoms, and complications of diabetes. The healthcare providers and the community need to be sensitized about the disease burden that Meghalaya is experiencing and accordingly work towards ensuring treatment for everyone in the community.

My study suggests the need to design healthcare services that address the growing

burden of chronic and NCDs among tribal populations. Effective strategies to ensure timely and appropriate management of diabetes require extensive collaboration between health facilities to ensure access to diagnostic tests and medicines (Venkataraman et al., 2009:107). Health professionals must be well-trained to provide quality care for diabetes (ibid). The challenges posed by diabetes can be addressed by strengthening the health system and having standard treatment protocols at all levels of health facilities. Diabetes management protocols should be accepted nationally, together with a “regulatory framework” for measures to address the diabetes burden (Venkataraman et al., 2009:107). Strengthening the health system is vital to enhance the utilization of NCD services. The health system can be strengthened by improving the quality of services, making healthcare accessible, generating awareness about NCD services in the community, and engaging frontline health workers such as the ASHAs to provide health education, awareness, and follow-up (Bhagyalakshmi & Kodali, 2019). ASHAs, who act as a bridge between the community and the health system, can be crucial in delivering NCD services to the community and need to be adequately compensated and also be regularised (ibid).

Findings from my study highlights the challenges faced by women living with diabetes in villages of Meghalaya dominated by tribal populations. Women have to travel to nearby towns and cities, thereby incurring huge out-of-pocket expenditures, especially during the COVID-19 pandemic, on the transportation and purchase of medicines. The difficulty in accessing healthcare services, especially among poor people living with diabetes in rural areas, was further exaggerated by the COVID-19 pandemic lockdown. The lack of medicine and diagnostic tests is an inherent problem in public health centers, but the supply of antidiabetic drugs was further disrupted during the lockdown. The suggestion commonly made and adopted in times of crisis, such as the COVID-19 pandemic, is the increased use of telemedicine in reaching out to the community. However, for people in rural areas, teleconsultation through smart devices is just a myth, especially for those who are economically weak as they cannot afford to buy a smartphone. Implementing telemedicine in rural and remote villages is challenging due to poor networks and an irregular electricity supply. Therefore, innovative technology that addresses these challenges is needed in healthcare research. This will enable equitable access to healthcare services during a crisis.

Further, strategies beyond telemedicine should be devised in times of crisis. Frontline workers need to be trained and sensitized regarding the health needs of the people. They should

be able to support the most marginalized section of the population deprived of basic health care services. Public health facilities must be equipped to provide care for chronic illnesses and make them more resilient during a crisis. Moreover, smooth implementation of HWCs should be ensured in rural and remote areas. Infrastructure strengthening is thus crucial to provide comprehensive diabetes care within the district hospital, thereby avoiding referral to Shillong, located more than 65 km from the hospital. Although some effort has been initiated to manage complications related to the kidney, such as establishing the Dialysis unit under the NHM, the absence of a specialist still raises the question of who will manage the case.

Gender is another determinant of health inequality. In the present study, most respondents were women, indicating that women suffer more from chronic morbidity such as diabetes. The Pnar tribe is known to practice matrilineal culture where children take the mother's clan name, and the youngest daughter is the heir of the family property, mainly ancestral property (Gassah, 1994). Therefore, the mother is solely responsible for caring for the children (Nongbri, 2008). In this situation, managing a demanding illness like diabetes is very challenging. Women in the present study reported sacrificing their health at the cost of their children's food and education, which is not different from women living with diabetes in a patrilineal society (Weaver, 2018). During the pandemic, women struggled for jobs, increasing their mental and physical stress (War & Kharkongor, 2021). These factors, which health professionals overlook, need adequate attention through other welfare programs to ease the burden of women in Meghalaya's matrilineal society. As envisioned in Meghalaya's CPHC guidelines, there is a need to reach out to the most vulnerable population groups, especially elderly women, widows, single mothers, and women suffering from disabilities. The intersection of their education and occupation further exaggerated their vulnerability. Their healthcare needs must be prioritized to ensure universal health care and health equity. Meghalaya's Health Policy 2021 rightly states that "serving the poorest is an act of compassion and justice, and also fulfills the constitutional principle of equity" (GoM, 2022:51). Thus, there is a need to strive for provisioning of comprehensive and inclusive healthcare for the people in Meghalaya in order to ensure that no one is left behind in the enjoyment of highest standard of health.

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LIST OF ANNEXURES:

Annexure 1 Health Indicators of Meghalaya according to National Family Health Surveys

Health Indicators	NFHS-1 (1992-1993)	NFHS-2 (1998-1999)	NFHS-3 (2005-2006)	NFHS-4 (2015-16)	NFHS-5 (2019-21)
Percentage of women aged 20-24 who married before age 18 years	28.1	25.5	24.5	16.9	16.9
Percentage of men aged 25-29 who married before age of 21 years	-	-	27.1	13.6	17.9
Total Fertility rate (Children per woman)	3.73	4.57	3.80	3.0	2.9
Percentage of unmet needs for Family Planning services	25.1	35.5	35.1	21.2	26.9
Percentage of unmet needs for spacing of births	20.6	23.4	23.2	15.3	18.3
Percentage of unmet needs for limiting children	4.6	12.1	11.9	-	-
Percentage of pregnant mothers who had at least 3 Antenatal visit	41.4	32.0	53.4	50.0*	52.2
Percentage of births assisted by Doctors/Nurses/LHV/ANM/other health personnel	37.9	20.6	31.7	53.8	64.0
Percentage of Institutional Births	31.0	17.3	29.7	51.4	58.1
Percentage of mothers who received post-natal care from doctors/Nurses/LHV/ ANM/other health personnel	-	-	28.8	47.5^	43.9
Percentage of Children 12-23 months fully immunized	9.7	14.3	32.8	61.4	63.8
Percentage of children age 9-59 months who received a vitamin A dose in the 6 months preceding the survey	-	-	19.9	57.8 ^s	61.0
Percentage of children with diarrhea in the 2 weeks preceding the survey who received ORS	41.5	22.4	67.7	77.4	73.2
Percentage of children with diarrhoea in the 2 weeks preceding the survey who were taken to a health facility	68.3	44.1	76.6	69.9	69.2
Percentage of children with ARI or fever in the 2 weeks preceding the survey taken to a health facility	-	-	51.6	74.9	72.9
Percentage of children under 3 years who were breastfed within one hour of birth	8.6	26.7	58.6	60.6	78.8
Percentage of Children 0-5 months exclusively breastfed	-	-	26.3	35.5	42.7
Percentage of children 6-9 months receiving solid or semi-solid foods and breast milk	-	-	76.3	67.4**	66.8

Percentage of children under 3 years who are stunted	47.1	44.9	41.7	43.8 ⁺	46.5
Percentage of children under 3 years who are wasted	17.8	13.3	28.2	15.3	12.1
Percentage of children under 3 years who are underweight	44.4	37.9	46.3	28.9	26.6
Percentage of children 6 - 35 months who are anemic	-	67.6	68.7	48.0	45.1
Infant Mortality Rate (IMR)	64	89	45	30	32.3
Percentage of ever-married women aged 15-49 who are anemic	-	63.3	45.4	56.4 ^{^^}	54.4
Percentage of pregnant women aged 15-49 who are anaemic	-	58.6	56.1	53.3	45.0
Percentage of ever-married men aged 15-49 who are anaemic	-	-	34.2	32.4 ^{***}	25.5
Percentage of ever-married women aged 15-49 whose body mass index is below normal	-	25.8	13.7	12.1	10.8
Percentage of ever-married men age 15-49 whose body mass is below normal	-	-	8.0	11.6	9.0
Percentage of ever-married women age 15-49 who are overweight and obese	-	5.8	7.1	12.2	11.5
Percentage of ever-married men age 15-49 who are overweight and obese	-	-	8.2	10.1	13.9
Percentage of currently married women who usually participate in household decisions	-	-	83.4	91.4	92.3
Percentage of women aged 15-49 who have heard of AIDS	26.7	44.2	56.8	13.3	14.5
Percentage of men aged 15-49 who have heard of AIDS	-	-	62.6	14.1	15.9
Percentage of women aged 15-49 who know that consistent use of condom reduces the chances of getting HIV/AIDS	-	-	24.1	47.0	54.1
Percentage of men aged 15-49 who know that consistent use of condom reduces the chances of getting HIV/AIDS	-	-	49.0	52.1	67.5

Source: NFHS reports various rounds

- *In NFHS-4, the number of visits has increased to 4.
- ^ The definition was modified in NFHS-4 as Mothers who received postnatal care from doctor/nurse/LHV/ANM/midwife/other health personnel within 2 days of delivery.
- **In NFHS-4, the specified age was 6-8 months
- ^^ The term non-pregnant women was used in NFHS-4
- ***the term ever married was deleted in NFHS-4
- \$ In NFHS 5, Children's age is reduced to 9-35 months
- + In NFHS 4 & 5, children's age is increased to five years



Annexure 2 List of villages visited in West Jaintia Hills District for fieldwork

Name of villages	No. of respondents
1. Nartiang	9
2. Kpermynsnieh	2
3. Mynsgad	2
4. Ionglwit	4
5. Lumtrep	3
6. Iongthma	2
7. Khliehchnong	1
8. Rakabah	4
9. Umladang	2
10. Takhniang	4
11. Mynkrem	2
12. Bambthong	1
13. Khliehriat	1
14. Madansynrang	1
15. Nonglatem	1
16. Ummulong	4
17. Wahiajer	7
18. Mookyndur	3
19. Moodymmmai	9
20. Tyrshang	1
Total	62

Annexure 3: Semi-structured interview guide for different category of healthcare professionals and traditional tribal healers

Annexure 3. 1: Semi-structured interview guide for the Officials at the State Health Directorate

Introduction-

- Name:
- Designation:
- Age:
- Sex:
- Marital Status:
- Religion:
- Educational Qualification:
- Years of working/joined work in:

Work Related Information:

- Year of working/joined work in:
- Name of the Place of work:
- What are your major work responsibilities as a-----

District Health Profile and NCD Related	1. What are the major health problems/diseases in the state? 2. What do you think about the prevalence of NCDs in the State? 3. Since when has the prevalence of NCDs increased in the state and why it has increased? 4. What is the level of prevalence of different NCDs in the district? What are the different initiatives undertaken by the district to address the NCDs. 5. What do you think are the risk factors that has led to the rise in prevalence of NCDs in the state? 6. Do you think certain dietary patterns in our community are the risk factors for the disease-hint at tobacco consumption, rice, salts and other food items that you may think 7. Can you discuss about the MHIS scheme and how it has helped the patients with NCDs in particular those suffering with diabetes?
NPCDCS Programme Related:	8. When was the NPCDCS program implemented in the state? 9. What are the major activities undertaken as a part of the programme in the district? 10. How do you prioritize and select the district for the implementation of the NPCDCS program? 11. In what ways NHM has contributed in strengthening the implementation of the programme at the state and district levels. 12. What are the efforts undertaken at the State level to prevent and control the burden of NCDs? 13. In what ways community participation and engagement with the community is undertaken with respect to the implementation of the programme. 14. What are the efforts being undertaken in order to generate awareness about NCDs in the state at the community level? 15. What is the pattern of health care utilization for NCDs-where do people prefer to seek the treatment and services for NCDs and why? 16. How is the procurement of equipment, drug and logistics carried out at the district level with respect to the programme? 17. Who has the authority to decide the different drugs that need to be procured for NCDs? What are the different drugs provided to be people as the part of the programme? 18. Can you please explain me how is the NPCDCS program financed? 19. How do you monitor and supervise field level activities? 20. What are the challenges in the implementation of the program in the State and the districts? 21. How do you see the program in the long run? 22. Is there any collaboration with the private organization/development agencies and international funding organizations to strengthen the functioning of the program?
Human Resources in Health and NCDs	23. Can you explain me the process of how is the recruitment of NCD staff being carried out? 24. What are the key challenges/barriers faced by the health workers in the implementation of the programme at the state and district levels? 25. How often the NHM staff is trained with respect to the implementation of the programme at the state and district levels?

	26. How do you ensure the motivation of the staff and workers in the implementation of the program during the pandemic? 27. What do you think about the high turn-over of staff? Is there a policy plan to address the same?
NCDs and Traditional Healers in Meghalaya	28. What do you think of the traditional healers providing treatment for NCDs in the state? 29. What do you think is the extent of utilization of traditional medicine for NCDs by the people in the State? 30. Is traditional medicine supported by the State as an alternative treatment method for NCDs? 31. Do you think there needs to be regulation for traditional healers?
COVID-19 pandemic and NCDs	32. In what ways COVID-19 pandemic impacted the functioning of the NCD programme from 2020 till 2022? 33. What are some of the measures undertaken post pandemic to strengthen the health service delivery with respect to NCDs in particular? 34. How do you see the role of the Health and Wellness in providing comprehensive health services particularly for NCDs? 35. What are some of the main problems you have encountered in the implementation of the program in the state? 36. Are there any other information that you think is important and would like to share? 37. Can you suggest me any other official who can share other information which you considered important for my study?

Annexure 3. 2: Semi-structured interview guide for the Health Officials at the State Nodal Agency, MHIS and District Program Management Unit, MHIS

Introduction- • Name: • Designation: • Age: • Sex: • Marital Status: • Religion: • Educational Qualification: • Training (s) received: • Years of working/joined work in: • Name of the hospital:	
General information about the scheme	1. What are the objectives/vision of the scheme? 2. Can you please share when and how was the MHIS/ (later merged with Ayushman Bharat in 2018) began in the State? 3. How was this transition made with respect to the population groups covered under the AB-PMJAY scheme? What were the main problems encountered in this? 4. Do everyone who had MHIS card were covered under the Ayushman Bharat-PMJAY scheme?

	5. Can you please explain in detail the various actors/institutions involved in the implementation of the scheme at the state and district level? 6. How is the scheme financed? What is the state-centre ratio for financing? 7. How many hospitals (public/private) are empanelled with the MHIS? Can you give me a list of the different hospital empanelled?
Functioning and implementation of the scheme	
Registration	8. How is the registration and the enrolment process for MHIS carried out? Please explain how the process of registration of patients is undertaken at the hospital? 9. What all documents are needed for issuing of the card and at the time of admissions? 10. What are the documents required for being eligible to be covered under the scheme? How long this process takes? 11. How many members of a family are covered under the scheme? 12. How long is the card valid-one year or two years? 13. People often forget to carry the card while they visit the hospital. How is this problem resolved while admitting the patient? 14. What are the main challenges faced in the ensuring proper registration of the people eligible under the scheme?
Services under the MHIS/AB-PMJAY	15. What are the expanded range of services provided under the AB-PMJAY scheme or what are the different package of services covered under the scheme? 16. How do you think the MHIS helping people living with NCDs, as there is a general perception that the scheme has enabled seek specialised curative services? 17. How does referral and hospitalisation done in case a patient is eligible for care under the scheme? 18. Is it only for hospitalisation or outpatient care-routine OPD is also covered? 19. With respect to diabetes care what are the major complications for which services were being provided under the AB scheme?
Reimbursement process	20. What is the process of claiming the reimbursement by patients in case patients paid money for seeking treatment? 21. Is the services provided completely cashless or do the patients have to deposit some money while discharging from the hospital? 22. In case of reimbursement to the patients in certain cases how much time does it, take for reimbursement of the bills? 23. Do patients need to have bank account number for claiming reimbursement? What happens if they do not have bank account? 24. Do they have to submit all the bills for reimbursements? 25. What about transportation charges and some diagnostics/pathological investigations made in private health sector facilities or medicine purchased outside the hospitals (if any)? 26. Is there a uniform protocol of reimbursement set by the State for all hospitals? 27. Do you maintain a disease wise record for reimbursement made? Is there a separate information for diabetes?

Monitoring and Supervision	28. How do you monitor the functioning of the scheme at the field level? 29. Is there a grievance and complaint mechanism for people utilizing the MHIS card? 30. How do you address those grievances and complaints that people have with respect to the implementation of the scheme? 31. Can you discuss in detail some of the main challenges in the implementation of the MHIS/AB scheme?

Annexure 3. 3 Semi-structured interview guide for the District Health Officials

Name of the person: Designation & Place of work: Age: Religion: Educational Qualification: Year of working/joined work in:	
1. When was the DM&HO set-up? what was its objective? Organogram of the organization 2. Can you please share the population enumeration of the district? 3. Who are the different types of health care providers in the district? 4. What is the structure of the district health system? Number of health facilities 5. What is the relationship of other health care providers with the public health service? 6. What is the district epidemiology, health status, health services, financial protection situation related to illness? 7. What are the programs implemented in the district? 8. When was the NHM implemented in the district? 9. How is NHM function together with the NPCDCS? 10. How do you see the functioning of the HWCs under AB?	

Annexure 3. 4 Semi-structured interview guide for the Finance-cum-Logistic Consultant of National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS)

Name of the person: Designation & Place of work: Age: Religion: Educational Qualification: Year of working/joined work in:	
General Questions	1. Can you tell me about the NPCDCS programme and your responsibilities in this programme? 2. Since when was the program implemented in the district? 3. When was the Population Based Screening started in the district? 4. When was the District NCD cell established? What are its functions? 5. How are the administrative works carried out? What are the administrative challenges faced? What are the measures taken to address it?
Human Resources for Health	6. Organogram of the cell with functions/Human Resource available-roles and responsibilities? 7. Any training received by the officials at the district NCD cell? What is the recruitment procedure? Any HR policy?

	8. How are opportunities for training being provided for staff working at the NCD clinic and also in the PHCs/SCs/HWCs including the ASHAs? Is there a plan for this? 9. How are the salaries of the staff for the program paid? 10. What are the Human Resource challenges face by the program? What are the measures taken to address it?
Infrastructure, Diagnostics and Medicines for the program	11. How many facilities have NCD clinic in the district? 12. How many PHCs/SCs/ HWCs conduct the Population Based Screening for NCDs? 13. Are equipment available in sufficient quantity for screening? Is there a challenge in availing the equipment? 14. Are NCD medicines supplies from the District NCD cell? Is there any challenge in supply of medicine? 15. Is there sufficient quantity of Information Education Communication materials available in the NCD cell? 16. Are there any logistics and financial impediments in implementation of the program? 17. Do you have any published reports
Financing	18. How is the program financed? 19. How do you coordinate with the NHM official regarding financing for the program? 20. Is there a delay in receiving the funds? What are the measures undertaken in case of delay? 21. What has been the contribution of the state government when it comes to funding?
Outreach Activities	22. How often are screening camps conducted by the health facilities? 23. Are there any community initiative undertaken within the district working along with the program? 24. How do you involve the community in this program?
Health Management Information Systems	25. Which Information Systems do you used for collating the NCD related data? 26. How are the data collected? How often do you receive data from the health facility? 27. Are the private health facilities also submitting data to the cell? 28. Where and when do you submit the data from the district NCD cell? How do you submit the data? 29. Are there any challenges in getting the data from the public health facilities? 30. What are the challenges faced in implementation of the program? What are the measures taken to address it? 31. In the context of COVID19 pandemic, did you experience any disruptions in any of the aspect related to the implementation of the program? 32. What are the disruptions you faced that hinders the smooth implementation of the program?

Annexure 3.5 Semi-structured interview guide for Medical Officers/Ayurvedic Physicians/Medicine Specialists

Introduction-

- Name:

• Designation: • Age: • Sex: • Marital Status: • Religion: • Educational Qualification: • Training (s) received: • Years of working/joined work in: • Name of the hospital:	
Prevalence and risk factors of NCDs in the State	1. Can you please share what are the common Non-Communicable Diseases (NCDs) in the State? Since when does the prevalence of diabetes (type-II) started rising in the state? 2. Can you please share, patients who are coming to your hospital to seek treatment for diabetes largely belong to which part of the district? 3. In your opinion, what are the reasons for the rise in the prevalence of NCDs, especially diabetes in the State? Are the reasons different for rural and urban areas? 4. Is there a gender difference in the prevalence of NCDs in general and diabetes (type-2) in particular? 5. Can you please share if the risk factors of diabetes for men and women same? 6. Do women previously diagnosed with gestational diabetes mellitus come and present with type-2 diabetes? What is the extent of such problem?
Treatment services related to diabetes	7. Could you please share your experience of treating people living with diabetes in terms of availability of testing facilities, access to medicines, ability of patients to afford etc.? 8. In case a patient visits the hospital with suspected diabetes, what is the usual protocol followed for diagnosis? Is there any change in diagnostic technology used for diabetes, say since the 1990s? 9. How are doctor-patient relationships built up? How do doctors know about past treatment given by them? 10. Can you please share if there is a gender differences in patient outcomes, complications and compliance to medicine, diet, exercise and follow-up? What could be the reasons for the same? 11. Do you refer complicated cases of diabetes? Is there a formal referral mechanism between the hospital and referral sites? 12. What are the barriers you face in providing services for diabetes during the COVID19 pandemic lockdown? 13. Do you think the diabetes care being provided by the hospital needs improvement? 14. In what ways PMJAY (MHIS) is helping patients with diabetes complications admitted to the hospital, access medical care? Is there any mechanism in the hospital where patients from BPL can access free diabetes care? 15. At the hospital, how do you maintain records of NCDs patients? Is there any Health Management Information System (HMIS) software used?

	16. Can you please share how much does a patients diagnosed with diabetes spent tentatively for treatment per month? 17. Are screening camps related to NCDs being organized by the hospital? How often and what is the response from the people in the community? 18. Is there any intervention undertaken by Churches or any NGOs in prevention and control of diabetes?
Perception regarding management of diabetes	19. In your opinion what could be the barriers among patients to self-management of diabetes? 20. Do you think the costs of diabetes care affects the access and utilisation of health services by people? 21. Can you please share your opinion on utilisation of traditional medicine for diabetes by patients? 22. Do you think matrilineal culture in Meghalaya influence self-management of diabetes? Can you please share how?

Annexure 3. 6 Semi-structured interview guides for Staff Nurses at the District Hospital and PHC

• Name: • Designation: • Age: • Sex: • Marital Status: • Religion: • Educational Qualification: • Training (s) received: • Years of working/joined work in: • Name of the hospital:	
General	1. What are your roles and responsibilities in the NCD clinic? 2. How do patients who seek treatment for NCD get registered? 3. Describe the flow of who are coming to the hospital to seek treatment for NCDs from entry to exit both as outpatients and inpatients. 4. Do you conduct the screening program in the community as well? 5. How is coordination achieved between different functions like laboratory, pharmacy, and physiotherapy so that patient has a comfort and ease of seeking care? 6. Have you received any training regarding NCDs? If no, is there any plan for it? 7. Do you face any challenges in carrying out the assigned roles and responsibilities?
Perception about NCDs	8. Do you think that the prevalence of NCDs has increased? 9. What do you think is the reason for its increase? 10. Based on your experience, the prevalence of NCDs and diabetes in particular is more common among male or female? 11. Is there any gender difference in compliance to treatment? 12. What might be the challenges faced by the patients living with NCDs and particular diabetes during the lockdown period?

Annexure 3.7 Semi-structured interview guide for Laboratory technician at the District Hospital and the PHC

• Name: • Designation: • Age: • Sex: • Marital Status: • Religion: • Educational Qualification: • Training (s) received: • Years of working/joined work in: • Name of the hospital:
1. How are diagnostics organized for diabetes and other related diagnostic tests? 2. What is the range of diagnostics used for diabetes and the cost of each? 3. Are outside arrangements for tests formalized/contracted? 4. What are the challenges you faced in carrying out the diagnostic tests for diabetes?

Annexure 3.8: Semi-structured interview guide for the Data Entry Operators at the District NCD cell and the District Hospital

Name of the person: Designation & Place of work: Age: Religion: Educational Qualification: Year of working/joined work in:
1. What are your roles and responsibilities? 2. How do you collect the data for NCDs? 3. How do you do the reporting? 4. Can you please provide me the data on the total number of NCDs patients? 5. What are the challenges you faced in reporting under the program?

Annexure 3.9 Semi-structured interview guide for the Pharmacists at the District Hospital and the PHC

Name of the person: Designation & Place of work: Age: Religion: Educational Qualification: Year of working/joined work in:
1. Do you dispense drug for NCDs? If yes, who supplied the NCDs drugs? 2. Do patients have to pay for drugs purchased in the in-hospital pharmacies? 3. Is there any subsidy allowed or any free drugs? 4. Any problems in getting adequate NCDs drugs? If not, what do you do?

Annexure 3. 10 Semi-structured interview guides for Senior Medical and Health Officers In-charge PHC and CHC

• Name [will be kept confidential]: • Designation: • Age: • Sex: • Marital Status: • Religion: • Educational Qualification: • Training (s) received: • Years of working/joined work in: • Name of the hospital:	
General Questions	1. When was the PHC upgraded to HWC? 2. What are the services being provided in the HWC/PHC? 3. When was the NPCDCS program implemented in the HWC/PHC? 4. Has the Population Based Screening Program started in your PHC/HWC and in the Sub centers under it?
Screening, Prevention and Treatment services for NCDs	5. Can you please describe how is the NCD screening program carried out in your PHC/HWC? 6. What are the preventive services given related to NCDs at the PHC/HWC? 7. What are the NCDs treated at the PHC/HWC? 8. How is diabetes diagnosed and treated at the PHC/HWC? 9. Is there any provision for teleconsultation or telemedicine with the higher public health facility? 10. If a patient with NCDs comes again and again- does he get to see the same doctors- Can he asks for it- how are doctor- patient relationships built up., how do doctors know about past treatment given by them?
Continuity of Care: The Referral Chain	11. Does the HWCs under the PHC/HWC referred the suspected NCDs cases here? 12. What are the NCDs you commonly referred from the PHC/HWC? 13. Is there a formal referral mechanism? 14. Is there an MOU or some informal understanding between primary and referral sites? is there any preference or advantage to those who come in by referral? 15. Is there feedback from referral site and provider to primary care provider? 16. What are the challenges you faced in ensuring that patients diagnosed with NCDs get continued health care services?
Human Resources for Health	17. Is there a separate Human Resource under the program for PHC/HWC? 18. How many MBBS doctors do you have? What is doctor- to patient ratio 19. How has the facility attracted the staff to work in rural areas? How are they retained here? 20. What are the special features of the remuneration package? 21. Is there a high turn-over? How is this addressed? 22. Have you been provided training for population-based screening for NCD program? Is there any orientation given to all the staff regarding the screening? 23. What are the HR challenges which the facility is facing? Measures taken to address it. Any HR policy?

Annexure 3.11 Semi-structured interview guide for the Accountant at the PHC

• Name: • Designation: • Age: • Sex: • Marital Status: • Religion: • Educational Qualification: • Training (s) received: • Years of working/joined work in: • Name of the hospital:	
Financing	1. What are the sources of financing for the HWC and NPCDCS program? 2. What are the sources of revenue- and how is revenue earnings sought to be maximized? 3. How much is the registration fees charged? 4. Is there any user charge for services utilized by patients?
Resource Allocation	5. Are there any incentives paid for the staff under the HWC and NPCDCS program? 6. Who all are paid for the incentives? How much are they paid? 7. What is the protocol followed for payment of incentive?

Annexure 3. 12 Semi-structured interview guide for the ANMs at the HWCs

• Name: • Designation: • Age: • Sex: • Marital Status: • Religion: • Educational Qualification: • Training (s) received: • Years of working/joined work in: • Name of the hospital:	
General	1. What is the total population served by the HWCs? 2. How many villages are there in under your HWCs? 3. How many ASHAs are there? 4. What are the services provided at the HWCs? 5. What is the status of manpower at the HWCs? 6. How often do you conduct outreach services? What are the services provided during the outreach program? 7. Have you been trained to conduct the population-based screening program? What are the contents of the training? 8. What are your roles and responsibilities related to the program?
NCDs Prevention	9. Do you provide any services related to the prevention of NCDs? 10. Is there any IEC material given to you? If yes, in which language, can you please show me? 11. Have you created awareness in the community about the program? 12. What are the forms of activities you did as part of creating awareness in the community regarding prevention of NCDs?

	13. Do you find any gender difference in utilizing the NCD services provided at the HWC?
Screening	14. Have you started with the population-based screening program? 15. Can you please explain how does the screening process initiated? 16. How do you conduct the program? 17. How many individuals have you screened till date? 18. What are the challenges you faced in conducting the population-based screening program?
Referral	19. What is the procedure follow for referring patients? 20. Where do you usually refer patients with high blood pressure and blood sugar? 21. Do patients come back for follow-up at the HWC?
Record and Report	22. How do you maintain the NCDs related record and report? 23. Where and how often do you submit the NCDs related report? 24. Is there any software used?
Incentives	25. Are you being provided with incentives under the program? 26. If yes, for what activities? 27. How much and is the procedure followed for payment of incentive?

Annexure 3. 13 Semi-structured interview guide for the Mid-Level Health Care Providers at the HWCs

• Name: • Designation: • Age: • Sex: • Marital Status: • Religion: • Educational Qualification: • Training (s) received: • Years of working/joined work in: • Name of the hospital:	
General	1. What are your roles and responsibilities? 2. What are the services do you provide under the HWC program? 3. How is coordination achieved with the ANMs and the ASHAs? 4. What do you think about the program? Is it going forward? If not what are the challenges in implementation of the program- both the HWC and the NPCDCS?
NCDs Prevention	5. How do you organize awareness program at the HWC and at the community? 6. What are the activities in which you do as part of prevention of NCDs in the community? 7. Is there any other organization in which you are working together in providing preventive services from the community?
Screening	8. Where do you usually organize the screening program? 9. What are the common NCDs screened by you? 10. What is the response from the community related to the screening program?

Treatment	11. Is there any provision for teleconsultation or telemedicine with the higher public health facility? 12. Do you find any gender difference in utilizing the NCD services provided at the HWC? If yes, what do you think is the reason for one gender to utilize the service but not the other? 13. What are the range of diseases you can prescribed medicine? 14. Do you get the supply of NCD drugs as well? How and from where do you indent the NCD drugs? 15. What are the challenges you faced in providing treatment and follow-up services for patients with hypertension and diabetes? 16. Is there any patients' group in the community?
Referral	17. Is there a formal mechanism for referring patients suspected with NCDs? 18. How are patients referred to the PHC? 19. Do patients comply to your advised for referral? If not, what are the problems in which they are facing in reaching the referred facilities?
Incentives	20. Are you being provided with incentives under the program? 21. If yes, for what activities? 22. How much and is the procedure followed for payment of incentive?
Record and Report	23. How do you maintain the NCDs related record and report? 24. Where and how often do you submit the NCDs related report? 25. Is there any software used?

Annexure 3. 14 Semi-structured interview guide for ASHAs

Name: Age: Religion: Working since/Years of working: Educational Qualifications: Village name: HWC/SC attached to: Total population of the village:	
General	1. What is the total population you served? 2. What are your roles and responsibilities related to the NPCDCS program? 3. What are the different activities you undertake with respect to NCDs 4. How much time do you allocate for work related to NCDs? 5. How often do you have to fill the CBAC form? 6. What are the major NCDs in your village? 7. How often do you conduct outreach service for NCDs? What are the services provided during the outreach program? 8. Have you been trained to conduct the population-based screening program? What are the contents of the training?
NCDs	9. Have you conducted the population enumeration for NCD screening? 10. What are the activities you carried you while conducting the population enumeration? 11. How do you increase awareness in the community about the program? 12. In what ways community participation is undertaken as a part for the NCD program.

	13. How do you create the awareness about health promotion and prevention of NCDs? 14. Have you mobilized the community for the screening? How do you mobilize the community for the screening? 15. How many individuals have you screened till date? 16. What are the challenges you faced in conducting the population enumeration? 17. How do you ensure that people living with NCDs in your community goes for follow-up? 18. How do you maintain the NCDs related record and report? Can you show? Do you have the early records of the patients who suffered from Diabetes? 19. From which year, have you collected information about NCDs from the community? 20. How many diabetes patients do you have in your village? 21. Have you come across any pregnant women suffering with gestational diabetes in your village, if yes can you share the details as I want to interview the women? 22. What do you think are the reasons for the increase in the diabetes in the community? 23. What kind of advice do you give to the patients diagnosed with diabetes 24. What are major dietary and life style changes the patients suffering with diabetes have to make? 25. What is the gender difference in the prevalence of diabetes in the community? 26. Where and how often do you submit the NCDs related report? 27. Were you explained the reasons for collecting the information? 28. Do you recollect any stories of COVID-19 times- when you might have helped diabetes patients in seeking timely medical help-be it screening, checking blood sugar, doing blood tests, providing drugs at home, regular Blood pressure monitoring, referral to higher facilities- 29. What were the main difficulties faced by people suffering from diabetes during the lockdown and throughout the pandemic period? 30. Covid-19 was deadly amongst patients with co-morbidity, did you witness any COVID-19 deaths in the community with diabetes as a c-morbidity. 31. What do you think are the risk factors for diabetes in your community? 32. What are the major challenges faced by you in delivering services for the NCDs and diabetes in particular?
Incentives	33. Have you been provided with incentives under the NPCDCS program? 34. If yes, for what activities? 35. How much are you paid as incentive

Annexure 3. 15 Semi-structured interview guide for dietitians at Private Hospitals

General Information:

- Name of the person:
- Designation:
- Age:
- Sex:
- Religion:
- Educational Qualification:
- Other professional qualification
- Year of working/joined work in:
- Is your job permanent or contractual?
- Total family members
- Marital Status:
- Children if any
- Monthly or Annual Income
- Name of the hospital:

Is this your first job, if not where all have you work as a Dietitian-
If worked in a public hospital, then how was the experience and what is the difference while working in private hospital.

Specific Information:

1. Can you explain me what are your main roles and responsibilities as a Dietitian?
2. How do you address the nutritional needs of patients with diabetes?
3. What are the dietary advises you gave particularly to patients with diabetes?
4. Is there any gender difference in complying to the dietary advised given by you?
5. Based on your experience what is the age and gender composition of the patients who comes to you are men or women?
6. While counselling patients with diabetes related to diet, how do you cope with the challenges posed by the patients or how do you negotiate with them? For instance, if they say they don't have the time to prepare cook as they are busy/cannot afford to buy and so on?
7. What advised do you usually gave to patients to prevent from hypoglycaemia?
8. In case patients have other problems such as hypertension, gastritis along with diabetes, how do you address their nutritional needs?
9. According to you what are the main socio-economic reasons for the increasing prevalence of diabetes in the state?
10. Based on your experience patients belonging to which socio-economic groups are able to follow and adhere to your advice?
11. Do you think that nutrition transition which we are undergoing is the sole reason for the rise in prevalence of diabetes? Can you identify some of the other factors at the state level which have resulted in the increasing prevalence in Meghalaya.
12. Do patients come to you and shared success story related to controlling their blood glucose level through diet?
13. How often do you provide dietary counselling for the same patient with diabetes?
14. How much do patient pays for each dietary counselling session?
15. What are the main challenges faced by you in performing your duties as a dietitian? This can be at the level of patients or at the level of institution. If you are free to answer
16. Do you think having a dietitian at the primary health facilities such as HWC and SCs is also very important.

Annexure 3. 16 Semi-structured interview guides for Traditional Tribal Healers

General Information:

Name
Sex
Age
Marital Status
Religion
Ethnicity
Educational qualification
Occupation (apart from being the traditional healer)
Income per month

General Questions

1. Since when did you started practicing traditional medicine?
2. Is there someone in your family who practiced traditional medicine earlier?
3. Do you have a permanent place for providing your service?

	4. Which are the other places you provide treatment? How do you decide where and when to go- weekly/daily- market/home? 5. How do patients come to know about your services? What measures do you take to 6. Who are the patients who regularly visit you- do which socio-economic background do you think they belong- e.g., age, gender, class, etc.? 7. Have you undergone any training? Who provided the training? Where was the training conducted? 8. How do update your skills and knowledge in treating people? 9. From where do you get the herbs for preparing medicine?
Perception about health and illness	10. According to you what does it mean to be healthy? 11. What according to you is illness? 12. What are the common illnesses do people in your community usually suffer from? 13. What do you think are the cause of these illnesses? 14. What are the ailments you usually provide treatment? 15. Do you maintain a record of treatment provided by you?
Knowledge and beliefs about Diabetes	16. Do you know about this disease called diabetes? 17. Can you please tell me what is it and what do you call it in local-term? 18. What do you think is the cause of diabetes? 19. Can you please tell me what are the symptoms of diabetes? 20. Do you think that the number of people living with diabetes is increasing in your village? Is diabetes a major disease in your community? 21. What do you think is the reason for the increase in the prevalence of diabetes in your village? 22. Do you think that diabetes can be prevented? What are the ways in which diabetes can be prevented? 23. Service provided for diabetes 24. In the last one year, how many patients with diabetes came to seek care from you? 25. How do you diagnosed and treat diabetes? How do you prescribe medicines orally or in written form? 26. Do you prepare medicine for treating diabetes by yourself? 27. When do you think patients usually come to you before or after seeking care from SC/PHC/CHC/private hospital? 28. Do you think regular follow-up is essential for people diagnosed with diabetes? 29. Have you seen any patients cured of diabetes as a result of the treatment given by you? Can you please share their contact details with me? 30. For how long do you think diabetes will last if a person suffers from it? 31. Could you please tell me what are the complications of diabetes? 32. Have you referred any diabetes patients to public health facilities in case the patient does not respond to the treatment provided by you? 33. How much do you charge for your service per visit? In what form do you usually receive the payment in cash or in kind? 34. In case the people do not have money or cannot afford to pay, what do you? Do you allow them to pay on instalment basis? 35. Do people from faraway places come to seek treatment from you?

Annexure 4 Semi-structured interview guide for respondents with diabetes

Name of the Block: Thadlaskein Name Village: Name of the locality: Socio-economic characteristic of respondent Name: Age: Sex: Religion: Ethnicity: Educational qualification: Occupation/Income per month: Marital Status: Type of family: Head of the household: No. of Children: Household size: Type of latrine used: Access to latrine: Major Source of drinking water: Management of garbage: Fuel used for cooking in the last 30 days: Accessibility to rations (colour of ration card): Types and amount of foods usually distributed by the PDS: Availability of mobile phone: Type of mobile phone used: Earning member of the family: Key decision maker in the house (for example in terms of where and when to go to the market):	
I. Health and Illness	1. Do you consider yourself to be healthy/own perception about current state of health? 2. Why do you think you are healthy? 3. What are the parameters you considered for a person to be healthy? 4. What is your understanding of illness? What do you think are the causes of illnesses? 5. What are the different types of illnesses or diseases which the people in your community suffer from? (to use local terms) 6. Do you know any long-term diseases? Can you please name them? 7. What do you think are the causes of these illnesses (social, cultural and medical explanation)?
Diabetes	8. Do you know about diabetes? How do you know about diabetes? 9. What is diabetes called locally? 10. Do you think that diabetes is an acute illness which lasts for short duration or is a long-term illness? 11. Do you have a family history of diabetes? If yes, who? 12. What was your age when you were diagnosed with diabetes? 13. Are you suffering from any other diseases? When were they diagnosed? Do you think that diabetes led to their occurrence? 14. What were the symptoms you experienced before you were advised to undergo the test? 15. Can you please explain in detail the entire process from the day you were first suspected with diabetes to the day the confirmatory test was made? 16. Where were you advised to undergo the test? How much do you pay for the test? 17. What happened after you got the report? To whom do you show it?

	18. Once confirmed that you are a diabetes patient, how do you feel? 19. Since the time of diagnosis do you think that your symptoms are predictable? do you think that the medicines you are taking help in reducing the symptoms of diabetes?
Gestational Diabetes	20. Were you diagnosed with diabetes during your pregnancy? If yes, in which year and for which child? 21. If yes, have you recovered from it after the delivery or do you think that now it is because of this that you are suffering from diabetes? 22. If not, is it because of gestational diabetes that you are still suffering from diabetes till now? 23. What were the tests advised to you? How and where do the doctor advised you to go for the tests? 24. Were you scared when the doctor told you that you are having gestational diabetes? How is it affecting you emotionally and mentally? 25. After knowing about the diagnosis, did you hide it from your in-laws and family members? If yes why? If no, why and what support did your in laws and family provide for you? 26. Is there anyone in your family who used to have gestational diabetes mellitus? 27. What were the precautions in which the doctor advised you to take? What changes did the doctor suggested during pregnancy because you were diagnosed with gestational diabetes mellitus? 28. How old is the child now? where did you deliver the child? Is the child male or female? 29. Did the child also suffer from diabetes now? 30. What were the extra care given to you by the health workers during delivery because of diabetes? 31. What were the medications given to you during your pregnancy? Could you please recall? 32. Do you think that the condition of gestational diabetes mellitus increased your treatment expenditure during pregnancy?

II. Utilization of Health Care Services	33. When do you usually seek care? 34. Who made the decision when and where to seek care? 35. How are those decisions made? What are your main concerns while making decision to seek care- (time, money, distance, etc.)? 36. Who accompany you when you seek care? 37. Who takes care of you when you are ill/sick? 38. Do you take care of other member of your family when they are sick? 39. What are the activities you usually do while taking care of them? 40. When you are sick who takes care of the household chores? 41. Is there anyone in your family who encourages you to go for regular follow-up? Do they accompany you for follow-up? 42. What are the measures you took to control your blood sugar? 43. Are you on insulin? Do you administer it by yourself or do you visit the health facility for getting the injection? Were you trained on how to administered the insulin? 44. How do you administer insulin? Is there anyone in your family who is supporting you in administering insulin? 45. How long have you been using insulin injection? Were you scared when you were told that you have to take insulin injection? 46. How do you store the medicine? Are you being provided with insulin pen or separate vial for insulin and syringes?
III. Occupation and Daily activities	47. What do you usually do daily? 48. What is your occupation? Is it government or private job? How long have you been working? 49. What are the different kinds of activities that you do in your occupation? 50. What are your job responsibilities and how much are you paid? 51. At your work place to whom do you usually report your grievances, for example when you are sick from who do you seek permission to take a break from work? 52. Is your employer a male or female? How is he or she treating you? 53. How much time do you spent at work and how much are you paid? 54. How much time do you spent for household chores? 55. When at work what time do you usually eat? 56. Does your occupation prohibit you to follow to the exercise and dietary advised given to you by the doctor? 57. Do you take part in any community level activities such as those which aim at improving the health status of the people living in your community?
IV. Health Seeking Behaviour	58. How often do you visit the health facility for follow-up of diabetes? Which health facility do you usually visit? 59. First source of treatment: 60. Second source of treatment:

	61. Reason for not going for follow-up: 62. How do you normally access the health facility? Do you use public or transport? How much do you spend to travel and other related non-medical non-expenditure such as food? 63. Who accompanies you for the treatment? 64. In case the doctor is not available, what did you do? 65. Do you seek care for diabetes from the traditional healer as well? How was the diagnosis made by the traditional healers? 66. How do they explain to you the disease? What are the types of treatment given by the traditional healers for diabetes? 67. What are the preventive measures suggested to you by the traditional healers? 68. Where are the traditional healers located? How often do you meet them and how long have you been seeking care from the traditional healers? 69. What are the major problems which you are facing in terms of going for follow-up (testing, treatment)?
V. Health System	70. Explain in detail your experience while seeking care for diabetes in terms of duration of conversation, with the doctor, going for the test and access to medicine? 71. How long do you have to wait in order to get to see the doctor? 72. Can you please recollect how long does it takes to meet the doctor to show the report? 73. What were the medicines that the doctor prescribed you to take? 74. Did the doctor explained you the disease, and the preventive measure that you should adopt such as changes to be made in your diet and physical activity? 75. Do you know that under the program you need to be counsel for the risk factors of diabetes? Were you counselled? What did the counsellor advise you? 76. How much money do you spent in the entire process of diagnosis and treatment of diabetes? 77. How do you manage to pay for the treatment? Who support you financially? 78. Is there someone in the village who provide money or loan when needed on emergency basis-for medical purpose? 79. Have you been hospitalized due to diabetes and its related complications in the last one year? 80. Date of admission: _____ Date of discharge: _____ 81. Duration of stay in the hospital: _____ Hospital Name: _____ 82. Reasons for not visiting the public health facility: 83. Were you covered on the Ayushman Bharat scheme? 84. Can you please explain how is the Ayushman Bharat scheme helping you with hospital admission? (to ask for document related to hospitalization) 85. What is your experience of accessing medical care under the Ayushman Bharat Scheme? What happen at the registration counter?

	86. How much money do they deduct from your card and how much do you have to spent from your pocket? 87. Were you given the bill charge during the admission process? 88. How long does it take from the time you apply for the smart card till the time you can used it when needed? 89. Can you please share how much do you spend for treatment (consultation fees, diagnostic tests, and drugs) in the last one year? How does the Ayushman Bharat Scheme helping you in cutting down the cost of treatment?
VI. Social Support	90. Are there any patients' group in the community? 91. How do you manage the challenges you faced in controlling your blood sugar? 92. Do you have any relative or friend whom you can share your problem with? 93. Is there any organization or associations who work for the welfare of the people living with diabetes in your village?
VII. Diet, exercise and medication	94. What type of diet do you usually take before being diagnosed with diabetes? how many times do you usually eat in a day? 95. What do you usually eat in breakfast and at what time? 96. What do you usually eat in lunch and at what time? 97. In the evening what do you usually have? 98. At what time and what do you have for dinner? 99. Do you take cold drinks? How often do you consume it? 100. Do you consume fried foods prepared in the market? How often? 101. Do you consume sugary food? What are those and how often do you consume them? 102. Where do you usually purchase those food items? 103. Do you think that certain foods that we eat is making us prone to diabetes? 104. How do you avoid the consumption of sugary and fatty foods? 105. Do you consume tobacco? In what form? How much and how often? since when do you start consuming tobacco? 106. Do you consume alcohol? In what form? How much and how often? since when do you start consuming alcohol? 107. Do you think that the changes suggested by the doctor led to major changes in your dietary pattern? 108. How do you manage in cooking food separately for yourself and for your family members? 109. Who is helping you in complying to dietary pattern? Do you think your children or family members help you in complying to the changes in dietary pattern? 110. Does this change in your diet has increased your financial burden? 111. What do you usually daily as part of exercise? 112. What are the different exercises you usually do? Were you able to do them regularly? 113. Who suggested you to do the exercise? 114. At what time do you exercise? 115. How do you manage the time for exercise? 116. What is the medicine prescribed for you related to diabetes? 117. Are you able to take them regularly?

	118. If not, what are the challenges in taking the medicine regularly? 119. Have you ever stopped taking the medicine? For how long and what is the reason? 120. What motivates you to comply to the advice given or what are the enablers for treatment compliance? 121. What are the factors that prevent you from complying to treatment? 122. How much do you monthly spend on diabetes medication?
VIII. Psychosocial Stress	123. What were the major advice given to you by the doctor once diagnosis of diabetes is made? 124. How did your life changes after being diagnosed with diabetes/own perception about change in state of health? 125. Were you able to make the changes as suggested by the doctor/health worker? 126. How is the diagnosis affecting you physically such as your ability to do the daily activities? 127. How is diabetes affecting your social life? How do others look at you after you have been diagnosed with diabetes? 128. How do you feel when the diagnosis of diabetes was made? Do you feel scared? Why so?
IX. Cultural Practices related to diabetes	129. There are various beliefs in the community about causes of illness, what is the common belief in the community regarding the cause of diabetes? 130. Can you please share stories of your previous encounters in the community? 131. Is there any home remedy which you are using for treating diabetes? what are those, can you please explain? 132. How do know that these are effective in controlling your sugar? 133. What according to you are the measures necessary for preventing diabetes? 134. Are there any common practices in the community which you think will prevent oneself from getting diabetes?
XI. Diabetes and COVID19	135. How did you understand about the outbreak of COVID19? 136. What were the advised given to you during the first and second wave of COVID19 pandemic? 137. In what ways was your treatment affected due to lockdown and COVID19? 138. How do you manage to reach the health facility during the first and the second wave of COVID19? 139. How has the first and second wave of COVID19 pandemic affect your follow-up? 140. Before the lockdown was imposed, how do you manage in seeking treatment? 141. How do you manage to purchase foods and medicines during the lockdown? Do you have enough stock? 142. Are you advised to take insulin? How do you manage to get insulin during the lockdown? Do you have to pay more for getting insulin?

	143. What are the major difficulties you faced in seeking care for diabetes during the lockdown period and throughout the first and second wave of the pandemic? 144. When and where was the last time you got your sugar tested? Who refer you there? 145. Are you aware that people living with diabetes are at higher risk of contracting COVID19? Are you stressed because of this? 146. Were you afraid of COVID19? Did this fear prevent you from going for follow-up 147. Were you diagnosed with COVID19? 148. Do you faced any complication in the last one year because you were not able to go for follow-up due to the restrictions? 149. What do you think of the COVID19 pandemic? How is it affecting you? 150. How did your life changes because of the outbreak of COVID19? 151. Did the health facility (SCs/HWCs or PHC) help you in receiving care for diabetes? I f yes in what ways?

Annexure 5 Semi-structured interview guide for caregivers of respondents with diabetes

Introduction Name Sex Age Marital Status Religion Ethnicity Educational qualification Occupation Income per month
General Questions 1. What are your roles and responsibilities related to taking care of the patient? 2. In what ways do you provide support to the patient? 3. What are the challenges you faced at home related to providing care for the patient? 4. What are the challenges you faced while seeking care for the patient? 5. How do you cope with the other activities at home? 6. Does having a family member living with diabetes in your family affect your life?

Annexure 6: Focus Group Discussion guide with members from the community, ANMs and MLHPs **Introduction:**

1. Have you heard of the NCD prevention and control program?
2. What do you think are the risk factors for NCDs such as diabetes, heart disease and cancer?
3. What do you think are the causes of illness in the community?
4. What are the signs and symptoms of NCDs, for instance for diabetes?
5. What are the important measures needed to be taken for management of diabetes?
6. Do you think that NCDs can be prevented? If yes, how?
7. How prevalent is tobacco and alcohol consumption in the community? Why is it so?
8. What are the services available at the sub center? Have you heard of the concept of HWC?
9. Where do you usually seek treatment and why?
10. Are there traditional tribal healers in your village? What are the services provided by them?

Annexure 7 Semi-structured interview guide for representative from Civil Society Organization

1. Given your long association as a journalist in the state working as a gender scholar what do you think are some of the main structural issues confronting women's health in the state of Meghalaya.
2. Despite being a matrilineal state, gender inequities is widely prevalent in the state-how does this reflect in the context of seeking and accessing healthcare?
3. In what ways the matrilineal society in Meghalaya is undergoing rapid transition in the last few years?
4. What are some of the main reasons for the higher rate of separation or divorce in the state? Does this have any relationship with the matrilineal nature of our society?
5. How this has impacted women's self-care especially when they are suffering with illness like diabetes?
6. I wanted to understand in the context of Meghalaya and among diverse tribal communities do we have institutionalised discrimination as is being faced by the tribal in the states of Jharkhand, Chhattisgarh? If yes, how is this reflected in the health care?
7. Do you think women belonging to different socio-economic status in our society experience institutionalised discrimination- say for example in seeking healthcare services at various health facilities? In what ways do we understand this?
8. I wanted to understand and discuss with you how the concept of inter-sectionality in feminist research shapes and influences women's status in Meghalaya.
9. Do women belonging to different social classes discriminate against women from lower social groups?
10. Poverty is widespread in Meghalaya and this is one of the major barrier in the seeking healthcare? What policy initiatives have been undertaken by the state to address this issue?
11. How does religion shapes health seeking behaviour? Why is it so strong in the context of Meghalaya?
12. Is there a dominance of certain communities in the policy making (for example-Khasis) of the state and how does this affect the service delivery for belong belonging to different groups?
13. I observe that there is a huge dependence of people on traditional healers and people have strong beliefs in faith healers and traditional healers? What could be the reasons for the same?
14. What are the roles of traditional institutions when it comes to health care delivery and how do they ensure the implementation of gender sensitive health policies?
15. In what different ways women have been involved in policy making in the state?
16. What measures can be adopted in order to achieve gender equality in Meghalaya's matrilineal society?

Annexure 8 Semi-structured interview guide for representative from international developmental organization

Introduction

Questions-

1. When it comes to women's health, what are the challenges in the state?
2. What are the challenges in which people faced with the health system?
3. Is there any inequities exist in terms of accessing health care services?
4. Is there any gender division of work in the health system? Who makes the decision?
5. Do you think that the background of health care workers influences the utilisation of health care services?
6. How this affects service delivery for health care in general and NCD in particular?
7. How does religion shapes health seeking behaviour? Why is it so strong in the context of Meghalaya?
8. What are the different beliefs related to health and illness in the state?
9. What are the reasons for the increased tobacco consumption in the state?
10. How is the health system creating awareness on tobacco consumption?
11. Why do people belief in faith healers and traditional healers?
12. What are the roles of traditional institutions when it comes to health care delivery?
13. What are the governance issues that led to poor health outcome in the state?
14. Are women involved in policy making in the state?
15. What measures can be adopted in order to achieve gender equality in Meghalaya's matrilineal society?

Annexure 9 Letter from the Senior Medical and Health Officer's Nartiang PHC requesting permission from village headmen for fieldwork in villages

Ha,

Tarik: 13/05/2021

U Rangbah Shnong Badonburom,
Jong ka Shnong.....
West Jaintia Hills District, Meghalaya

Subject:- Jingkyrpad ban shah ia ka jingleit lum jingtip ha ka shnong jong phi naki
briew ba don ia ka jingpang shini

Rangbah Shnong Badonburom,

Da kane nga Kyrpad ia phi ba phin sngewbha ban shah ia I Alacrity Muksor, I
ba dang pule ia ka PhD ha Indian Institute of Technology, Guwahati ban wan sha ka shnong
jong phi na ka bynta ka jingpule jong I ha ka ba ia dei bad ka jingpang shini. Ha kane ka
jingwad bniah in sa donkam ban ia kren bad ki briew kiba don ia ka jingpang shini, kumjuh
ruh bad ki nongai dawai pnar. Kane kan dei tang na ka bynta ka jingpule jong I kaba I
donkam ban pyndep.

Nga ngeit skhem ba phin shah ia I bad ba phin ai ka jingkyrshan jong phi ia I
khnang ba in lah ban pyndep ia ki jingdonkam jong I kat kumba la bthah da ka jaka pule jong
i.

Khublei Shibun


Dr. R. Pohsnem
Sr. Medical & Health Officer,
In-Charge Nartiang PHC
Dr. R. Pohsnem
Medical & Health Officer
I/c Nartiang P.H.C.

Annexure 9 Letter from the Senior Medical and Health Officer's Nartiang PHC requesting permission from village headmen for fieldwork in villages (English Translation)

Date: 13/05/2021

To,

The Respected Village Headman,

Of Village

West Jaintia Hills District, Meghalaya

Subject: Request for permission to collect data from people living with diabetes in your Village

Respected Village Headman,

With this letter, I request you to kindly allow, Ms. Alacrity Muksor, a PhD student at Indian Institute of Technology Guwahati to come to your village for the purpose of her study related to diabetes. In this research, she will need to talk with the people who have diabetes and also with traditional tribal healers. This is strictly for the purpose of her study which she need to fulfill as part of her PhD thesis work.

I hope you will permit her and provide her with all the support she needs in accomplishing her fieldwork.

Thanking You,

Dr. R. Pohsnem

Senior Medical & Health Officer,
In Charge, Nartiang PHC

Annexure 10 Entering the Field: A note on participant observations at public health facilities and study villages:

District Medical and Health Officer's Office:

After getting permission from the DM&HO, I conducted field visits at health facilities. I first visited the DM&HO's office located in Jowai town. The purpose of the visit was to collect information related to the district health system in general and the NPCDCS program in particular. Fieldwork at the DM&HO's office began by collecting and analyzing the secondary data related to NCDs in the district, followed by interviews with health staff, workers and patients with diabetes. The other data collection methods adopted during visits to DM&HO's office included everyday conversation, discussions, and observations. During the process, I also participated in the discussion related to COVID-19 whenever the DSO called for a meeting at her office. As I was seen as an "insider," given my past work experience as a nurse at a PHC in the district, at the National Health System Resource Center (NHSRC),⁸⁷ and as a doctoral researcher, I was permitted to take part, listen and observe the activities that were being organised in the office. After collecting the required information from the DM&HO's office, I visited the District Hospital.

Jowai Civil Hospital (JCH), Ialong-District Hospital:

On the 28th of October 2020, as suggested by the DSO and the nodal officer of the NPCDCS program, I visited the Jowai Civil Hospital, located in Ialong village, 20 minutes from the district headquarter, Jowai, to meet the Medical Superintendent (MS). After obtaining permission from concerned officials associated with medicine and nursing, I started field work at the District Hospital. On the same day, I met the Nodal Officer after the Nursing Superintendent informed him about my purpose for visiting the hospital. The Nodal Officer gave a brief description of the program and overview of how the department was working to address cases of chronic disease like diabetes.

I have also visited NCD clinics to directly observe how patients were diagnosed with diabetes. However, the pandemic made in-depth interviews at the hospital difficult due to the physical distancing norms, given the limited space at the clinic. Hence, I could only observe. Further, at the Ayurvedic clinic of JCH, Ialong, the Ayurvedic physician, helped me identify women with diabetes. Thus, with the help of staff nurses and the Ayurvedic Physician, I met patients and collected their mobile phone numbers. This way, I could take telephonic interviews with the patients identified from JCH, Ialong, where the NCD clinic is located. The daily visit was made to the JCH, Ialong, for one month, from 28th October to 28th November 2020. As suggested by the Nursing Superintendent and to understand the program's functioning, I sat in the NCD clinic with the Staff Nurse conducting the screening and observed her work. I also collected information from the ward for NCD-related cases admitted in the hospital.

The "NCD nurse" on duty used to reach the hospital at 10:00 AM, after which she assisted the other nurses on emergency duty. She used to assist in giving injections for dog bites and other emergency-related procedures in the room opposite the emergency OPD. At 11:00 AM, patients started visiting the clinic. NCD nurse started the screening process. Patients were called on a first come basis- she checked their blood pressure, weight, and height. Once the nurse was done with her routine questions, I would explain them about my research and sought their consent. After permission, I also

⁸⁷ Technical Support organization for the National Health Mission, Ministry of Health and Family Welfare, Government of India, New Delhi.

asked for patients' details, history of NCDs and Tuberculosis, and if they were aware of the program. I also interacted and observed the Data Entry Operator and how she collected the NCD cases from the ward and entered into the reporting format. During this time, I communicated with the patients and observed the program's implementation at JCH, Ialong. The detailed findings are discussed in the analysis chapters.

Nartiang PHC and its Health and Wellness Centres (HWCs):

From 30th November 2020 till 14th January 2021, I visited Nartiang PHC. In between, I visited the six SCs/HWCs attached. I travelled to the PHC in shared cabs, and it took 25 minutes to reach Nartiang village where the PHC is located. During the visit to Mynsngad HWC, I travelled by shared cabs as there was no difficulty in getting the cabs, unlike the visit to other HWCs where vehicles were scarce. In this case, personal arrangements were made to reach the field. The road conditions to Nartiang and Mynsngad villages are better when compared to the other villages visited.

At the PHC, after taking the interviews of the Senior Medical & Health Officer (Sr. M&HO) in charge in the visitor's room, a visit was made to the outpatient department (OPD). At the OPD, the Sr. M&HO showed me how registers for NCD are being maintained. Before the visit, the Sr. M&HO informed that the information they collected in the doctor's register related to the NCD was again entered in the NCD register by the staff nurse assigned to conduct the screening. After a thorough discussion with the other Medical Officer, it was decided that the flow of patients should be organized in such a way that the time of both the patients and the doctors will not be wasted unnecessarily. When the patients come to the PHC, they would first get themselves registered, after which the doctor will examine them and advise them to go to the emergency OPD for screening. I attended emergency OPD daily during my visit to the PHC. This also helped in identifying outpatients with suspected cases of diabetes. For RBS, if the doctors advise, patients are instructed to go to the laboratory in Room No. 10, where the laboratory technician on duty will do the test. After getting the report, the patients showed it to the nurse on duty and then accordingly reported to the doctor, who advised treatment. I had explained to the doctors about the study that I also needed to interview patients diagnosed with diabetes, so I requested them to let me know in case of a new diagnosis, which they did. Participant Observation has contributed immensely to the data collection process. Through this method, I got to experience and understand the reality of how the program is implemented at the PHC level. For example, getting more insights into how the data are recorded in the field and how the reports are sent. Rather than collecting the report, I gained a better understanding of the data through participation. I was also invited to participate in the population-based screening program and interviewed the ASHAs, ANMs, and MLHPs during this period.

The NS and some of the nurses at the district hospital and the PHC are familiar me, so I had their full support during data collection process. The fact that they have already known me as a nurse made my presence not so strange to them anymore. Thus, I could participate and observe the setting in its natural form. My acquaintance enabled me to access crucial information.

Entering the Villages:

I began the second phase of data collection on December 2020-January 2021, which involves field visit to the homes of women living with diabetes in villages under Nartiang PHC. Before going to the villages, I first visited Nartiang PHC to meet the Senior Medical and Health Officer in charge of the PHC to request his guidance on approaching the headmen of these villages. The Officer suggested that I write a letter requesting their permission to visit their villages which will then sign by him. After the permission letters were ready, I consulted the Nartiang PHC field staff, including the Lady Health

Visitor, the Public Health Nurse, and the vaccinator, on how to approach the villages. As decided along with them, I began visiting people in Nartiang Village, after which I proceeded to other villages. Both the Lady Health Visitor and the vaccinator are also residents of Nartiang Village. From our discussion, it was decided that initially, the vaccinator will take me to the village headman and then to the houses of people with diabetes. On the subsequent visit, it was decided that the ASHA will accompany me. On this day, I met the vaccinator at Nartiang PHC, and along with her, we met the headman of Nartiang Pohchnong Village. After getting the village headman's permission, we proceeded to the community. Similarly, the process was followed for other villages. Concerning villages under Ummulong CHC, village headmen's permission was no longer required as the lockdown was relaxed by this time. During their home visit, I visited Wahiajer village, along with the Mid-Level Healthcare Provider and the ASHAs. I received enormous support from the MLHP, who accompanied me through the home visit and participated in the interview process. In other villages under Ummulong CHC, the ASHAs guided me to the houses of women diagnosed with diabetes.

Given that I got support from the health system, it is easier for me to access the villages. The frontline health workers, such as the ASHAs/ANMs/Surveillance Workers/MLHPs, introduced me to women as “a nurse undergoing further study.” Introduction by frontline healthcare providers facilitated the rapport-building process. After we introduced each other, women no longer considered me a stranger when they learned I belonged to Ummulong Village. People from different villages frequently visited Ummulong Village for many purposes because it is central to their economic activities and for seeking treatment in private clinics. Further, the fact that we speak the same language made them feel that I am one of them or that we are the same. They share their contact details without hesitation to share more details about their illness experiences. Women also called the me and informed about their health status. I also visited them at work, such as the marketplaces in their shops, and observed their activity. People in villages welcomed me wholeheartedly to their houses and shared their experiences in detail without any reservations. As part of the Pnar culture, most houses offered me either *Kwai* (betel nut) or tea.

Annexure 11 Informed consent form for Women with Diabetes

Experiences of Women with Diabetes: A Study in West Jaintia Hills District

Good morning/Afternoon/Evening! My name is Alacrity Muksor. I am a PhD candidate, at the Department of Humanities and Social Sciences, Indian Institute of Technology Guwahati. I am conducting a study on experiences of women with diabetes in West Jaintia Hills District. Currently, I am doing my fieldwork to collect the data for my study.

Your participation is invaluable for successful completion the study. However, the decision to participate in the study is not mandatory. It entirely depends on your willingness to be part of the study. Please feel free to ask me any question related to the study or in case you want further information on the interview. If you are not comfortable in answering any question due to some reason, you can ignore the question. Also, in case you want to discontinue the interview in between, please let me know.

If you agree to participate in the study, there are set of questions that needs to be answered by you and it will take approximately 45-60 minutes. The interview will be audio-recorded with your permission. Please rest assured all the information that you shared will be kept confidential including your name and address. Your privacy will be protected throughout the study. You have the right to withdraw from the study, if you want to do so at any time during the study.

Your participation in the study will not provide direct benefits to you but your voice will help in addressing the challenges related to non-communicable disease in the state.

I would highly acknowledge and greatly appreciate your kind cooperation with me for successful completion of the study.

Please tick if you agree to participate in the study

- ☐ I hereby agree to take part in the interview
- ☐ I also agree to audio-record my interview
- ☐ I do not agree to be audio-recorded during the interview

Signature/thumb impression of Respondent: _____

Date: _____

Researcher's signature: _____

Thank you for being a part of this study!

Annexure 12 Informed consent form for Healthcare Professionals**Experiences of Women with Diabetes: A Study in West Jaintia Hills District**

Good morning/afternoon/evening! My name is Alacrity Muksor. I am a PhD candidate, at the Department of Humanities and Social Sciences, Indian Institute of Technology-Guwahati. I am conducting a study on experiences of women with diabetes in West Jaintia Hills District. Currently, I am doing my field work to collect the data for my study.

Your participation is invaluable for successful completion the study. However, the decision to participate in the study is not mandatory. It entirely depends on your willingness to be part of the study. Please feel free to ask me any question related to the study or in case you want further information on the interview. If you are not comfortable in answering any question due to some reason, you can ignore the question. Also, in case you want to discontinue the interview in between, please let me know.

If you agree to participate in the study, there are set of questions that needs to be answered by you and it will take approximately 45-60 minutes. The interview will be audio-recorded with your permission. Please rest assured all the information that you shared will be kept confidential including your name and address. Your privacy will be protected throughout the study. You have the right to withdraw from the study, if you want to do so at any time during the study.

I would highly acknowledge and greatly appreciate your kind cooperation with me for successful completion of the study.

Please tick if you agree to participate in the study

- ☐ I hereby agree to take part in the interview
- ☐ I also agree to audio-record my interview
- ☐ I do not agree to be audio-recorded during the interview

Signature of Respondent: _____

Date: _____

Researcher's signature: _____

Thank you for being a part of this study!

Alacrity Muksor

Annexure 13 Background characteristics of healthcare officials, providers, and frontline workers

Health Officials at the State Health Directorate and District Health Administration (DM&HO)					
Sl. No.	Designation	Age	Sex	Religion	Education
1	State Nodal Officer-cum-Joint Director of Health Services (Maternal and Child Health & Family Welfare).	51	F	Christian (Protestant)	MBBS
2	State Epidemiologist/State Program Officer	31	M	Christian (Protestant)	MPH, Ph.D. Scholar
3	State Program Coordinator	35	M	Christian (Protestant)	MBA in Hospital Management
4	Finance-cum-Logistic Consultant	42	F	Christian (Protestant)	Master of Commerce
5	DM&HO	56	M	Christian (Protestant)	MBBS
6	District Program Manager	42	M	Christian (Protestant)	MBA
7	District Nodal Officer	44	F	Christian (Protestant)	MBBS, MPH
8	Finance-cum-Logistic Consultant	33	M	Christian (Protestant)	MBA
9	Data Entry Operator	25	F	Christian (Protestant)	Graduate
10	Pharmacist (District Drug Ware House)	32	M	Christian (Protestant)	B. Pharm
Healthcare Providers at the District Hospital, Primary Health Centre and Health and Wellness Centres					
11	Medicine Specialist	42	M	Christian (Roman Catholic)	MD, Medicine
12	Medicine Specialist	30	M	Christian (Protestant)	MD, Medicine
13	Ayurvedic Physician	40	F	Christian (Protestant)	Bachelor of Aurvedic Medicines
14	Sr. Medical and Health Officer	43	M	Indigenous religion	MBBS
15	Medical Officer	29	M	Christian (Protestant)	MBBS
16	Community Health Officer	45	F	Christian (Protestant)	GNM
17	Staff Nurse	30	F	Indigenous religion	ANM
18	Staff Nurse	38	F	Christian (Protestant)	GNM
19	Staff Nurse	29	F	Christian (Protestant)	General Nursing and Midwifery (GNM)
20	Staff Nurse	30	F	Christian (Protestant)	General Nursing and Midwifery (GNM)
21	Pharmacist	40	F	Indigenous tribal religion mixed with Hinduism	B. Pharm
22	Pharmacist	33	F	Christian (Roman Catholic)	B.Pharm
23	Pharmacist	34	M	Christian (Protestant)	B.Pharm
24	Laboratory Technician	32	F	Indigenous religion	BSc. MLT
25	Laboratory Technician	28	F	Christian (Protestant)	Bsc. MLT
26	Data Entry Operator	28	F	Christian (Protestant)	BA
27	MLHP 1	27	F	Christian (Protestant)	GNM
28	MLHP 2	30	F	Christian (Roman Catholic)	GNM
29	MLHP 3	32	F	Christian (Protestant)	BSc. Nursing
30	MLHP 4	26	F	Christian (Protestant)	GNM

31	MLHP 5	25	F	Christian (Roman Catholic)	GNM
32	MLHP 6	26	M	Christian (Roman Catholic)	GNM
33	MLHP 7	28	F	Christian (Protestant)	GNM
34	MLHP 8	31	F	Christian (Roman Catholic)	GNM
35	MLHP 9	29	F	Christian (Protestant)	GNM
36	MLHP 10	34	F	Christian (Roman Catholic)	GNM
37	ANM 1	46	F	Christian (Protestant)	Matriculation
38	ANM 2	45	F	Christian (Protestant)	Matriculation
39	ANM 3	26	F	Christian (Protestant)	Higher Secondary
40	ANM 4	40	F	Christian (Protestant)	Matriculation
41	ANM 5	42	F	Christian (Protestant)	Matriculation
42	ANM 6	35	F	Christian (Protestant)	Higher Secondary
43	ANM 7	46	F	Christian (Protestant)	Matriculation
44	ANM 8	39	F	Christian (Protestant)	Matriculation
45	ANM 9	29	F	Christian (Protestant)	Higher Secondary
46	ANM 10	30	F	Christian (Protestant)	Higher Secondary
47	ANM 11	27	F	Indigenous tribal religion	Higher Secondary
48	ANM 12	52	F	Christian (Protestant)	Matriculation
49	ANM 13	24	F	Christian (Protestant)	Higher Secondary
50	ASHA 1	42	F	Indigenous religion blend with Hinduism	Class X
51	ASHA 2	56	F	Christian (Protestant)	Class VIII
52	ASHA 3	23	F	Christian (Roman Catholic)	BA graduate
53	ASHA 4	29	F	Christian (Protestant)	Class IX
54	ASHA 5	51	F	Christian (Protestant)	Class X
55	ASHA 6	38	F	Christian (Protestant)	Class IV
56	ASHA 7	52	F	Christian (Roman Catholic)	Class X
57	ASHA 8	44	F	Christian (Protestant)	Class IX
58	ASHA 9	28	F	Christian (Protestant)	Class X
59	ASHA 10	43	F	Christian (Protestant)	Class IX
60	ASHA 11	39	F	Christian (Protestant)	Class VIII
61	ASHA 12	36	F	Christian (Protestant)	Class X
62	ASHA 13	27	F	Christian (Roman Catholic)	Class X
63	ASHA 14	29	F	Christian (Protestant)	Class X
64	ASHA 15	30	F	Christian (Protestant)	Class IX

Source: Data compiled from fieldnotes

Annexure 14 Background characteristics of healthcare providers at private health facilities

S1. No.	Designation	Age	Sex	Religion	Education
1.	Medical Superintendent and Diabetes Consultant	52	F	Christian (Protestant)	MBBS and DNB in family medicine
2	Medicine Specialist	41	M	Christian (Roman Catholic)	MD, Medicine
3	Medicine Specialist	46	M	Hindu	MD, Medicine
4	Medicine Specialist	42	M	Hindu	MD in Medicine
5	Medicine Specialist	35	M	Christian (Protestant)	MD General Medicine, Post Graduate Diploma in Family Medicine, Distance fellowship in Diabetes Mellitus.
6	Obstetrician and Gynecologist	39	F	Christian (Protestant)	MS, Obstetrics and Gynecology
7	General Surgeon	34	F	Hindu	MS, General Surgery
8	Allopathic Doctor	46	M	Christian (Roman Catholic)	MBBS
9	Homeopathic Doctor	33	M	Indigenous tribal religion	BHMS
10	Chief Dietitian	33	F	Christian (Protestant)	MSc. Clinical Nutrition and Dietetics
11	Dietitian	38	F	Christian (Protestant)	BSc. In Clinical Nutrition and Dietetics
12	Dietitian	47	F	Hindu	Msc. in Nutrition and Dietetics
13	Dietitian	36	F	Christian (Protestant)	MSc. Food Nutrition and Dietetics
14	Diabetes Educator	36	F	Christian (Protestant)	GNM
15	Staff Nurse	45	F	Christian (Roman Catholic)	GNM
16	Staff Nurse	25	F	Christian (Protestant)	GNM
17	Traditional tribal healers	56	M	Indigenous tribal religion	Honorary Doctorate Degree-Doctor of Traditional Medicine (DTM) and Doctor of Medicinal and Herbal Sciences (DMHS) provided by Martin Luther Christian University
18	Traditional tribal healers	56	F	Christian (Roman Catholic)	Class III
19	Traditional tribal healers	54	F	Christian (Protestant)	Class X
20	Traditional tribal healers	45	F	Indigenous religion blend with Hinduism	Class V
21	Traditional tribal healers	63	M	Indigenous tribal religion	Class III
22	Traditional tribal healers	80	M	Christian (Protestant)	Class I
23	Traditional tribal healers	76	M	Christian (Protestant)	Graduate
24	Informal Practitioners	63	F	Christian (Protestant)	Class II

Annexure 15 Background characteristics of caregivers

Caregivers	Age	Gender	Education	Occupation	Religion
C1	18	F	X	Student	Christian
C2	20	F	XIII-dropped out	Unemployed	Christian
C3	32	F	XII	Teacher	Christian
C4	40	F	VIII	ASHA	Indigenous blend with Hinduism
C5	31	F	IX	Daily wage labourer	Christian
C6	30	F	BA	Unemployed	Christian
C7	26	F	VII	Daily wage labourer	Indigenous blend with Hinduism
C8	34	F	XII	Teacher	Indigenous religion
C9	36	F	VI	Daily wage labourer	Christian
C10	26	F	V	Daily wage labourer	Indigenous religion

Annexure 16 Illness narratives of five selected women

Narrative 1:

Tension, Stress, and Diabetes in Everyday Life

Socioeconomic position:

Daphi is 55 years old; she has completed her Bachelor's degree in Arts and works as a teacher in a private school in Looksi near her village, Mootyarchiah. She is a Christian, and her denomination is Presbyterian. Her monthly income is INR 10,000/- (USD 120.93). She has six children- two daughters and four sons. All her children are still studying except the eldest, who has completed his Bachelor of Arts. She was diagnosed with diabetes in 2006. Her husband separated from her eight years ago. As mentioned earlier, Daphi is a teacher. However, owing to the lockdown introduced during COVID-19, she is spending her time at home working hard to meet the needs of the family, given the fact that she is the family's sole breadwinner. She also explained how stressful her work is. She said:

I used to do tailoring, where I stitched clothes for people and grew some vegetables so I did not have to buy them from the market. I am working really hard. I am doing rice cultivation, too, even when I am this sick. I am really busy; my health has worn out. I used to earn (INR) 12-13,000/- (USD 145.13-157.22) per month, (INR) 10,000/- (USD 120.93) as salary, and the remaining amount from my other earning source, i.e., tailoring. I am sure to get (INR) 10,000/- (USD 120.93) monthly. During the COVID-19 pandemic, as the head of the school is my cousin, she still pays me, but for others, she could not pay them. I used to spend the money on house rent and food. I have to send money every week to my children for their rent and school as they live and study in Jowai (town). For children with a single mother like me, I must work hard and feed them whatever food I can. I also have to pay d to pay for their education. When I look at my children, I am worried. But I thank God that my children are good. I am trying not to worry. I tried to comfort my soul by being on terms with God. I have to always turn to God so that I will feel good...

I cannot stop working hard; even now, none of my children has gotten a job. Because they do not have a father, I have to work alone. He ran away. Just imagine I have to work alone and have six children so I will be stressed. I have also to educate them. So, I will naturally be stressed...please pray for me to be well and healthy to keep my children alive...

The above narrative that Daphi shared shows that working at a private school run by her relatives enables her to earn during the COVID-19 lockdown. Otherwise, it would have brought more stress to her as she was abandoned by her husband and had to raise her children alone.

Her narratives also indicate the struggles she has to undertake in order to raise her children alone.

Illness History:

She narrated the history of diagnosis with diabetes as follows:

I was diagnosed with diabetes for the last 14 years (in 2006) at North Eastern Indira Gandhi Regional Institute of Health and Medical Sciences (NEIGRIHMS) when I visited the hospital for a check-up as I was feeling very weak. I visited NEIGRIHMS because my cousin's sister advised me. After the doctors did all the tests, they found that I had sugar disease and was given sugar medicine. All I could remember was that I took the treatment from NEIGRIHMS for 4-5 months only, after which I stopped. I did not seek treatment from NEIGRIHMS for long as it is far from my village (around 111 km). Also, the allopathic treatment does not match me. When I take medicine *phareng* (allopathic medicine), my stomach becomes *slew* (feel uncomfortable). During the last 14 years, I used to seek treatment here and there, and I do not understand my illness. But now I decided to switch to Ayurvedic medicine. There is one medicine that the Ayurvedic doctor at Ialong (public district hospital) prescribed me that I found very helpful. It is known as BGR-34. It is not available at the hospital. I have to buy it from the doctor's private clinic, which costs around (INR) 600/- (USD 7.23) for a strip of 10 tablets. When I take the medicine, I feel like I am gaining energy, and even my *niangmi* (measles) also decreases. I am really feeling good with the treatment provided by the doctor. I am very grateful to her. I am only seeking treatment from Ialong as I do not have to spend more on transportation. Had I gone to seek treatment from private doctors who charged more, I would not be able to feed my children. Although I am feeling better now, I think this biting sensation in my feet and joints are due to diabetes. I pay less attention to myself as I try to meet my children's needs more. However, I cannot live without sugar medicine. If I do not take the medicine, I can feel my sugar becoming serious. Because my sugar was so serious earlier, maybe this sugar disease has affected my nerve. I do not think this sugar will get cured. It will stay in the human body. I think it will last till death. But I do not want to die so soon, as my children are still young.

The above narratives of Daphi show how she uses her agency to decide the systems of medicine she should choose for diabetes treatment, given the fact that she cannot tolerate allopathic medicine and the tertiary hospital is far from her village. Although she has to pay for the medicine at the public hospital, she considers it comparatively better had she visited a private clinic. In a private clinic, the expenditure would be higher as she must pay for the doctor's consultation charge and medicines. Further, her narrative shows that her responsibilities as a single mother prevented her from taking good care of herself. The symptoms she experiences suggest complications of diabetes where in her lay understanding, "maybe this sugar disease has affected my nerve." Concerning her experiences with the symptoms of diabetes, she said:

When I am stitching, my eyes are getting disturbed. I thought I would get my eye check-up done. When cut by a knife, the scars always stay, the way this sugar disease is such

that I am hungry many times. In the night, I used to urinate three times...I used to drink lots of water, I imagine that when you drink lots of water, you will urinate frequently...I feel like eating all the time, I feel hungry always...so you will always want always to eat, always feeling hungry.

Tension as the cause of diabetes:

Daphi is the only daughter and the youngest, so she had to care for her mother alone despite having two brothers. Her mother told her that her father died when she was nine days old. He was killed while he was in the military service.

Daphi spoke about the tremendous stressful situations during the eight years (1998-2006) as she cared for her ailing mother. There is no family history of diabetes. When asked about her perceived cause of diabetes, she narrated how caring for her mother for over eight years after she suffered a stroke. She said her mother did not have a history of diabetes but had a history of hypertension. She said her mother got a stroke because of hypertension. Her mother died 13-14 years ago. She was paralyzed for eight years and was always lying in bed. She said:

I think it is because my tension was very high when I was taking care of my mother. My mother was like a baby, she was bedridden, and she used to urinate seventeen to eighteen times a day, and I had to change. It was stressful, and that is why I got this sugar. I am thinking like that. Who can carry their mother for seven to eight years, and that too three to four times a day? I had to carry her always when she wanted the sun, I had to carry her when she wanted to take a bath, I had to carry her. I think the years before she died, my sugar started. I had been sleeping for just four hours every night for eight years. I have been thinking like that for eight years and four months. I used to carry her even during my pregnancy. Had her death been delayed, I would have died because I was not getting the chance to care for myself as I was caring for my mother. Now that my poor mother has died so I can take care of myself. My children were also very small in the year my mother died. People told me that they used to see me talking to myself while walking my lips used to move. My friends told me I used to talk to myself and was about to go crazy then. People told me I always used to talk alone; I have lots of problems, you see. Three weeks after my mother died, people told me I used to talk alone. After her death, my house was snatched away by our relative and her sisters. I cannot explain all the difficulties. I think it is because I was so stressed that I am getting the disease. It was during this time that my children's father also deserted me. He left me alone to take care of the children.

The narrative shared by Daphi indicates that she associates diabetes with tension. According to her, the long duration of the caregiving role that she undertook for her mother made her suffer from diabetes. Further, the other form of oppression she faced, where her family and relatives exploited her after her mother's death, worsened her health and well-being. Daphi also suffered from many other illnesses besides diabetes. She shared:

I have so many illnesses. I have a Sinus problem; my cholesterol is also very high... then I got diabetes. If I think too much, my chest will have so much pain. But I have not yet gotten it checked. If I can stop feeling sad and depressed, I will not have chest pain. When I am feeling very depressed, it became severe. Every time I feel depressed in my life, my chest is paining. I tried to make myself happy in the midst of difficulties. My children are still studying. I have to buy books one at a time for my daughter as she is studying in the science stream. I feel bad about making my children work as maids in people's houses. I feel I am taking care of myself less as I try to meet my children's needs more. Now also, because I am getting lots of medicine from the civil [public] hospital, I do not need to incur huge expenditures by going to private hospitals. Even when I lament, I still work hard, but sometimes I pretend I did not feel my suffering...

Treatment for diabetes:

When the study was conducted, she was treated at an Ayurvedic clinic at the district hospital. But for the medicines which are not available, she has to purchase from the pharmacy outside, for instance, BGR-34, which costs around INR 600/- (USD 7.23) per bottle. She cannot recall the exact amount. She purchased the medicine from the doctor's clinic, including the medicine for her skin problem costing INR 300/- (USD 3.62). She is currently spending INR 800/- (USD 9.64) for the treatment as the medicine is unavailable at the hospital. She used to spend INR 150/- (USD 1.81) per test for RBS in the private diagnostic centre whenever she wanted to know her RBS and found it very costly. She said I only requested them just for the test. In civil Ialong, it is free of cost. But she also said she is confused with the many tests she was advised to do:

They advised me on so many tests that I do not understand them. I do not understand them. Even if I studied till my BA, I am very foolish and know nothing about medicines or health-related.

Regarding the sugar tests, she said she also used to visit the PHC in her Village, Iooksi PHC, but antidiabetic medicine was unavailable. She said: When I do not go to the doctor, I just wanted to know my sugar level, so I visited the PHC to get the sugar test done. While staying with her children at Jowai, she used to go to the Urban Primary Health Centre, where it was charged INR 20/- (USD). In her village, she also used to visit the Pharmacist. She said:

There is a lady who used to study in Guwahati, and she is providing medicine in Iooksi. She is very brilliant and knowledgeable in providing treatment. Sometimes I used to go to her for the sugar test. She used to charge (INR) 20/- (USD 0.24) for checking BP and (INR) 20/- (USD 0.24) for sugar, but she did not charge so much. That person had gone to study for many years in Guwahati. She also has a license.

Daphi also narrated her experience of utilizing the healthcare services at the Primary Health Centre. She said:

I observed that these PHCs in villages do not even have medicines, especially what is it...oh, it is allopathic. They do not have enough medicines.... the only one available is ayurvedic and homeopathic. It is very difficult for the poor and the needy to depend on allopathic medicine. What to do? This government does not think about the poor. Maybe they are giving, but where are the medicines going? This allopathy is very difficult for the poor. I do not understand how this government is functioning...from what I saw, whenever I went there to get medicines, I never got them. I do not understand it...I have determined to take Ayurvedic medicine as medicines are always available. As of now, I am taking eight tablets in the morning and eight tablets in the night- for sugar, cholesterol, and BP. I cannot afford a private hospital like Healing Hospital (in Shillong).

Based on her friend's suggestions, Daphi initially used traditional medicine to treat her diabetes. However, she also has a conflict as her belief does not allow her to use traditional medicine. Moreover, it did not provide relief for her symptoms. She shared:

There are people at Amlarem who give herbal sugar medicine. They used to pack it in a leave, I requested my friend to bring it for me, and I cooked it once. I paid (INR) 1,200/- (USD 14.47) for the sugar medicine. The medicine was not helping me, so I stopped taking it now. They said many people were cured, but I do not believe it. I do not believe in '*Kombiraij*,' (referring to traditional healers), who used to do magic. I do not believe in him as I am a Christian. I do not believe in those things. My mother also did not believe in such things. She hated them the most. I used to tell the healer that I only needed medicine for diabetes, I do not want you to do any magic...

The outbreak of the COVID-19 pandemic made it more difficult for her to visit health facilities for follow-up. Even when the lockdown was relaxed, the local drivers charged costly travel fares as they had to take only a few passengers to maintain the COVID-19 protocol notified by the district authority. She said:

I found it difficult to travel because of the cost. I thought of going this week for check-ups, but I do not know when. I used to spend (INR) 500/- (USD 6.03) for travel fare, but I only got two strips of medicines from Ialong (public district hospital); otherwise, I have to buy most of it from outside. Still, it is better than private clinics.

The narrative of Daphi shows the situation of the youngest daughter from a low-income group who had to struggle in a caregiving role for her parents and, at the same time, her children. These burdens of caregiving, responsibilities, and household management pose major risks to a woman's overall health and well-being, especially in the absence of support abandonment by husbands. As Daphi mentioned, the tension of providing care for her mother for a long time has made her suffer from diabetes.

Narrative 2

Mary and Family History of Diabetes in Study Villages

Socioeconomic position:

Mary, 58 years is a Christian and belongs to the Presbyterian denomination. She lives in Shangpung, a village located at a distance of approximately 18 km from the hospital. Mary has completed her matriculation and is a teacher by profession. She teaches lower Primary students 1 to 5-deficit schools located in her village and is paid by the state government. Her approximate income per month is INR 35,000/- (USD 421.91). She has seven children- five daughters and two sons. All of them are educated. The youngest is studying in class ten, except the eldest, who is not educated as she suffered a disability following a seizure when she was five months old. Her other children work outside the state, and one of her daughters (the third one) is a nurse working in Kolkata.

Mary lives with her husband and her eldest daughter along with her 10-year-old granddaughter. Mary had two siblings, but they have both passed away and now she is taking care of their children too, along with her own children. She has eight grandchildren. Her husband works in the Public Health Engineering Department as Khalasi/Peon but is posted in the field and not in the office. Mary used to go to school daily from 9 am to 1 pm except on weekends, but in 2020 when the interview was conducted, the school was closed due to the COVID-19 pandemic lockdown.

Illness experiences:

Mary narrated her experience in detail since the day she was first diagnosed with diabetes and how she was diagnosed with diabetes in 2016. She said:

I was diagnosed with diabetes after visiting the physiotherapist, Dr. Francis, in Shillong. I visited the physiotherapist because of knee joint pain. The physiotherapist informed me injection needs to be given to the knee because of the pain, but I first need to check the blood sugar. He told me that if I have diabetes, the injection cannot be given. So, before taking the injection, I visited the private diagnostics center nearby the physiotherapist's clinic in Shillong to check my blood sugar. The findings were normal at that time. It was 116 mg/dl. So, I returned to the physiotherapist's clinic and showed him the report. On reading the report, he found the test result to be normal. Hence, he administered the injection. After two weeks, I took the injection, my vision started becoming blurred. I could not see beyond 10 meters, and could not even read car numbers, so I decided to visit the Gupta eye clinic in Shillong. In the clinic, my sugar was again checked, and it was found to be more than 200 mg/dl. The doctor then referred me to a specialist and suggested the need to undergo further tests to confirm if I have diabetes. I always thought it was due to the problem with my eyes. It is only when they told me at Gupta eye centre

that it is not because of the eyes, it could be diabetes that I went to seek treatment for diabetes from Lifeline Shillong. As Shillong is far so I shifted to Dr. Catherine's private clinic in my village, Changpung, where I was prescribed antidiabetic for 10 days. After taking the ten days treatment, my sugar decreased to about 85-90 mg/dl. The doctor advised me to discontinue the medicine and control my sugar through dietary modification. The doctors told me not to take too much sugar medicine as they are harmful. She gave me ten tablets of the antidiabetic medicine at first. However, in December 2017, I suffered from typhoid and was hospitalized at Lifeline Hospital. After they did all the blood tests, it was found that my sugar was more than 300mg/dl (HbA1c was 8.7). The doctors again started giving me sugar medicine and since then, I continued the follow-up at Lifeline Hospital.

I think all this while before I was diagnosed with sugar disease, it is not manifesting because I was able to control it through dietary management. But now, because of the injection and at the same time, I am growing older, and my sugar increases. I tried controlling my sugar long ago because our family has a history of sugar. My elder sister has it my mother has it. I avoided sugary food and also followed the diet that my sister, who has diabetes, also follows. Despite taking care of my diet to prevent getting sugar disease, I still got sugar disease. I think it is because of that injection that my sugar increases....

During the same year, i.e., 2017, Mary was trying to switch to Ayurvedic medicine because she heard from her friends that taking allopathic medicine for a long will affect her kidney, so she became scared. She said:

Because I was scared to take the allopathic medicine that is why I went to Dr. Eva (Ayurvedic doctor at the public district hospital) I told her I am really afraid of taking this allopathic medicine can you please give me Ayurvedic medicine? I heard people say that this allopathic medicine will affect the kidney if we take it for a long duration. The doctor then provided me with the Ayurvedic medicine. I think even after one year I took the Ayurvedic medicine, my sugar was neither decreasing nor increasing. It was always around 190-200. In September 2018, I suffered from a lower back ache, so I visited Dr. Bernard (a neurologist at Lifeline Hospital). After getting the treatment from him for my back ache for one month, my RBS shoot up to 628 (mg/dl). Then I told Dr. Eva that it is not good for me to take your medicine. I think I have to take allopathic medicine only and will only take those ayurvedic medicine that prevents my kidney from damage. I am still taking the medicine regularly. I also asked the doctor if I needed to protect my liver too, and she said yes, it would be fine if I took that medicine too. It is very dangerous to take this allopathic medicine, but I cannot help it. My sugar shoots up to more than 600 (mg/dl), so I have to take the allopathic sugar medicine right....

In the same year, i.e., 2018, she switched the treatment to Civil Hospital Shillong because meeting the doctor at Lifeline Hospital was difficult. When she arrived in Shillong from her village, the doctor was no longer available. Besides, he only sees 50 patients per day. She said:

My friend, an ENT specialist at Civil Hospital Shillong, suggested I visit the Medicine Specialist, Dr. Benny, for treatment. Dr. Benny advised me to take sugar medicine twice daily if my RBS is more than 200 (mg/dl) and once if it is more than 140 (mg/dl). As the

prescribed medicines were unavailable at Civil Hospital, I had to purchase them from a private pharmacy. I am taking treatment at Civil Hospital Shillong, and my blood sugar is under control. But now I cannot go to Shillong for a check-up because there is corona (COVID-19). If I go there, I have to quarantine myself, so I did not go for a check-up. As I could not visit Shillong anymore, so my friend who is working as Manager in the company Aloe vera Forever Living Product used to get the sugar medicine for me. My children used to send the image of the prescription through WhatsApp. Regarding sugar medicine, now I have the experience of taking it myself. Dr. Benny told me that if my RBS is 200 or 300 (mg/dl), I have to take them twice a day, but if it is below 140, then I have to take it once a day...now I am taking it once a day. I became my doctor, and once my sugar goes up, I will know if there will be a change in my body. I feel uncomfortable, I feel like *tkhan* (tiredness/bodyache), and it reaches my head just like it is burning. When I go for sugar testing, it will always increase to 200 or more. When sugar is not there, I feel fresh and will not get it tested.

She also used to go for regular follow-ups at the PHC in her village to check her BP and RBS. Mary was conscious that she was at risk for diabetes as her mother and sister died because of diabetes. This was explained to her by her doctor. As she narrated:

Doctors told me that our family has a history of diabetes, so I also got this sugar. My mother also has a sugar disease, and my sister also. My mother got a stroke from sugar and BP, my maternal aunt is also suffering from sugar, and even her daughter is also suffering from sugar. So, people said that sugar is because of the blood, something like that. The doctor told me that our family has a history of sugar so for that reason I was taking care of myself to prevent it. But now that I got it, I learned that it passed on, right, this Satan (Devil) passed it on.

Dietary practices:

Mary is one of the few women who could follow strict dietary management to control her blood sugar. This is because of her financial condition, as she has a secured job and a regular income source. Moreover, her mother and one of her sisters were diagnosed and passed away due to diabetes in 2007. She said she had been careful with her diet since then. She said:

I avoided eating potatoes, anything sweet like sugar, and all vegetables grown underground. However, I eat all other foods such as white rice (basmati), bread, vegetables like cabbage, mustard, *iarain* (wild leafy vegetables), *sla patho* (pumpkin leaves). The food that I avoided included sugar and potato- the moment I ate that potato, I could feel that my sugar has increased. Earlier also, I could never eat or drink anything sweet. It seemed that the sugar was already in my body, so I cannot tolerate anything sweet. I did not even eat pork as people told me that those who eat pork are very prone to getting sugar.

After she was diagnosed with diabetes, she was also given a diet chart by Lifeline, a private hospital in Shillong. Although she could not maintain the timing, she makes sure she eats the foods as written in the diet chart, like eating oats and bread and drinking milk during breakfast.

She avoided pork, red meat, and oily foods for lunch and dinner but ate fish and boiled chicken. She said:

The moment I wake up in the morning, I drink water, then drink aloe vera juice and amla juice. I used to drink that first, it is not because the doctor advised me to, but because it is my thinking, after 10-15 minutes I take the diabetes medicine. After 30 minutes, I have my breakfast, I used to drink milk, white oats, bread, and a biscuit-like cream cracker. I used to have tea time around 3 pm, along with horse gram, *bam khasi* (a traditional snack made of rice flour), bread, and biscuit. I used to have lunch around 11 am, but when I go to school, I used to eat whenever I am free. For dinner, I used to have *atta*, but now I do not feel I have the time to prepare *atta* it is because I do not feel like having it; otherwise, I could have made time for it. I prefer to eat little rice with three tablespoons of *tohja* (pulses). *Tohja* is very good to eat but only a little and not much. I used to eat basmati rice as I do not like brown it does not taste good. Imagine if we eat food that does not taste good and eat only a little, it will be difficult to work right.

Besides being able to comply with dietary advice, Mary also goes for a morning walk regularly. She said:

I regularly go for a morning walk at 5 am. I wake up at 4:30 am. The morning walk was a great medicine and refreshing the whole day. It is very beneficial for health. Even before I got this sugar disease, I am a person who likes to go for morning walks.

Despite living with diabetes, Mary shared that she could perform her daily activities, and diabetes does not affect her physical appearance. She said:

It is not affecting me that much. Many people did not even know that I have sugar because there was not even a slight change in me. People used to say that for those with sugar, their physical appearance also changes. They look gloomy, so it will be visible that they have sugar. But for me, people said they did not see any change. They do not know that I have sugar. I do not feel any change either. I do not think it is affecting me that much. When it becomes serious, it usually affects my eyes. But I can still read because I have my glasses. I used to go to school regularly, I never missed even a day...

Mary also believed that her faith would cure her from diabetes. She said:

My sugar disease will go away because earlier it was so high. Now it has decreased. I believe that by the blood of Jesus Christ, I will be completely healed....it will go away completely.

The narrative of Mary shows how she is susceptible to diabetes, given the fact that most of her relatives, including her mother, had diabetes. However, given her better socio-economic status and the financial resources to access treatment services at a good private hospital in Shillong and this has helped her in controlling her blood sugar. Further, her secured source of income enables her to adhere to her diabetes dietary regimen. Her optimistic attitude is reflected in her

daily life, where she said people do not know she has sugar disease as it did not prevent her from performing her daily tasks.

Narrative 3

The case of Co-Morbidity: Diabetes and Kidney Stones

Socioeconomic position:

Dashisha is 35 years old, never attended school, and is a Catholic Christian. She works as a daily wage labourer and was abandoned by her husband. She lives in a kutcha house in a village approximately 31 km from Jowai Civil Hospital, Ialong, and 8 km from the nearest Primary Health Centre. Her kutcha house was constructed temporarily on her maternal aunt's land as her mother did not let her live with her despite being the youngest. Although she used to work as a daily wage labourer, after the diagnosis of diabetes, she stopped working as her health was being affected. She said:

Since I got this sugar disease, I cannot go to work, so I am simply sitting. I want to live a healthy life longer for my children.

She has two sons, aged 16 and 14 years old. Her eldest son is working as a daily wage labourer at a house construction site in Shillong and earns INR 400/- (USD 4.82) per day as a wage. He studied only up to Class II and dropped out of school. Her youngest son, who used to go to school and studied up to class VII, dropped out because of the COVID-19 pandemic lockdown. She said that as the school was on and off. Therefore, he quit and is also working as a daily wage labourer at the site where they made cement water tanks and was paid INR 350/- (USD 4.22) as a daily wage. The family's monthly average income is INR 7,000/- (USD 84.38). The earning members of the family are her two sons, as she had stopped working at the request of her sons given her health condition.

Illness history:

She was diagnosed with diabetes at a public district hospital in 2018. She continuously blames herself for her illness. She narrates her illness history as follows:

Since 2018, I had kidney stones and was admitted to the hospital in Ialong (public district hospital). The doctor advised me to do many tests, and the results show that I have sugar.

Since then, the doctors advised me to avoid foods grown underground, like yam and potatoes. After a few months, I got relief from the symptoms of diabetes, so I thought sugar had disappeared. I think it disappeared once. But it was my mistake that it started again. You see, it has once disappeared...doctor advised me not to eat too much rice but only a little and to drink water before having food. I used to do that, so a few months ago, I was healthy and could go to work. It was my own mistake that I started eating yam, potato, and pumpkin. It was during the COVID-19 pandemic lockdown that it started again, and till now, it has not yet been cured. It was my fault; I made a mistake. I thought it had disappeared. I do not know it, then. It is only now that I knew about sugar that once it catches us, we cannot eat those kinds of food and always have to avoid them. Earlier, I used to think it was like many other diseases. How will I know this sugar disease is so *khor* (tough)? From now on, I will not eat. If only I were going to be healthy, let me be deprived of potato and yam.

The above narrative indicates that Dashisha was not aware of the chronic nature of diabetes and that there is a need for long-term dietary management. She considers diabetes a short-term illness that “disappeared” when its symptoms. Further, her limited knowledge related to diabetes is based on word of mouth or hearsay. She said:

People say that when it is increasing too much, we can die. People said when it shoots up, people will die right when the medicine is not matching...people say that. But in my opinion, I feel this sugar can be controlled through dietary modification.

She shared her experiences with the symptoms and how they had prompted her to seek treatment. She narrated:

At first, my body was shrinking, then it was swelling, and I felt *rkhin* (tightness that made her feel uncomfortable) in my leg, and my hands also felt '*rkhin*'. When I first (2018) got it (sugar), I was swelling like that too. Then I started thinking, why did I become *rkhin*? Why am I swelling like this swelling in my leg in my face whenever I wake up, and when I press my forehead, it will create a mark of my finger? In my leg also, it was like it was swelling, and I felt *rkhin* in my hands also. Whenever I am looking down, I feel like there is a heavy weight in my head, like a tingling sensation *rmi* (irritating sensation) like that it used to be. There is also biting with a tingling sensation in my head in the leg, and in my hands, it is like biting *tdin tdin* (expression of being pierced), even in my nails in my flesh...in my fingers also, there is the tingling pain. And my body also feels *suh tkhan* (cramping) like that biting from my waist to the backbones. Even the vein in my neck also has a severe feeling of *suh tkhan*, and even the neck from behind also has the feeling of severe *suh tkhan*. I cannot sit for long also; I always want to sleep. I have to tell my children to massage. When I woke up, I used to feel that my body became warm. I feel uncomfortable and restless. My body is also burning, and my head is also the same...at times, I used to feel feverish. It is like that ...

Dashisha narrated her symptoms using different words to express the pain and unpleasant experiences with different symptoms that prompted her to seek treatment in 2018 and be diagnosed with diabetes. Before 2020, she did not experience the symptoms anymore, so she

thought she had recovered. However, after the relaxation of the lockdown (the first wave of the COVID-19 pandemic) around September 2020, she started experiencing the symptoms again, which she guessed could be due to the increase in her sugar level. She said it was because she ate the tubers she was advised to avoid. She narrated the story as follows:

I started feeling better for a long time (2019-2020), so I thought it was cured. I do not know that this sugar will stay forever. I thought then that now I am healthy and good, so I stopped taking the medicine for a long time. During the lockdown (first wave 2020), I was careless with my diet, so the sugar started increasing again. I went to check it in Mukhep (a nearby village) as Wapung PHC was under micro containment and found it had increased to 494 (mg/dl), so the pharmacy doctor (pharmacist) was scared and told me, "It has increased a lot, please go and get it checked by the doctor go to a big doctor it is not right like this." When the micro containment was lifted, I again went to the doctor in Wapung PHC, in our center in our block. I went for a check-up here, and the doctor found that my sugar level was the same, so he provided me with insulin. After taking the insulin from there also for a month, the sugar did not decrease. The doctor again advised me (in November 2020) to go for testing. After the test result was shown to the doctor, he said we cannot treat you here because it is very high now. The doctor advised me to go to Shillong, but I told him I could not afford I did not have the money. So, he told me to go at least to Ialong (a village where the public district hospital is located), which is nearer, the travel cost is somehow affordable, and the doctor fee will also be lesser. The doctor from here advised me to take all the documents when I visit Ialong. In Ialong, Dr. Kilang examined me, but he advised me to take the antidiabetic medicine from his (private) clinic. However, whenever I visit Ialong for a check-up, I only want to meet Dr. Kilang. I prefer him. But the last time I went, I met another male doctor who is dark in complexion....

Dashisha's further narratives show that she is unaware of the long-term nature of diabetes, and the need for follow-up has increased her RBS so much that she has to take insulin injections. Her condition is such that the doctor at the primary health centre cannot treat her anymore and has to refer her to private hospitals in Shillong. But her economic condition does not allow her to visit good private hospitals in Shillong. Therefore, she has no choice but to visit the public district hospital with poor quality of care for diabetes. However, the doctor at the public hospital referred her to his private clinic again, leading to treatment expenditure. The total amount she spent on medicine, food, and travel was approximately INR 2,000/- (USD 24.11) per month. She also shared how she had to negotiate with the pharmacist when she visited the doctor for a follow-up after the COVID-19 pandemic lockdown was relaxed due to insufficient cash to pay for the medicine. She said:

As I am poor, my money was not enough.... even on that day (she cannot recall the day, but it was in November 2020), I only took (INR) 500/- (USD 6.03). So, I requested the pharmacist if she would permit me to take only a few medicines for that day and take the

rest when I got the money. But the lady who dispenses the medicine in the doctor's pharmacy was so kind that she said- "during this time, there is no work...so I can understand you have less money," she gave me her phone number and also said- "if you can come and collect the medicine twice or thrice little by little from today till the day next month where you have to meet the doctor...come and collect them few at a time but do not stop coming." As I did not have the money to take all of them, I went thrice to collect the medicine, and then the day to meet the doctor arrived. She gave me two strips at a time...for two strips, I paid (INR) 800/- (USD 9.64). Had it been some other pharmacy, they would not allow me to take the medicine in small quantities often. I have to spend my sons' earnings on medicine. I am spending the money on medicine while my sons work simultaneously.

Dashisha also shared how financial problems prevent her from seeking care for her other health problems. She said:

I used to have an eye problem and seek treatment from Shillong in Gupta, but now I do not have the money to go there. Now I do not know if it is because my eyes are having problems or because the sugar is too much that my eyes are blurred...I told the doctor when I visited the Ialong (public district hospital). But he told me it was already late (around 2 pm) and he (the eye specialist) would not be there anymore. He told me, "Come tomorrow..."

She was advised for surgery to remove the kidney stones but did not undergo it due to financial constraints and lack of family support, given their low-income status. Her husband had also separated from her. She said that if she undergoes surgery, she cannot work anymore.

Dashisha has two brothers and one sister, and she is the youngest. She shared her problems that although she is the youngest, she is not living with her mother as her mother favours her sons more. Her uncles gave the land for building the house only to the eldest sister but not Dashisha. She said: "For me, they did not give me any land. Because I am the youngest, they expect me to live with my mother. Even the land where my house is now is of my maternal aunt. She said she will take it away someday as she has many children and grandchildren." She also shared that she used to think a lot regarding a place to build her house as one day her aunt might take away the land. She said I am considering where I will get the money to buy land and where I will live after my aunt takes away her land.

In this world, so many things do not work well. Our family always has conflicts, so we live in different houses. My mother is happy with my brothers and elder sister, but I do not mind. She gave birth to them and gave birth to me, too. It depends on her choice. Whatever makes her soul satisfied and happy....as long as she is happy to let her be.... even if my mother's house is pucca, there is no need for creating problems. It is not like I will not go back there (die). What is the need for arguing and fighting? Many people do not understand. They said if it is us, we will not let it happen (referring to the customary

law where the youngest daughter has rights over ancestral properties). I just want to be a good person....

She also said she used to pray to God for a good husband and to take all her problems away. She again expressed her longing for a girl child as the people in her village told her that if her children were girls, they could have taken care of her properly. She also said that if they were girls, she did not want many husbands, but as her children were boys so she, if she found a good man, she still wished to have a daughter. She constantly mentioned her desire to have a girl child. She said:

What to do? I do not have a father for my children. I am poor, and my children are both boys. I still want a girl child. If there is a good man, I still want as a daughter who will take proper care of me...

Dashisha's narrative shows that she suffers from other social problems as well. However, her doctor advised her not to think too much. She said: Doctors told me, "If you have an illness like this and think too much, it will not get cured...."

She also shared that she does not want her two sons to know about her illness as she is afraid, they will feel sad, and she does not want them to be so. But later, she said she decided to tell her eldest son as she was scared, they would come to know after she died. She said:

I do not want my children to know as they are still very young and their thinking is also narrow...but could not help it, I told my eldest son...

After she talked about her illness to the eldest son, he felt so bad that he could not even eat properly. The family he is living with informed her about her son's situation. Her son told her not to think too much, that she should eat properly, and not stay late at night. She said- I told my son that as the disease passes through the blood, you should not *diang mynsiem* (a belief that there should be someone to receive one's last breath) her when she dies. After this, her son felt very sad and wept. She said I told him: "When I die, do not receive my last breath as the disease is hereditary, so I do not want it to pass to you...then he felt very sad and wept."

Given the amount of stress that Dashisha has to undergo, she needs some support; for her, the source of support is her religion. She said:

As a Christian, I used to go to the Father (Priest) to pray for me. We used to write our prayer requests. I requested my friends to write the prayer request for me, those who knew English. The father used to read the paper and pray for us. Because I cannot afford the treatment, I commit myself to God. With the power of prayers and faith, my kidney stones are now not there. It is not pain anymore. We used to explain to him about the

stones. I used to pray every night at home as advised by the Father. I think it is because God is helping me, so now there is a slight change... now I am feeling better. I am so poor that I cannot seek treatment from far...

The lack of social and financial support has left Dashisha helpless. Financial constraints prevent her from seeking proper medical treatment from a good hospital. Therefore, she has no choice but to depend on her faith to cure her illness. She has faith that prayers can heal all her illnesses.

Narrative 4

Diabetes Complications: Chronic Kidney Diseases

Socio-economic status-

Philari, 68 years old, lives in Takhniang village, 20 km from the nearest PHC, 31 km from Jowai, and approximately 90 km from Shillong. Philari is a Christian and did not attend schooling. She was diagnosed with diabetes 12 years ago (in 2009). She is a homemaker and takes care of children. Her husband died 13 years ago (2008), and the cause of death, according to her children, is due to diabetes. Her husband used to be a school teacher in a government lower primary school in their own village. Currently, she is financially dependent on her children and her husband's monthly pension of INR 10,000/- (USD 120.93). She had 15 pregnancies, but eleven survived, and now she has four sons and seven daughters. Two of her children also have diabetes. However, Philari shared that her parents did not suffer from diabetes. She used to live with her two daughters who are unmarried yet and all her other children live separately in their own houses both within and outside the village. In 2018, her youngest daughter started living together with her partner. There was no ritual ceremony or marriage. This is a common practice and is accepted in the community. Philari was unhappy with her youngest son-in-law, so she gave them a place to live separately. This is against the Pnar custom, where the youngest has to take care of their mother as they are the ones who have the right to inherit the ancestral property. Therefore, she lives with her eighth daughter, Nishan, 30 years old and unmarried. Nishan has completed her graduation in their own semi-pucca house. Anisha is the one who is currently taking care of her mother.

Narrative of illness experiences:

Philari shared her experiences with illness after her husband died. She said she was married in 1978 when she was 18 years old. She tried to recall the year of her marriage to estimate the years she had been living with illness. She said that after her husband died, she started becoming sick. She narrated her illness experience as follows:

After he died, then I started becoming sick. I was well only for one year following the year he died. Now I have to undergo regular dialysis, and it has been two years since I have been going to Newlife (a private hospital in Shillong) for dialysis. I was ill for the past 12 years, but before I was diagnosed with diabetes, I had joint pain. We did not even visit the hospital instead visited a private clinic at Jowai for treatment. I took the treatment for joint (knee) pain for four years with the same doctor, Dr. Ken. After that, people told me that even Dr. Ronie in Jowai also provides treatment for joint pain, so we switched to him. As Ken's medicines are very costly, I do not want to hide that we are poor and cannot afford them as we do not have the money then we visited Ronie. I think I took the joint pain medicine from Ronie for four years. After that (in 2018), I started feeling very weak always, and then my vision also started becoming blurred. Hence, I visited the *macy* (as per the daughter who was also present during the interview, she said her mother meant the Urban Primary Health Centre, Ladthadlaboh) at Jowai. After they examined me, they did the blood tests, and they told me that my sugar was very high (800mg/dl). Then they referred me to Dr. Ban (medicine specialist). That lady doctor at Ladthadlaboh (the UPHC) told me to go urgently to Dr. Ban, that private doctor in his clinic, and that we should not delay. Then I asked them you are referring me to the private doctor right, I did not carry enough money so I cannot go there. If I go there, I will not have money to go back home, so I did not go and returned home. So, I did not go, and I stayed at home for two days after which I went to Dr. Ban. When I reached Dr. Ban's clinic, he examined me, and then he told me how I could tolerate it. It was very severe. He told me to take the slip and go to Lifeline (a private diagnostic center at Jowai) immediately to do the tests. When I reached there as I was very serious, so they did the test for me first even when many people were standing there and waiting before me. Then the lady at the diagnostic center said to take this report *kong* (the local word when addressing a woman) and go to Ialong to Dr. Ban (by this time, Dr. Ban, the Medicine specialist, had gone to the Jowai Civil Hospital, Ialong as he is working there). When I reached Ialong, I showed the report to Dr. Ban, who admitted me to the civil hospital. I was in the hospital for seven days and was discharged. For one month, they gave me an injection (insulin), and I was asked to continue at home for one month. My sugar was around 800 (mg/dl) when I was hospitalized in Ialong (public District Hospital). My daughter used to give me the insulin injection at home when the doctor told us to continue for some time at home. After my discharge, I started taking the antidiabetic medicine from his private clinic, because Civil (another name for the public District Hospital) is very far for me. After that, I continue taking medicine for joint pain and sugar, BP. As the joint pain still persisted, so I visited Civil Hospital, Shillong where they told me that I needed to cut my feet from the knee joint. They said that because I was having a biting sensation and severe pain so they needed to cut it. But I refused, and since I refused, they do not even give me medicine, so I stopped going there. They told me that I needed to get admitted to cut my feet, but you know I do not want it. Imagine if they cut my leg, how will I be able to go here and there? So, I decided to let it be. But as the days go by, I started becoming serious again then I visited NEIGRIHMS (medical college and hospital in the outskirts of Shillong). When I reached NEIGRIHMS, they did all kinds of tests and gave me lots of

medicine, but they did not admit me. They told me to come again for a follow-up after one month. When I reached home, I took the medicines for only 15 days, and I felt like I am going to die at that instant, so I became scared to take the medicines. Then I switched to the medicines which I used to take from Dr. Robert's private clinic. But in 2019, again, I became very serious (symptoms), so my children took me first to Nartiang PHC, who told us to go to a big hospital. Then we went to Newlife and where they did all the tests, and they told me that my kidneys are spoiled because I was taking too much of medicines. Then I explained to the doctors and showed them the medicine which I was prescribed by the doctors at NEIGRIHMS. I told them that when I take this medicine, I feel like I am going to die, so I became scared and stopped taking it. Then they told me it was my mistake for not continuing with the medicine from NEIGRIHMS, they said you made a mistake. Had I taken it would not become like this. When I was taking treatment from NEIGRIHMS, only one of my kidneys was spoiled, but it is not even one year since my other kidney was also spoiled. They told me I made a mistake. Had I gone to NEIGRIHMS again they could have changed the medicine to that which had less power. They said, this one has big power if only you realized to go to them, you would have not become like this. Then I told them could not think of that. I was cursing NEIGRIM and told myself this is the reason why people are afraid of going to NEIGRIM because those who go there always die. From that time, I was afraid to go to NEIGRIM and even take their medicine. In Newlife, they gave me the same medicine but which has less power. But now I do not take the medicine anymore as my sugar is very low (hypoglycemia- Since 2020, her RBS decreased, but I have had to do the dialysis after every alternate day, and it has been two years since I started going for dialysis. I wanted to stop going, but I cannot bear the pain if I did not go.

The anecdote of her illness history is summarized in Table 1.

Table 1 Summary of her illness experiences and sources of treatment in the last 12 years

Sl. No.	Timeline	Illness	Source	Cost
1.	2009-2010	Joint Pain	Private clinic, Jowai Dr. Ken (for four years)	Cannot recall
2.	2013-2014	Joint pain	Private clinic, Jowai Dr. Ronie (for four years)	Cannot recall
3.	2018	Her vision started becoming blurred	Urban Primary Health Centre, Jowai- referred her to Dr. Ban's private clinic- a medicine specialist working in Jowai Civil Hospital, Ialong as her RBS was very high (800mg/dl)	Cannot recall
4.	2018	Diagnosed with diabetes and was hospitalized as her sugar was very high in JCH, Ialong. In the same year, she was also diagnosed with hypertension	The doctor diagnosed her with diabetes after the result of the test was out. The doctor referred her to Lifeline private diagnostic centre, Jowai, for the test	Cannot recall
5.	2018	Joint pain became severe	Civil Hospital Shillong. Advised for amputation- by the doctor- but she cannot recall the name of the doctor	Cannot recall
6.	2018	Joint pain became severe	As she refused the amputation at Civil Hospital, Ialong so she shifted to NEIGRIHMS	Cannot recall
7.	2018	Diabetes	Switched to Dr. Robert	Cannot recall

8.	2019	Symptoms became serious	Visited Nartiang PHC but referred to higher center	-
9.	2019	Acute kidney failure (one side)	Newlife private hospital, Shillong- dialysis was initiated-	Travel fare- INR 2000/- (USD 24.11) per visit*3= INR 6,000/- (USD 72.33) per week Injection- INR 1,500/- (18.08) per injection Blood tests- INR 2,000-5,000/- (24.11-60.27) Cost of dialysis- INR 2,775/- (USD 33.45)
10.	2019	The other side of her kidney was also spoiled	Dialysis was continued at Newlife Hospital	Approximately more than INR 33,825/- (407.74) per week
11	2020	Hypoglycemia	Treatment continued at Newlife Hospital	Approximately more than INR 33,825/- (407.74) per week
12	2021	She became breathless and unconscious	Newlife Hospital	INR 44,000/- (USD 530.40)

The source of medical expenditure came from selling off her assets, such as pine trees (commonly sold in the community to be used as wood), from the land she and her husband had purchased. She cannot estimate the amount of land she has sold or the trees, but she is afraid that her children will have nothing to inherit from her.

She attributed the reason for diabetes to arthritis medicine. She said it was because the doctor in the private clinic did not check her properly and treated her without doing any tests but only gave her medicine. She regretted that she only visited private clinics and not hospitals when her illness began initially. Philari's health has worsened as without dialysis, it is impossible for her to sit and talk to her family members. It is only after dialysis on every alternate day that she could at least walk, sit and converse with her family members. Since 2019 she started going for dialysis thrice a week. Every time they go, they have to reserve a car for INR 2,000/- (USD 24.11) per visit and incur huge treatment expenditures (Table 1).

Experiences with recent (3rd July 2021) hospitalization:

Philari also narrated her hospitalization experiences and the pain and suffering she had undergone. She narrated:

Last year (2020), I was admitted to Newlife because I was about to die. They admitted me for 13 days. We spent lots of money even during that time. This year too, they admitted me to the ICU on the 3rd of July 2021, I guess. We went from here. I was very serious, and I could not breathe. When we reached there, because it was in the middle of the night so the person who used to do the dialysis had gone home, so they could not do it that time. But even if she was there, they would not be able to do it because I became unconscious the moment I reached there. I was admitted for two nights. After they did the dialysis the next day, I became all right again. We spent (INR) 44, 000/- (USD 530.40), but I do not know whether they deducted from the smart card. But that was the amount of money I spent. My daughter went to pay the bill, I did not understand when she was explaining the bill to me...I was really scared when I saw the woman lying beside me die.

On that day (3rd July 2021), she said she had decided not to go to the hospital anymore. She said:

Imagine, it is not even the day for me to go for dialysis, and I already became like that, so I thought of not going anymore. What is the point of going there? I will tolerate it whether I die or live, I do not care. I told my children to wait till morning. But I felt something different which changed my decision. I was thinking when I already knew that if I go there, I will be better, and if I do not go, then I die if I die, will God not be angry with me, and will I become a sinner? There (referring to hell), I will live in suffering for eternity, so I decided to go. I told them okay, take me there (Newlife Hospital). Otherwise, I had already decided to not go even if I died, but when I thought of that, I agreed to go to the hospital. While on the way to the hospital, I was still conscious, but after reaching the hospital, I became unconscious. In the morning, after I woke up, I realized that I was wearing a hospital dress, there were wires (referring to the intravenous lines) all over my body, and they showed me one wire they said look at this wire you bought INR 10,000/- (USD 120.93), then I asked them the wire (intravenous lines) you only used it once and now you will throw it. They said yes, and I told them my money was wasted- they laughed at me for saying this.

Philari's life, as she narrated, became difficult after her husband passed away, who is her primary support for her and their children. This has led to her sadness, leading to illness coupled with complications that worsened her condition. Even along with her illness, she cannot help but think about her family at the same time feeling guilty for the financial expenditure incurred for her treatment. She said:

When I *pyrkhat* (stress) then I became tired and then feel suffocated, *pyrkhat*. I cannot stop thinking, but I do not know if it is leading to illness. Now nobody is earning in the family and contributing to the household. Moreover, I have to go and take the treatment always like this. I only spend the money on myself whatever is left, I spent it on myself

only, so I cannot stop *pyrkhat* even if it makes people sick, but I do not know how to stop it...

Narrative 5

The case of Diabetic Foot, Complications, and Increased Medical Expenditure

Socioeconomic status:

Queency was 50 years old and lives in Bambthong village, located approximately 17 km from Nartiang PHC and 42 km from Jowai Civil Hospital, Ialong. She is a Christian and belongs to the Church of God (Protestant) denomination. She is dependent on her children for a living. Her husband, too, is dependent on their children. She has nine children- six females and three males. She lives with her youngest daughter and her two unmarried sons. Her other six children were married and are living in separate houses. Six of her children cultivate ginger, broom, and turmeric on their land. The fourth daughter studied up to graduation and is working as a teacher under Sarva Shiksha Abhiyan (SSA) at Umladang village, a village adjacent to Bambthong village. Her children are living in and around the village.

Illness History:

Queency was very weak. Therefore, most of the information was shared by her caregivers. She could only talk about how and when she was diagnosed with diabetes. She said:

I was diagnosed with diabetes three years ago (2017) after I visited a private eye clinic in Jowai. The doctor at the eye clinic advised me to visit a Medicine Specialist for further diagnosis as I was having a blurring vision. I visited a private doctor who advised me to do the test at the Lifeline private diagnostic centre in Jowai. After two-three months of the treatment, my vision became clear, and I could see properly.

According to the information provided by 30-year-old her son-in-law, Jerry she used to go for regular check-ups at a private clinic in Jowai town until 2020, when she stopped taking treatment. He said the reason for her to stop was because her friends in the village told her that diabetes can be cured only through diet and exercise. He said she strictly adhere to the diet and she thought that now she is cured of diabetes so she stopped going for follow-ups. Jerry (30) said:

Yes, we used to go for follow-ups for diabetes when it became serious. For instance, she fell once before the pandemic, sometime in February 2020. We used to go to a private doctor in Jowai, but she did not take the medicine for less than a year. But we did not know as she did not tell us. My sister-in-law told us only when it became serious (when the wound was not healing and the wound became bigger). When I reached their house, I saw the infection and took her to the hospital. She did not tell us if it was because she

did not have the money that she was taking treatment from the informal providers (near their village). She was told by her friends in the village that if she takes herbal medicine and is able to restrict her diet, sugar would disappear.

Jerry (30) expressed his disappointment with his mother-in-law using traditional medicine. He said:

This *dawai pnar* (referring to medicine provided by informal providers) is not helping her. It is not working; we need to be responsible because this *dawai pnar* we cannot understand it. When a disease is serious, it seems difficult to manage as well.

Her 18-year-old youngest daughter, Heini shared how the wound initially began:

It was in November 2020 (cannot recall the date) that my mother was pricked by a sharp object while going for a morning walk. My mother informed us about this. I told her to apply nail polish to the scratch, and she felt good. But the scratch led to pain and swelling in her left limb. The wound gradually increased, and to cure the wound, she started taking medicine from an informal provider at Mynso, a village near our village. But it did not help her. The size of the wound increased, and she was having much pain due to the swelling. We took her to Jowai Civil Hospital, Ialong, and after two weeks, she was infected due to the scratch.

It became clear from discussions that Queency was admitted to the public district hospital with a complaint of pain and swelling in her left ankle in November 2020. She was unconscious at the hospital. Her youngest daughter, Heini, 18 years, was taking care of her at the hospital. During the hospitalization period, insulin was administered to her by the nurses as her RBS was very high.

After being discharged from the public district hospital, she visited Nartiang PHC for wound dressing. She looked weak during her visit to Nartiang PHC on 5th January 2021, so I could not ask her many questions. She seemed in much pain as the wound in her left limb became big, and her muscles became visible. Most of the questions were asked from Queency's youngest daughter Heini (18), and her fourth son-in-law, Jerry (30), after giving their consent and convenience to talk. When asked why she was discharged when her condition was not improving, her daughter said- we requested the discharge as the mother did not find the treatment helping her. She feels bad for us that we had spent a lot on her.

As the treatment expenditure was very high so her son-in-law, Jerry (30), started to apply for Queency the smart card, he said:

We just applied for the smart card when she was admitted to the hospital. We only applied for the smart card after realizing the treatment expenditure was very high. We thought that it is only diabetes; hence we do not have to spend much money. But after three to

four days, we realized the expenditure was very high, so we consulted the nurse, who suggested using the smart card. I visited the Block Development Officer's office to apply for her smart card, the fastest way to get it. We gave them her Epic (Voter ID card) as it is a document required to get the smart card.

The smart card was used as and when they purchased the medicine or do the test. But when asked how they pay, Heini (18) said she still uses cash, and the smart card is just for the pharmacist at the private pharmacy outside the hospital to issue the cash memos. Similarly, when they visit Lifeline private hospital for the tests, they have to first pay from their pocket, and accordingly, the cash memos will be issued to them. When asked what they did do with the cash memos, she said she threw them and that nobody explained to them that the money would get reimbursed. Concerning the treatment expenditure, Jerry (30), who was taking care of the expenditure, said:

We used to spend only (INR) 3,000/- (USD 36.21) daily on medicines. For blood tests, we have to spend up to (INR) 5,000/- (USD 60.35) as they told us to do four to five types of tests. Once you have to take her for the test, then *ngak ngak ne* (an expression referring to the extreme cost of the test). I used to give INR 5,000- 6,000/- (USD 60.35- 72.42) to my sister-in-law for 4-5 days at once. We spent around (INR) 70,000 (USD 844.95) for the two months of hospitalization (November- December 2020). The smart card is not really helping.... even the gloves they told us to buy...it is only for the bed that we did not have to pay for.

They were advised to do most tests at Lifeline private hospital. Jerry (30) is a truck driver and earns approximately INR 10,000/- (USD 120.77) monthly. He used to help Queency with the treatment expenditure. However, when asked if the money is reimbursed in her bank account, Heini (18) said their mother does not have a bank account. She said- *da pyndam ko ka da pyn iap ko ka* (my mother has closed her bank account). When asked why, she said:

It was a long time since my mother had no account since we were small. During that time, my mother was afraid of using Aadhar. In those times, people in our village were still afraid of Aadhar as they were told that if you are not using it, they would not be able to take money from the bank. Since then, she took all her money from the bank and closed her account, I think it was in the late 2000s.

Queency was discharged from the hospital based on her request as she did not find the treatment provided to her at the hospital effective. Besides that, she always wanted to get discharged as she felt guilty about placing the financial burden on her children. The doctor at the public district hospital where she was admitted treated the wound and advised her to regular dressing in the nearest public health facility. There is one HWC near her house, and it takes five minutes

via car, but the staff there said there is no proper equipment for treating the wound. Her family decided to take her to the PHC for regular dressing. Jerry (30) said:

We asked the sub-centre if they could do the dressing, but they told us that they do not have the required equipment to do the dressing. Otherwise, why would we go and stay at Nartiang (a relative house in order to be able to go for daily dressing)? It is much easier to stay at home in our village, but because of the dressing, we have to stay with our aunt in Nartiang village...

Queency's village is far from the PHC, and commuting daily is a challenge for both the patient and the family, so now they decided to stay in her sister's house in the village where the PHC is located. But still, they have to spend INR 200/- (USD 2.41) daily for the fare from her sister's house to the PHC as they have to reserve the local cab as she cannot walk to the PHC. Due to the wound, she was facing difficulty in walking.

Queency was also advised to continue with insulin even after discharge. Queency's daughter shared that they bought the insulin pen that cost around INR 1,300/- (USD 15.69), and it is a temporary one which means they have to purchase the pen again in case the insulin gets over. They bought the insulin pen from a pharmacy outside the hospital based on the advice of the medicine specialist at Jowai Civil Hospital, Ialong. However, the insulin pen stopped working for the last week (from 28th December 2020 to 5th January 2021). Now that it became dysfunctional, they have to purchase a new one while there is lots of insulin still available in the insulin pen. Insulin is supposed to be stored inside a refrigerator, but the fact that they did not have a refrigerator in their houses (they kept it 'just like that' in the almirah in the kitchen. The insulin was usually administered by her daughter, Heini (18), whom the nurses at Jowai Civil Hospital, Ialong taught. Heini (18) shared that the nurse had instructed her to administer the insulin based on her blood sugar reading. She was also taught how to check the RBS of her mother.

As Queency did not get to take the insulin because the insulin pen got damaged. There is a constant increase in her RBS (always more than 300mg/dl). The test report (380mg/dl on 5th January 2021) was shown to Dr. Lara at the Nartiang PHC, who then advised her to take the oral hypoglycaemic agent, i.e., metformin, because she cannot use insulin. In addition, the doctor also advised the family member to take her again to Jowai Civil Hospital, Ialong. But Queency refused to go to the hospital. On 12th July 2021, Queency became serious, and as she was also anemic, she had to undergo a blood transfusion. Heini (18) shared that all the blood transfused when hospitalized in November 2020 came out of her vagina two days back. But

she did not want to visit the hospital because she fears the mandatory COVID-19 test and guilt of treatment expenditure. Instead, they called the informal providers to their homes to provide treatment for Queency. Heini (18) shared:

Dr. Bthuh⁸⁸ had given her IV fluids in the house because our mother refused to go to the hospital. Our mother refused treatment because she fears visiting the hospital and feels guilty about putting the financial burden on us. She was also afraid that she might have to do surgery for the removal of her uterus, as told to us by the doctors. She does not want her uterus to be removed.

Her daughter shared that since January 2021, her mother had taken medicine for diabetes from a traditional healer from Umroi. For her leg, she had taken it from the traditional healer near their village.

The reason for Queency's refusal to go to the hospital was because of financial constraints. Her daughter said that although they have the smart card, the fact that they have to pay first is a problem. The context of the pandemic and lockdown has led to a reduction in the earning capacity of her family members. Her case shows how limited knowledge about the importance of care and management of diabetes in rural areas has led to numerous complications, increased out-of-pocket expenditure, and premature mortality.

*Queency passed away in July 2021 due to many complications resulting from her illnesses

Annexure 17 Background characteristics of health officials associated with the MHIS-PMJAY

Sl. No.	Designation	Age	Gender	Religion	Educational qualification
1	State Manager	37	Female	Christian (Protestant)	Masters in Mass Communication and Media Studies
2	Claims Officer	37	Male	Christian (Protestant)	Bachelor in Computer Science Application
3	Medical Officer	32	Male	Indigenous religion	MBBS
1	District Programme Manager	33	Male	Christian (Roman Catholic)	Master in Business Administration (MBA)
2	Medical Officer	36	Male	Christian (Protestant)	MBBS

⁸⁸ An informal provider in their village. According to the information shared by health officials, he is an unqualified practitioner. I tried to meet him during fieldwork in the villages, but the people in the community said he is not available.

3	Ayushman Mitra	28	Male	Christian (Protestant)	12 passed

Annexure 18 Field Photos captured during fieldwork



Photo 1 A woman respondent in her house, captured and produce with her consent



Photo 2 Locally grown fruits and vegetables used by Women as a means to cure diabetes (Above- bitter vegetables; Below- dal like fruit, known locally as *sama*)



Photo 3 Houses in one of the study villages



Photo 4 Drying of small fish in respondent's house



Annexure 19 Publications, conferences and workshops attended

Publications:

- Muksor A., & Parmar, D. (2023). Cultural Beliefs and Practices in Self-Management of Diabetes among Pnar Women in Meghalaya, India. *The Science of Diabetes Self-Management and Care* (by Sage) 49 (6), pp. 462-476.
- Muksor A., & Parmar, D. (2023). Mid-Level Healthcare Providers (MLHPs): Insights from West Jaintia Hills District, Meghalaya. *Economic and Political Weekly Journal*, LV (38), pp. 26-29.
- Muksor, A. & Parmar, D. (2022). Living with Diabetes in Times of COVID-19 Pandemic: A Qualitative Study from West Jaintia Hills, Meghalaya, India. *Journal of North East India Studies*, Volume 12: Issue 1, Jan-Jun. 2022, pp. 8-32.
- Muksor, A. (2022). Barriers to Diabetes Management: Patients and Healthcare Providers' Perspectives. Souvenir of the Meghalaya Medical Services Association. Published for the 22nd Scientific Conference cum General Body Meeting. The theme of the meeting was- 'Medical Professionals: Health and Wellness?'. The Conference was organized from 27th to 28th May 2022 at the State Convention Centre, Shillong.
- Hinge, G., Muksor, A., et al. (2020). Integrated Risk of Virus Outbreaks. In Manish Kumar Goyal and Anil Kumar Gupta *Integrated Risk of Pandemic: Covid-19 Impacts, Resilience and Recommendations*. ISSN 2662-4885, ISSN 2662-4893 (electronic). Springer.

Papers under Revision:

- The paper titled "Implementation of the National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases, and Stroke (NPCDCS) in Meghalaya," Authored by Alacrity Muksor and Dr. Daksha Parmar, is in the peer review process.
- The paper submitted to Sage journal entitled "Living conditions of tribal female older adults with diabetes in rural Meghalaya, India: A qualitative study" by Alacrity Muksor and Dr. Daksha Parmar is under the process of revision.

Work in Progress by Alacrity Muksor & Dr. Daksha Parmar:

- Challenges Faced by Tribal Women in Seeking Diabetes Care: A Qualitative Study from Meghalaya State in Northeast India.
- Are the State-Funded Health Insurance Scheme Easing the Financial Burden of People Living with Non-Communicable Diseases (NCDs)? Voices from the West Jaintia Hills of Meghalaya.

Paper Presentations:

- The paper entitled "Experiences and Challenges of People Living with Diabetes during the COVID-19 Pandemic: Qualitative Insights from Rural Meghalaya, India" was presented at the Indian Association for Social Sciences and Health International Conference organized from 15th to 17th March 2023 at SHARDA University, Greater NOIDA. Alacrity Muksor and Dr. Daksha Parmar are the authors of the paper and are in the peer-review process.
- The paper titled "Living with Diabetes in Times of COVID-19 Pandemic: A Qualitative Study from West Jaintia Hills, Meghalaya, India" was selected for oral presentation at the Graduate

Research Meet-2023, organized by the Department of Humanities and Social Sciences, IIT-Guwahati on the 6th and 7th January 2023. The paper is authored by Alacrity Muksor.

- The paper titled “Implementation of the National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases, and Stroke (NPCDCS) in Meghalaya,” Authored by Alacrity Muksor and Dr. Daksha Parmar, was presented in the North East Research Conclave organized by IIT Guwahati from the 20th to 22nd May 2022 at IIT Guwahati, Assam.
- The paper titled “The Archetype of Public District Hospital- A Case Study of Ganesh Hospital, Meghalaya,” Authored by Alacrity Muksor, was presented at the Annual Conference of the Indian Association for Social Sciences and Health in Collaboration with IIT-Mandi. The conference was organized from the 8th to the 10th of December 2019 at IIT-Mandi, Himachal Pradesh.
- The paper titled “Ganesh Das Hospital: Benchmark for the Public District Hospital,” Authored by Alacrity Muksor, was presented at the Graduate Research Meet-2019, organized by the Department of Humanities and Social Sciences, IIT-Guwahati on the 1st and 2nd November, 2019.
- The paper titled “Pattern of Major Morbidity among Adult Population in India and its Determinants: An analysis using IHDS-I & IHDS-II,” Authored by Alacrity Muksor, Dr. Priyanka Dixit and Dr. Daksha Parmar, was presented in the International Conference on Nutraceuticals and Chronic Diseases. The Department of Bio-Sciences and Bio-Engineering, IIT-Guwahati, organized the conference from 23rd to 25th September 2019.

Conferences and Workshops attended:

- Attended a two-day workshop on “From Evidence to Action Series workshop on the North-Eastern Region of India” organized by TISS, Mumbai, in Guwahati on the 10th and 11th of November 2022. The workshop is related to the follow-up of the GATS-2 project. Attended along with Supervisor Dr. Daksha Parmar.
- Attended a two-day virtual workshop on GIS (Geographical Information System) Applications in Social Sciences. The workshop was conducted on the 13th and 14th of May 2022 and was organized by the Discipline of Humanities and Social Sciences Centre, Indian Institute of Technology Gandhinagar.
- Attended a two-day e-workshop on “Qualitative Research with NVivo” organized by Commacad Team. The e-workshop was conducted on the 7th and 8th of August 2021.
- Attended the Access to Medicines, TRIPS, and Patents Workshop organized by TISS, Mumbai, Jan Swasthya Abhiyan, and Third World Network at TISS, Mumbai (17th -21st December 2019).
- Rapporteur for the COPASAH Global Symposium on Citizenship, Governance, and Accountability in Health 2019 (15th -18th October 2019) in India Habitat Centre, New Delhi.

Newspaper Article:

- Authored the article titled “COVID-19 in Rural India-XXXVII: How Ummulong Village in Meghalaya is Struggling to Cope with the Lockdown” in the 37th report series, that provides glimpses into the impact of COVID-19-related policies on life in rural India. The series, commissioned by the Society for Social and Economic Research, comprises reports from

various scholars conducting village studies in different parts of India.
<https://www.newsclick.in/Ummulong-Village-Meghalaya-Struggling-Cope-with-Lockdown>

- Authored the article titled “Challenge of Diabetes Management in West Jaintia Hills of Meghalaya” and was published in the newspaper Syllad- The Rising Meghalaya. The article gives a brief insight into current Ph.D. research work: <https://www.syllad.com/challenge-of-diabetes-management-in-west-jaintia-hills-of-meghalaya/>

