

Living with Diabetes in times of COVID-19 pandemic: A Qualitative Study from West Jaintia Hills, Meghalaya, India

Alacrity Muksor and Daksha Parmar

The COVID-19 pandemic lockdown imposed to break the chain of virus transmission brought numerous challenges to people living with Type 2 diabetes. The present paper attempts to explore and understand the challenges faced by people living with diabetes and the variation in experiences based on their socioeconomic context. This qualitative study was conducted during the pandemic's first and second waves in rural areas of West Jaintia Hills District, predominantly inhabited by the Pnar tribe. In-depth interviews with 90 Pnar men and women living with diabetes were conducted. Findings from the present study reveal the perception that COVID-19 was not severe, limited knowledge about complications arising out of diabetes, and impact of the lockdown, multiplied to increase the vulnerability of the tribal populations living in the hilly and difficult terrain of the district. Therefore, addressing the burden of chronic illnesses in rural tribal areas pandemics by providing comprehensive care and services at public health facilities.

Keywords: Diabetes, Pnar tribe, Jaintia Hills, Meghalaya, COVID-19, Pandemic, Lockdown, Inequality

Introduction

Type 2 Diabetes (henceforth "diabetes"), a metabolic disease is caused due to increased blood glucose levels (Sapra & Bhandari, 2021). It is a chronic condition that can lead to complications such as heart attack, stroke, kidney failure, vision impairment, and limb amputation if it is not controlled (Phillips, 2020). People living with diabetes are usually advised to follow a strict diet plan, undertake regular exercises, and maintain sound mental health for good glucose and strict adherence to medications is also necessary (Grabowski et al, 2021; Verma et al, 2021). People living with diabetes are never allowed to forget that they are suffering from diabetes even for an hour (Weaver, 2019). Thus, they have to take extensive care of themselves, affecting them

Alacrity Muksor and Dr. Daksha Parmar are Doctoral Scholar and Assistant Professor respectively at the Department of Humanities and Social Sciences, Indian Institute of Technology Guwahati, Assam- 781039, India. [Email: alacritymuksor@iitg.ac.in]

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, endocrinologists, and podiatrists. These different healthcare providers function together to achieve the desired blood glucose level and prevent complications (Mohseni et al, 2021).

With the outbreak of COVID-19, the vulnerabilities of people with co-morbidity such as diabetes increased manifolds. They are at a higher risk of getting infected, falling severely sick once infected, and face difficulties in accessing health care 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 lockdown introduced by most countries. The lockdown has led to sudden change in daily routine, reduced physical activity, and difficulty in accessing the basic needs (Nachimuthu et al, 2020; Pal & Bhadada, 2020; Gamble et al, 2020). The disruptions caused by a raging pandemic and with 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 living 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).

Several social and cultural factors, however, 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. Education, occupation, social class/caste, and income are the main indicators of socioeconomic status used in research to understand health inequalities. The interplay of socio-economic-political context directly affects the intermediary factors such as housing, food, health system, behavior, and genetic and psychosocial factors. For example, in a welfare state, health care is made accessible to everyone, thereby reducing health inequity. But with the adoption of neoliberal policies, health inequity widened as the out-of-pocket expenditure (OOPE) increased manifold. In India, it is reported that every year 70 per cent of health expenses are met by people and nearly 7 per cent of the Indian population is pushed into poverty due to high OOPE (Rao, 2018). Haire-Joshu and Hill-Briggs (2019) mentioned five social determinants of health whose influence occurs at an individual and population level. The five social determinants include socioeconomic status, living and working conditions, multi-sector domains, sociocultural context, and socio-political context acting interdependently. Moreover, studies have shown that individuals with socioeconomic stability have better diabetes outcomes than those who are financially weak (Arutselvi, 2018). Thus, selfmanagement of diabetes varies across individuals belonging to different social groups. The social 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 clearly impacted the already marginalized social groups and intensified their vulnerabilities. It is in this context that the present study was conducted among the Pnar tribe or the indigenous people in rural areas of Meghalaya. Studies have shown increase in prevalence of lifestyle diseases such as cardiovascular diseases and type 2 diabetes among the indigenous population. This is due to the shift from traditional to modern lifestyle thereby increasing their risk to Non-Communicable Diseases (NCDs) (Government of India, 2018). According to the data from the Disease Burden Profile of Meghalaya, the proportion of total disease burden from NCDs is the highest at 52.3 percent (Indian Council of Medical Research, Public Health Foundation of India, and Institute for Health Metrics and Evaluation, 2017). In Meghalaya, where 80% of the population resides in rural areas, according to the census 2011, diabetes is widely prevalent. The results from the "random survey" of diabetes using hospital records, diabetes screening camps and door to door survey conducted by Syiem et al, (2012) found out that the average prevalence of diabetes amongst the urban Khasi and Jaintia (also known as the Pnar tribe) populations of Meghalaya was 9.89 % and 12.5% respectively. As per the National Family Health Survey-5 (2019-2020) district factsheet for West Jaintia Hills district, the percentage of women and men (15 years and above), whose Blood Sugar is more than 140 mg/ dl is 8.8 % and 7.8% respectively and for Meghalava it was 9.5% and 13.9% respectively. This rise in prevalence of NCDs among the tribal populations have an important bearing on the health system especially in the rural areas. Among the northeast states of India, Meghalaya has the worst health condition after Assam. For instance the Infant Mortality Rate of Assam and Meghalaya according to NFHS-5 (2019-20) was 31.9 and and 32.3 per 1,000 live births respectively. When compared to the urban, the condition in rural areas are far worst as "rural areas in NE states are very backward", lack connectivity and poor public health infrastructure (Singh, 2017).

Numerous studies have been conducted on the impact of lockdown on diabetes in developed and urban areas of developing countries, including India (Nachimuthu et al, 2020; Ghosh et al, 2020; Sauchelli et al, 2021; Grabowski et al, 2021; Verma et al, 2021). However, there are limited studies conducted in rural areas and negligible in rural areas of the northeastern states. Therefore, the present study aims to understand how the COVID-19 pandemic and the subsequent lockdown impacted the selfmanagement of diabetes across different socioeconomic groups, especially in the context of the tribal population living in rural areas of Meghalaya. The specific objectives of the study include- i) To explore the lived experiences of the Pnar tribe in general with COVID19 and COVID19 vaccination and to understand their experiences during the COVID19 pandemic lockdown. ii) To understand how the general perception of the community about COVID19 shaped and influence the lived experiences of people living with diabetes during the pandemic. iii) The study also aim to understand how the experiences of seeking care for diabetes during the pandemic varies across people from different socio-economic groups. In this state the COVID19 pandemic lockdown from March 24, 2020 as per the announcement made by the Central Government. On April 13, 2020, the State reported the first case of COVID19. As of May 24, 2020, the number of cases in the State was 14 with one death due to COVID19. Nevertheless, the lockdown was relaxed in a phase-wise manner following the Central Government guidance since June 2020. By December 14, 2020, the State reported 12, 866 cases and 128 deaths (Das, 2020). During the second wave, the number of COVID19 cases was increased in the State. In May 2021, the lockdown was again announced in the district and was lifted on June 19 2021. The total number of cases and deaths reported in the State as of August 31 2021 was 75,836 and 1,311 respectively.¹

The present paper is divided into five sections. The first section introduces the paper, the second section described the methods adopted for the study, and the third section explain the main findings from the field The fourth section is the discussion and the last section concludes the paper.

Methods

Research setting and respondents: The present study was conducted in 19 villages across Thadlaskein rural block in West Jaintia Hills District, Meghalaya, predominantly inhabited by the Pnar or the Jaintia tribe. Fieldwork for the study was carried out between October 2020 to August 2022 and divided into three phases. The Institute Human Ethics Committee (IHEC), IIT Guwahati, granted ethics approval for the study. Using convenience sampling, participants for the study were selected from the District Hospital, Primary Health Centre (PHC) and the Health and Wellness Centres (HWCs). Given that the study was conducted during the first and second wave of COVID19 pandemic, only a few people living with diabetes had accessed these facilities. There was fear among people as many of them were not visiting the facilities. Therefore, for additional respondents, frontline health workers, especially the 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 individuals with diabetes and whose data was in the medical records were included. A total of 90 respondents participated in the present study, and the response rate was 100% (See Table 1). Telephonic interviews were conducted for those individuals selected from the health facilities (n=13). This was done because there was a space constraint at health facilities. Hence it is difficult to maintain physical distance while taking the interview. For individuals selected from the community, interviews were conducted at the respondents' home, while following the COVID19 protocol of sitting outdoors, wearing masks and maintaining physical distance. In addition, interaction with other members of the community was also made to understand the general perception on COVID19 and COVID19 vaccines. Before conducting interviews, consent form was explained to the respondents, and confidentiality was assured. Names of respondents, villages and health facilities have been changed wherever necessary to maintain their confidentiality.

Data collection methods: Besides in-depth interviews with people living with diabetes, observations, informal discussions, group discussions, and everyday conversations were also the data collection methods used. An open-ended interview schedule that was written in English was developed. The interview was conducted in Pnar language

and lasted between 45-60 minutes. The interview schedule for people living with diabetes collected information related to the socioeconomic characteristics of respondents; history of diagnosis and experiences with symptoms of diabetes; experiences and challenges of seeking care during the COVID-19 pandemic lockdown; perception on COVID-19 vaccination as preventive measures from complications due to diabetes. The researchers transcribed the recorded interviews and later translated them into English.

Data analysis: The transcripts were reviewed, and gaps were identified for further fieldwork that was required. The researchers conducted an open coding of field notes, and interview transcripts. The coded data was then reviewed to develop themes. Themes were reviewed by the researchers and then finalized. The data was read repeatedly to ensure the validity of themes, which emerged from the study.

Supplementary methods: To understand more about the lives of the people in villages during COVID19 pandemic, 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. During this period, COVID19 restrictions were lifted as the number of COVID19 cases has reduced drastically in the State and the district. Analysis of local media such as "U Nongsain Hima" "Rupang", "Wyrta" through their YouTube channel on how the COVID-19 pandemic and COVID-19 vaccine were reported during the period between May-June 2021 was also conducted.

Findings

Socio-demographic characteristics of respondents: All (n=90) respondents belonged to Pnar tribe except one whose parents had migrated from Punjab. Most (n=71) of the respondents interviewed across 19 villages were women. An effort was made to increase the number of male respondents in the study area by increasing the number of villages. However, based on the record of the frontline workers maintained at all Health and Wellness Centres, the majority were women. According to the health officials, this is due to men's poor health-seeking behavior in Meghalaya, which is also evident during fieldwork. Table 2 shows the socio-demographic and economic status of the respondents interviewed.

Epidemiology of COVID-19 in Meghalaya

During the first wave of the COVID-19 pandemic that began in January 2020, the spread of the disease in India was mainly confined to urban areas, but previous history of pandemic suggested that rural areas have an equal chance of getting affected (Sundararaman & Ranjan, 2020). The lockdown was therefore imposed throughout the country, both rural and urban. In Meghalaya, too, people were locked in their homes from March 2020 when the lockdown was announced nationally. It was only in April 2020 that the first case of COVID-19 was reported in the State. The first case was a well-known doctor at a private hospital in Shillong. The moment the State

authority announced the detection of the first case, there were fears among people. The fear was more especially among those who had traveled to Shillong and met the doctor for a medical check-up with the permission of the district authority. Consequently, the Meghalya government gave orders that all those who visited the hospital on or after March 2020 need to register for the tests and quarantine (The Hindu, 2020). The fear started subsiding after the result of those who were tested mostly turned out to be negative. This incident made people in the State question about the disease. As the number of cases started rising slowly, people started learning more about its signs and symptoms based on their observations from their family, neighbors, or relatives. The transmission of COVID-19 in northeast states was slow compared to other states in India such as Maharashtra and Gujarat (Sundararaman & Ranjan, 2020). In West Jaintia Hills District, the first COVID-19 case was reported on 3 June 2020, when the lockdown was relaxed partially as the lockdown negatively impacted people's lives (Syllad- The Rising Meghalaya, 2020).

How COVID-19 was perceived in the study villages

In this section, to contextualize the study we will briefly explain how most people in the villages perceived COVID-19. According to them, 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, considered a "political issue." Most elderly men and women interacted in the study villages commented:

The State simply wants to increase the number of COVID-19 cases to get more funds from the center and that people who they said were tested positive for COVID19 do not really get the required assistance. This is "*kjut politik*" (*kjut is* a Pnar word for disease or illness and *politik* means politic).

According to the people in villages, the symptom of COVID19, 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, an elderly widow Hannah (60), who lived with diabetes since the past three years, studied up to Class III and was financially dependent on her children shared:

We do not understand this disease; this "synrum" (sneezing) "wadat" (headache) has always been there. Our elders said whenever this season (winter) arrives; this "synrum" and "wadat" will also come. It is these symptoms only that the government considered COVID19. It is just that, earlier they do 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, the number of COVID-19 cases increased and became more serious. Based on the data collected from the official Twitter account of the Government of Meghalaya (@MeghalayaGov), the number of deaths reported

in the district increased from 10 deaths on May 18, 2021, to 34 deaths on May 26, 2021. Still most people were not convinced or believed in COVID-19 pandemic. They still attribute 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 also been acknowledged that the rural areas have also been affected during this wave. This was evident even in the West Jaintia Hills district, where a majority of the population resides in rural areas.

As there was a spread of COVID-19 in villages during the second wave in 2021, so active surveillance to detect COVID-19 cases was conducted by the public health workers. 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 the private clinics. The other argument that the people in the community made was the absence of medical care for people who tested positive. This was because those who were tested positive, were just advised for home isolation.

Life during COVID19 pandemic lockdown

During both 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 "LMN" village, it was observed that all the shops were opened, 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 (45), who worked as a farmer, denied COVID-19 when he was interviewed during the second wave. He shared:

In our village, there was no restriction at all; there was no corona. Recently [in 2021], there were six deaths in our village. The health department said they died due to COVID 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 denial of COVID19 in the study villages. The other incident Iaineh (45) 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? When we are deprived of food, he will not come and give us food, right? 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.

Barriers to visiting healthcare facilities during the COVID19 pandemic

In the villages, it was observed that people with fever, cough, and cold refused to go

to the hospital and visited the private clinic instead. The main reason for not visiting the hospital was that Rapid Antigen Test (RAT) was conducted for all individuals with symptoms such as fever, cough, shortness of breath. Interaction with members of the community in villages reveals that they became suspicious of the healthcare system too. A group of men who resides in remote villages said:

They just say it is the corona, but it is not. It is typical to us. We always used to suffer from "*khairih*" (fever), "*indoh*" (common cold) "*khaikyoh*" (cough). It was there earlier as well (*kani ka kjut toh kawa juh em hi cha I, mynchwa leh*). It is better not to go to the hospital as when they do the test they will say it is corona.

The belief that COVID-19 was merely common cold acts as barrier even among people who are living with diabetes. However, the problem was much more complex as for few respondents who believe that COVID-19 exists, they also stopped visiting hospitals as they were scared of contracting the virus. Thus in both the case people stopped visiting hospitals- one was the fear of being tested for COVID19 and the other was of getting infected with it during the hospital visit.

Access to healthcare facilities during the COVID19 pandemic lockdown-

Respondents' socioeconomic status and their place of residence influenced access to the health facilities. Living in rural areas, far from health facilities, makes follow-up for diabetes very challenging. About 23 women (n=21) and men (n=2) reported facing challenges in traveling to health facilities during both the first and second waves of the COVID19 pandemic lockdown. Consider Milan, 57 years old Pnar woman, who works as a farmer, and lives in "HIJ" village located 23.3 km from the nearest PHC. She said she had stopped treatment for two months (April to June 2021). When asked for the reason for discontinuing treatment, she said-

I do not feel anything now, and I am all right. My children used to take me to the hospital when I felt that my sugar is high, as I would have a tingling sensation in my hands, feet, and head.

She was diagnosed with diabetes in 2001. However, as Milan said, she did not get her Random Blood Sugar (RBS) tested for two months, so the female surveillance worker at her village who accompanied the researcher during fieldwork checked her RBS. The result was staggering. Her RBS was 521 mg/dl! on this day (July 9, 2021) when the interview was conducted. However, shortages of vehicles increased travel costs due to restrictions imposed during the lockdown, and the fact that the nearby PHC was under micro-containment made the situation more difficult for Milan. She was left with no choice but to reserve a vehicle the next day and visit a private clinic in a village located at a distance of 27.6 km from her village. When asked about the cost of reserving a car, she said:

Every time I go, the driver used to charge Rs.1000-1200 because while going, it is difficult to get a cab, and while coming back, if I happen to get the exact car, then I don't need to pay. But if I get the medicine late and the cab I reserved earlier had gone, I have

to book a different taxi again for Rs.1000.

In rural Meghalaya, transportation was a problem even in pre COVID-19 times. Only a few local vehicles (mostly Maruti 800) were available, and mostly in the morning as people living in the villages used to go to the market in the nearby towns. People have to reserve vehicles during a health emergency, which is expensive. This situation worsened during the lockdown, and the drivers were charging exorbitant prices even when the lockdown was relaxed. Hence, the cost of transportation itself restricted people from poor socioeconomic backgrounds from visiting health facilities located in other villages and towns.

However, respondents (n=6) with a better socioeconomic status shared that they could visit the health facility for follow-up of diabetes care as they own a car. For instance, Teressa, 58 years old Pnar woman, who worked as a Lower Division clerk in the office of the Jaintia Hills Autonomous District Council (JHADC), was diagnosed with diabetes in 2009 at a private hospital. The hospital is located in Shillong, at a distance of 62.7 km from her village. Since the diagnosis was made, she had visited the private hospital once in three months for follow-up. During the lockdown, given that she had a car, it was not a problem to visit the hospital. After showing the prescription slip, the police permitted them to go. Her relatively middle-class situation and the fact they owned a car enabled her to access the private hospital even during lockdown, which was not the privilege most of the other respondents enjoyed.

Nonetheless, even among respondents with better socioeconomic status, fear was a barrier to visiting the hospital for follow-up. This fear and acceptance of COVID-19 are mainly seen among respondents who have children working as nurses and doctors. For instance, Liana (66), a widow and a retired government servant, shared:

I was supposed to visit the doctor, but I was scared, as my daughter who is working in a private hospital as a nurse, is not letting me visit the hospital physically. My daughter is afraid that I will get a COVID-19 infection, she said she will get the sugar medicine for me. She said there are around 20 COVID-19 patients in the hospital.

Lack of comprehensive care for diabetes at public health facilities

Women (n=30) and men (n=4) respondents who belong to poor social groups have no choice but to depend on public health facilities such as the District Hospital and the PHC for diabetes care. For instance, Sanki, 55 years old Pnar woman, who worked as daily wage labourer, was diagnosed with diabetes in 2017 in the District Hospital. She lives in a village located 10 minutes reach the district hospital, on October 30, 2020, She visited the District Hospital for follow-up. During her follow-up visit, the pharmacist gave her oral antidiabetic medicine free of cost for one month as per the advice of the doctor. She was also advised to do many tests such as HbA1c², Kidney Function Tests (KFT), and serum lipid profile in a private hospital, located 2.2 km from the district hospital, as the tests were not available 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.

Thus, Sanki had no other option but to simply go home. Although she can access the public hospital during the COVID-19 pandemic lockdown, she could not get comprehensive diabetes care due to poor services available at the public health facilities and her poor economic condition.

Disruptions in the supply of antidiabetic drugs at the PHC during the COVID-19 pandemic was one of the challenges for people living with diabetes and belonging to low socioeconomic backgrounds. Syntiew, 55 years old, Pnar woman, widow, and worked as a stone crusher, was diagnosed with diabetes in July 2020. When she visited the PHC for follow-up the next month, i.e., August 2020, she said:

I could not get any medicine from the dispensary [referring to the PHC-people in the villages call PHC, dispensary]. If it did not happen like that, I would have taken medicine from the dispensary only. The doctor told me, "this medicine we do not get anymore, please don't mind. You have to purchase it." For one entire month I had a fear of taking medicine from anywhere randomly. I was just unable to get the medicine. From that time, I was told to take "mahajon"³ medicine, but I didn't have the money to purchase it.

As Syntiew (55) could not afford to purchase the antidiabetic medicine from a private pharmacy so she shifted to ayurvedic medicine. She could do this only because her 17-year-old son was working as a helper in the Ayurvedic doctor's house in her own village in "PQR", gave her medicines and treatment in exchange for her son's wages.

Access to antidiabetic medicine and diagnostic for diabetes

Table 3 shows the different sources through which men and women access antidiabetic medicine. Less than 50% (47.37% men and 45.07% women) of the respondents reported that they could take antidiabetic medicine during the COVID-19 pandemic lockdown. These respondents shared that their doctor had already given them enough antidiabetic medicine for the lockdown period. Nonetheless, 13.33% of the respondents did not take antidiabetic medicine for two months or more, and 28.89% shared that although they had stopped taking antidiabetic medicine, but tried to control their blood sugar through diet and exercise. The reason they shared was "difficulty in getting vehicle to go for follow-up", "did not feel the need to take medicine as I did not experience symptoms anymore," and so on.

Self-monitoring of blood sugar can be done at home, provided a glucometer and other consumables are available. Only a few respondents (n=6) could afford to buy a glucometer. Those respondents women (n=4) and men (n=2) belonged to a better socioeconomic group. For instance, Langki, 59 years old, a Pnar man, is a retired government servant. He was diagnosed with diabetes in 2017. Besides being educated, he also had a secured source of income. Further, his son-in-law who is a doctor working at a Public Hospital in Shillong, used to support him a lot when it came to seeking care and also monitoring his health status. When Langki (59) got COVID-19 in May 2021, his son-in-law made sure that he got admitted to a hospital where he works so that he could take good care of him as he had comorbidity of diabetes. Langki said he used to check his RBS regularly by himself and accordingly took medications. During his interview on June 29, 2021, he said that his sugar level was

75 mg/dl, he shared:

The doctors told me not to worry as below 100 is normal. Now it is always below 100, but I am still taking treatment. If my sugar is low, I will take medicine only once a day, but if it is high, I will take it twice.

Similarly, Emma 66 years old Pnar woman, retired government servant who used to work in a Bank, too, had a glucometer at home. She also has two daughters who are nurses. 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 respondent, Ridaka, 58 years old Pnar woman who was educated up to Class X and worked as a school teacher, used to check her RBS regularly as her children had bought the glucometer for her. Ridaka shared:

I cannot go to Shillong for a check-up because there is the coronavirus. 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 if my RBS is 200 or 300, then I have to take it 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 own doctor, 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 respondents, as well as the social capital in terms of having professionally qualified relatives and children, enables individuals belonging to higher-income social groups to properly and regularly self-manage their diabetes even during the pandemic and the lockdown.

However, this was not possible for the majority of respondents who belonged to poor socioeconomic households and faced severe difficulties in ensuring regular checking of blood sugar as seeking diabetes care was highly costly. For instance, Syntiew (55), as discussed earlier, found it difficult even to purchase medicine from a private pharmacy, let alone a glucometer. Phyrnai (65), an elderly widow who suffered eye complications due to diabetes and is financially dependent on her children, who are working as daily wage laborer 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 should buy a glucometer. She said my sugar keeps fluctuating, so I need to check it regularly. She helped me in getting the glucometer, and cost Rs. 3 000, which is very costly.

Forced dependence on alternative therapy to control blood sugar

The COVID-19 pandemic lockdown impacted travel to a health facility for followup, especially in the case of chronic diseases like diabetes. The impact was more severe for the respondents living in rural and remote areas of the district who had no choice but to rely on alternative therapies or utilize little knowledge that they gained related to controlling blood sugar. For instance, Phas, 46 years old Pnar woman, drank passion fruit⁴ leave juices to control her blood sugar for one month (May 2021) when the lockdown was imposed in the district. 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 diagnosed with diabetes in 2016. When asked who advised her to take passion fruit leave juices to control her sugar, Manda, the ASHA who is also Phas's sister and was present during the interview, said:

During my visit to the Children's Hospital, the hospital's owner informed me about it. He showed me the fruit on his mobile. As I told him that 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: "Don't you have free drugs to give her as the cost of medicine is too costly for her to afford?" The high cost of transportation and medicine could also be the reason why Phas (46) used the passion fruit leaf juice for one month.

Vulnerabilities to COVID-19

People living with diabetes were worst affected due to pandemic and the accompanying lockdown resulting in severe complications. This is evident from the data shared by one of the private hospitals in Shillong. Due to the lack of well-equipped healthcare facilities within the district, people were forced to visit the private hospitals in Shillong, traveling more than 60kms.

The analysis of the data 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, whereas 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.

However, in the present study, out of the 90, four respondents, one man and three women, were infected with COVID-19 during the second wave of the COVID-19 pandemic, i.e., in 2021. The woman, Naphi, 53 years, who worked as a school teacher and was diagnosed with diabetes on January 11, 2021, succumbed to COVID-19 on June 3, 2021. Langki, the man discussed earlier, was cured of COVID-19 and did not suffer from any complications. The difference between the two was the time between the onset of symptoms and when the respondent consulted the physician. Langki said: "I attended a funeral on May 19, 2021, but they did not tell me it was COVID-19 death. The deceased had fever and cough, so I suspected it could be COVID-19 death".

On May 26, 2021, he started developing symptoms, and immediately sought medical help. And the next day, he was admitted to the hospital where his son-in-law was working. Being a member of the Village COVID-19 Management Committee

(VCMC), he said he had also taken both doses of COVID-19 vaccination to set an example for the community. However, for Naphi, the situation was different. On May 21, 2021, when active surveillance for COVID-19 was conducted in her village, one of her close friends was tested positive for COVID-19. According to the ASHA, Naphi became very scared and tried to avoid taking the COVID-19 test. However, on May 23 Naphi started developing symptoms but it was only on June 1, 2021, that she agreed to go to a private hospital in Jowai located at a distance of approximately 27 km from her village. She was 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".

However, Phawa (65), a widow who got infected with COVID-19 during the second wave in 2021 and was advised for home isolation, shared:

In 2021 when I was tested for COVID-19 and was kept under home isolation, the health workers from Jowai, Civil Shillong, and then NEIGRIHMS used to call us. However, nobody from the dispensary CHC, that covered the village where she lives] had come to check on me. I think I was cured from COVID19 and did not suffer complications due to "God's grace".

Attitude of the community towards vaccination

With the coming of COVID-19 vaccines, the perception of the community about COVID19 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, Kyntiew, the Public Health Nurse at the PHC 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 that were prioritized to go for vaccination was shared through the announcement made by the village administration. In the "XYZ" village, Meena (48), studied up to class IX and worked as a small trader selling clothes, shared: "The village administration had warned us that if we do not take the vaccine, they will not be allowed to carry on with our work".

Meena (48), who was 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 both hypertension and diabetes; therefore, she was scared that the vaccine will make her illness complicated. Whereas according to the protocol, people who have 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.

Fear of death post COVID-19 vaccination

The community's attitude towards vaccination became more complex when two people in "ABC" village who got infected with COVID-19 died. There was fear that people seemed to now believe the dreadfulness of the disease. 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 "ABC" village, one man who was at their house said- "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 that "we are not dying".

People in the villages shared "even people who were vaccinated still got corona and still die of the disease". They also argue that "people even die after taking the vaccination". Also, based on the order given by the district administration, people who are at a higher risk of getting the disease should get vaccinated. Otherwise they will not be allowed to carry out their business, be it driving local vehicles, trading, etc. This surprisingly made the people more suspicious and they said- "what kind of vaccines is it that, that they have to force us to take? There must be something beyond". Their argument was that- fear of death post-vaccination.

The local, news channels streamed on YouTube was flooded with news about the refusal of COVID-19 vaccines by people across the State. The video that was streamed on June 16 2021 in the T7 News channel was about countering the order given by the Deputy Commissioner of East Khasi Hills District regarding mandatory vaccination of traders and shopkeepers. 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 that the people should inform him if they are denied to open their shop so that he will talk to the administration. He further stated that if their concerns are not heard, then they are ready to file the Public Interest Litigation (PIL). 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 Rs. 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.

COVID-19 Vaccine and the perception of people living with diabetes

Being a part of the community, people living with diabetes also developed their views

concerning COVID-19 vaccines. Out of the 90 respondents, 50 were interviewed in 2021 after the COVID19 vaccine was introduced. Almost 50% (n=21) did not take the vaccine. There was a mixed response from them, both positive and negative, but most of the respondents who are living with diabetes shared that they were weak and were afraid to take the vaccine. The other fear was the fact that they are old and have hypertension. In this case, they fear that the vaccine will worsen their condition. For instance, Eda (68) 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 anything]. I am already old enough that is the reason I do not take it. I was thinking that since I am growing old already and I simply sit at home, if my power is gone, then I will die anyway. I only feel like that, so I don't take the vaccine.

The response was similar even with respondents who are educated and work in the government sector. For instance, Nika (66), Pnar woman studied up to matriculation and was a retired government servant, shared:

I thought, as I am already old, and I cannot eat properly, if I take the vaccine, I 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 what the government protocol was, 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 the prevention of 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 makes people scared of the COVID19 vaccine.

The perception regarding COVID19 vaccine was not shaped by education alone but also by their worldviews. For instance, Bih (55), a widow, did not receive any formal education and worked as a daily wage laborer shared:

Out of all the people from my locality, I am the only one who had 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 when I was young that I would regret the world if I die. Now we are so old so it is okay even if we die, I am nt afraid.

Discussion

The present paper highlights the difficulties faced by people living with diabetes in the hilly tribal areas of Meghalaya and how the COVID-19 pandemic lockdown exacerbated their vulnerabilities. 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 is one of the factors that determine the utilization of health care services (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 their own vehicle, which is not the privilege for many respondents in the present study.

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 had led to high out-of-pocket expenditure (Oosterhoff et al, 2021). In the present study too, respondents reported that unless they have a minimum of Rs. 1000 rupees in their bag, they could not visit any doctor. The outbreak of the pandemic and its impact on their financial status act as a barrier in routine care for diabetes. The lack of adequate health facilities available within the district forced people to visit Shillong and thereby incurring huge expenditure on travel as well. 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. In Meghalaya, public health facilities in rural areas, still struggle to ensure regular supply of antidiabetic medicine, diagnostic tests for diabetes and even counselling services. This is clearly reflected in the present study. As reported by WHO (2020), there was a disruption in the supply of antidiabetic drugs in the the 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 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 had also been documented that it is poverty that causes diabetes and its complications resulting from poorly controlled blood sugar.

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, (2021), 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, in the present study, it was found that the frequency of blood sugar monitoring varies across respondents depending on their ability to access health care facilities and their ability

to purchase a glucometer which was largely influenced by their socioeconomic status.

It is well-documented that the chance of getting admitted into the Intensive Care Unit (ICU) is higher among people living with diabetes who get infected with COVID-19 (Tiwari et al, 2021). This is true in the case of the present study, where one respondent died during the second wave as there was a delay in seeking treatment due to excessive fear, preventing immediate action. Al-Moteri et al, (2021) used the fear-drive theory and other theories to discuss the change in behavior of people living with diabetes during the COVID-19 pandemic lockdown. As per the fear-drive theory, fear motivates individuals to adopt a change to relieve the negative consequences of the risk. In the case of COVID-19, fear encourage people to take preventive measures to prevent themselves from getting infected with COVID-19 (Al-Moteri et al, 2021). In most of the villages visited, there was a denial of COVID19 and there were discrepancies and inconsistencies in the perception of COVID-19. However, excessive fear restricted most respondents from taking preventive action, such as taking the vaccine.

In India, non-adherence to medication is quite common due to low literacy levels and difficulties accessing healthcare facilities even during pre-COVID-19 times (Verma et al, 2021). This is similar to the present study, where respondents with low literacy level or education considered diabetes to be a short-term illness. Consequently, they stopped treatment when their doctor told them their sugar was under control. Effective management of diabetes, or any chronic condition, requires coordinated efforts from the healthcare team, patients, families, and other partners in the local community, including a favorable environment that allows for and promotes a coordinated response. Poor treatment outcomes are commonly attributed to patients' lack of "knowledge" and poor treatment "compliance". Few researchers have studied sociocultural issues in Low and Middle-Income Countries while exploring associations between stress, depression, and diabetes, suggesting the need to complement the biomedical approach for diabetes management with a psychosocial approach (Bhojani et al, 2013).

Gender is another determinant of health inequality. In the present study majority of the respondents were women, which indicates that women suffer more from chronic morbidity such as diabetes. The Pnar tribe are known to practice matrilineal culture where children takes the clan name of the mother and the youngest daughter is the heir of the family property that are mainly ancestral property (Gassah, 1994). Therefore, the sole responsibility of taking care of children is by the mother (Nongbri, 2008). In this situation, managing a demanding illness like diabetes is very challenging. Women in the present study reported to have sacrificed their health at the cost of their children's food and education, and this is not different from women living with diabetes in a patrilineal society (Weaver, 2019). During the pandemic, they had to struggle for jobs and thereby increased both their mental and physical stress (War and Kharkongor, 2021). These factors, which is overlooked by the health professionals needs adequate attention through other welfare programs to ease the burden of women in Meghalaya's matrilineal society.

Individuals with diabetes, mainly belonging to marginalized and disadvantaged populations and the elderly, deprived of social support, are not always able to practice self-care and modify drug doses. These populations depend on 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 notion that "people in villages do not suffer from diabetes" had led to the 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 signs, symptoms and complications of diabetes. With the outbreak of COVID-19 pandemic, limited knowledge about the long term nature of diabetes and the need for regular follow-up, people with diabetes in villages have no other choice but to wait for the withdrawal of the lockdown. Nonetheless, this impact is not the same across social groups as evident in the present study where educated, respondents with secured jobs and income could follow self-management of diabetes even during the lockdown.

Conclusions

The present study highlights the challenges faced by people living with diabetes in villages of Meghalaya dominated by tribal population. The suggestion commonly made and adopted in times of crisis 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 those who are economically weak as they cannot afford to buy a smartphone and in rural areas there are also electricity and network issues. Due to poor quality of services available in public health facilities, [although they are accessible] people have to travel to nearby town and city, thereby incurring huge out-of-pocket expenditure especially during the COVID19 pandemic on transportation and in 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 during the time of crisis such as the COVID19 pandemic should be beyond Telemedicine. Frontline workers need to be trained and sensitized the need to provide support to the most marginalized section of the population who are deprived of even basic health care services. Public health facilities needs to be equipped to provide care for chronic illnesses and make them more resilient during crisis. In rural and remote villages, implementing telemedicine is challenging due to poor networks and an irregular electricity supply. Therefore, in healthcare research, innovating technology that addresses these challenges is needed to ensure equitable access to healthcare services during a crisis. Moreover ensuring the smooth implementation of Health and Wellness Centres (HWCS) in rural and remote areas is very crucial.

Notes

1. Based on the data collected from the official Twitter account of the Government of Meghalaya (@MeghalayaGov) accessed on August 31, 2021, available at https://twitter.com/MeghalayaGov

2. HbA1c or glycated hemoglobin- as the name suggests, it is a fraction of hemoglobin in the RBCs with glucose attached to it.

3. In the Pnar language, *mahajon* means rich. Here she means medicine of the rich.

4. 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.

Acknowledgements

We would like to thank the District Medical and Health Officer, and the District Nodal Officer of the NPCDCS program, West Jaintia Hills District for permitting us to conduct the study. Visit the villages was possible because of the permission granted by the village headmen, our gratitude goes to them as well. We are indebted to the health care providers and the respondents from the community for their priceless contribution. The study is possible because of their kind cooperation and willingness to share their experiences.

References

- Agarwal, V., G. Singh, & S.K. Misra. (2017). Diabetes Sweeping Rural Areas: Findings from Community Based Study in Rural Agra, India. *International Journal of Medicine and Public Health* 7(4), 207-13.
- Al-Moteri, M., V. Plummer, H.A.M. Youssef, R.W.H. Yaseen, M. Al Malki, AAI. Elryah & AA Karani. (2022). The Experiences of People with Diabetes during COVID-19 Pandemic Lockdown. *International Journal of Environmental Research and Public Health*, 19, 340.
- Arutselvi, D. (2018). Coping with diabetes as an everyday experience: A study from urban Chennai. *National Medical Journal of India* 31(1), 35-38.
- Atieno, L. (2020). "NCDs and COVID-19: What you need to know?". *The New Times*, April 9. https://www.newtimes.co.rw/lifestyle/ncds-and-covid-19-what-you-need-know
- Basu, S., & S. Garg. (2017). The barriers and challenges toward addressing the social and cultural factors influencing diabetes self-management in Indian populations. *Journal of Social Health and Diabetes*, 5, 71-6.
- Beck, J-P. (2020). "The forgotten patients: COVID-19 and the impact on people living with non-communicable diseases". *HealthcareITNews*, June 17. https://www.healthcareitnews.com/blog/europe/forgotten-patients-covid-19-and-impact-people-living-non-communicable-diseasess
- Bharati, D. R., R. Pal, S. Kar, R. Rekha, T. V. Yamuna, & M. Basu. (2011). Prevalence and determinants of diabetes mellitus in Puducherry, South India. *Journal of pharmacy & bioallied sciences*, 3(4), 513–518.
- Bhojani U., Mishra, A., Amruthavalli, S., Devedasan, N., Kolsteren, P., Henauw S. D., & Criel, B. (2013). Constraints faced by urban poor in managing diabetes care: patients' perspectives from South India. *Global Health Action*, 6, 22258.

- Chaufan, C., & Weitz, R. (2009). The Elephant in the Room: The Invisibility of Poverty in Research on Type 2 Diabetes. *Humanity & Society*, 33(1-2).74-98.
- Das, M. (2020). "3 die of COVID19 in Meghalaya, toll 128". *Times of India*, December 14. https://timesofindia.indiatimes.com/city/shillong/3-die-of-covid-19-inmeghalaya-toll-128/articleshow/79716893.cms
- Gamble, A., Pham, Q., Goyal S., & Cafazzo, J.A. (2020). The Challenges of COVID-19 for People Living With Diabetes: Considerations for Digital Health. *JMIR Diabetes*, 5(2), e19581.
- Gassah, L.S. (1994). Jaintia. In *People of India (States series): Meghalaya (Volume XXXII)*, General editor- K. S. Singh, editors- B. Pakem, Shibani Roy and Arabinda Basu. Anthropological Survey of India, Seagull Books, Calcutta.
- Ghosh, A., Arora, B., Gupta, R., Anoop, S. & Misra, A. (2020). Effects of nationwide lockdown during COVID-19 epidemic on lifestyle and other medical issues of patients with type 2 diabetes in north India. *Diabetes Metabolic Syndrome*, 14(5), 917-920.
- Government of India. (2018). *Report of the Expert Committee on Tribal Health: Tribal Health in India; bridging the gap and a roadmap for the future*. Available from: https://nhsrcindia.org/report-expert-committee-tribal-health [Last accessed on 2020 September 20]
- Grabowski, D., Overgaard, M., Meldgaard, J., Johansen, L.B. & Willaing, I. (2021). Disrupted Self-Management and Adaption to New Diabetes Routines: A Qualitative Study of How People with Diabetes Managed Their Illness during the COVID-19 Lockdown. *Diabetology* 2(1), 1-15.
- Haire-Joshu, D., & Hill-Briggs F. (2019). The Next Generation of Diabetes Translation: A Path to Health Equity. *Annual Review of Public Health*, 40,391–410.
- Hartmann-Boyce, J., Morris, E., Goyder, C., Kinton, J., Perring, J., Nunan, D., & Mahtani et al. (2020). "Diabetes and COVID-19: Risks, Management, and Learnings From Other National Disasters". *Diabetes Care*, 43(8),1695-1703.
- Indian Council of Medical Research, Public Health Foundation of India, and Institute for Health Metrics and Evaluation. (2017). *India: Health of the Nation's States-The India State-Level Disease Burden Initiative*.
- International Institute for Population Sciences (IIPS) and ICF. (2021). National Family Health Survey (NFHS-5), 2020-21: India, IIPS.
- Jeermison, R.K. (2012). Perception of Health Care Option and Therapy Seeking Behaviour of Tangkhul Nagas. *Journal of North East India Studies*, 2 (1), 22-39.
- Joshi, R., Atal, S., Fatima, Z., Balakrishnan, S., Sharma, S., & Joshi, A. (2020). Diabetes care during COVID-19 lockdown at a tertiary care centre in India. *Diabetes research and clinical practice*, 166, 108316.
- Kundap, R.P, Vidhate, K.B. & Fernandez, K. (2015). Assessment of Prevalence of Diabetes among Rural Population of Pune District, India. *National Journal of Community Medicine*, 6(3), 385-389.

- Mohseni, M., Ahmadi, S., Azami-Aghdash, S., Isfahani, H.M., Moosavi, A., Fardid, M., Etemadi, M. & Ghazanfari, F. (2021). Challenges of routine diabetes care during COVID-19 era: A systematic search and narrative review. *Primary Care Diabetes*, 15(6), 918-922.
- Nachimuthu, S., Vijayalakshmi, R., Sudha M. & Viswanathan, V. (2020). Coping with diabetes during the COVID 19 lockdown in India: Results of an online pilot survey. *Diabetes Metabolic Syndrome*, 14(4),579-582.
- Nongbri, T. (2008). Gender, Matriliny, and Entrepreneurship: The Khasis of North-East India. Zubaan. India
- Núñez, A., Sreeganga, S.D., & Ramaprasad, A. (2021). Access to Healthcare during COVID-19. *International Journal of Environmental Research and Public Health*, 18(6), 2980.
- Oosterhoff, P., Saprii, L., Kharlyngdoh, D., & Albert, S. (2021). When the Hen Crows: Obstacles that Prevent Indigenous Women from Influencing Health-care policies-A Case Study of Shillong, Meghalaya, India. In R.J. War & G.C. Kharkongor (Eds.). *Gender, Sexuality & Society in Northeast India* (First edition). Shillong, Meghalaya, India, Martin Luther Christian University Press.
- Pal, R., & Bhadada, S.K. (2020). "COVID-19 and non-communicable diseases". *Postgraduate Medical Journal* 96:429–430. https://doi.org/10.1136/postgradmedj-2020-137742
- Pardhan, S., Islam, M.S., López-Sánchez, G.F., Upadhyaya, T., & Sapkota, R.P. (2021). Self-isolation negatively impacts self-management of diabetes during the coronavirus (COVID-19) pandemic. *Diabetology and Metabolic Syndrome*, 13(1), 123.
- Phillips, T. (2020). The Everyday Politics of Risk: Managing Diabetes in Fiji. *Medical Anthropology*, 39(8), 735-750.
- Rao, N. (2018). Who Is Paying for India's Healthcare? Available at https:// science.thewire.in/health/who-is-paying-for-indias-healthcare/ Accessed on February 10, 2023
- Sahu, B.P. & Kumar, S. (2014). National Rural Health Mission in Meghalaya: A Review of Past Performance and Future Directions. *Journal of North East India Studies*, 4 (1), 1-12.
- Sapra, A., & P. Bhandari. "Diabetes Mellitus". [Updated 2021 September 18]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK551501/
- Sauchelli, S., Bradley, J., England, C., Searle, A. & Whitmarsh, A. (2021). Exploring support needs of people living with diabetes during the coronavirus COVID-19 pandemic: insights from a UK survey. *BMJ Open Diabetes Research Care*, 9(1), e002162.

- Sciberras, J., Camilleri L.M., & Cuschieri, S. (2020). The burden of type 2 diabetes pre-and during the COVID-19 pandemic - a review. *Journal of Diabetes and Metabolic Disorder* 19(2),1-9.
- Singh, K.S. (2017). The Self Perceived Morbidity and its Determinants in North East India, *Journal of North East India Studies*, 7 (1): 93-114.
- Singh, P.S., Sharma, H., Zafar, K.S., Singh, P.K., Yadav, S.K., Gautam, R.K., & Pious, T. (2017). Prevalence of type 2 diabetes mellitus in rural population of Indiaa study from Western Uttar Pradesh. *International Journal of Research in Medical Sciences* 5 (4), 1363-7.
- Sundararaman, T., & Ranjan, A. (2020). Challenges to India's Rural Healthcare System in the Context of Covid-19. *Review of Agrarian Studies*, 10 (1), 128-142.
- Syiem, D., Lyngdoh, W., Warjri, P., Tariang, D., Dkhar, A., & Diengdoh, A.M.R.. (2012). Prevalence of diabetes amongst the Khasi and Jaintia population of Meghalaya. *The North Eastern Hill University Journal* 10 (1).
- Syllad- The Rising Meghalaya. (2020). *First COVID case reported in Jowai*. Available at https://www.syllad.com/first-covid-case-reported-in-jowai/ Accessed on 17 January 2023.
- The Hindu (2020). *Meghalaya registers first COVID-19 positive case*. Available at https://www.thehindu.com/news/national/other-states/meghalaya-registers-first-covid-19-positive-case/article31334933.ece Accessed on 17 January 2023.
- Tiwari, A., D. Kumar, M.S. Ansari, S.K. Chaubey, N.R. Gupta, V. Agarwal, K.P. Chandra et al. (2021). Impact of lockdown on self-care management among patients with type 2 Diabetes Mellitus residing in Lucknow city, India A cross-sectional study. *Clinical Epidemiology and Global Health* 10,100703.
- Verma, AK., Beg, M.M.A., Bhatt, D., Dev, K., Alsahli, M.A., Rahmani, A.H., & Goyal, Y. (2021). Assessment and Management of Diabetic Patients During the COVID-19 Pandemic. *Diabetes Metabolic Syndrome and Obesity: Targets and Therapy* 14, 3131-3146.
- Verma, M., Sharma, P., Chaudhari, A., Sharma, M., & Kalra, S. (2021). Effect of Lockdown on Diabetes Care During the COVID-19 Pandemic: Result of a Telephone-Based Survey Among Patients Attending a Diabetic Clinic in Northern India. *Cureus* 13(10), e18489.
- War, R.J. & Kharkongor, G.C. (2021). Gender, Sexuality & Society in Northeast India (First edition). Shillong, Meghalaya, India, Martin Luther Christian University Press.
- Weaver, L.J. (2019). Sugar and Tension: Diabetes and Gender in Modern India. Rutgers University Press.
- World Health Organisation. (2020). *Rapid assessment of service delivery for NCDs during the COVID-19 pandemic*. https://www.who.int/publications/m/item/rapid-assessment-of-service-delivery-for-ncds-during-the-covid-19-pandemic

Zaman, F. A., and A. Borang. (2014). "Prevalence of diabetes mellitus amongst rural hilly population of North Eastern India and its relationship with associated risk factors and related comorbidities". *Journal of natural science, biology, and medicine*, 5(2), 383–388. https://doi.org/10.4103/0976-9668.136195

Sl. No. Facilities where respondents were identified	Women	Men	No. of respondents
1 From the community through HWCs/SCs and with the help of Community Health Workers	58	15	73
2 Primary Health Centre	3	0	3
3 NCD Clinic, District Hospital	6	3	9
4 Ayurvedic Clinic, District Hospital	2	0	2
5 Inpatient ward, District Hospital	2	1	3
Tota	ıl 71	19	90

Table 1 Identification of Respondents

	Women (n=71)		Men	(n=19)	Total (n=90)	
	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage
Age (in years)	1	1.41	0	0.00	1	1.11
1. <30 years						
2. 30-40	5	7.04	2	10.53	7	7.78
3. 41-50	12	16.90	6	31.58	18	20.00
4. 51-60	28	39.44	5	26.32	33	36.67
5. 61-70	18	25.35	2	10.53	20	22.22
6. 71-80	5	7.04	3	15.79	8	8.89
7. >80	2	2.82	1	5.26	3	3.33
Marital Status						
1. Unmarried	1	1.14	0	0.00	1	1.11
2. Married	38	53.52	16	84.21	54	60.00
3. Widowed/widower	27	38.03	2	10.53	29	32.22
4. Separated/Abandoned	5	7.04	1	5.26	6	6.67
Educational Qualification						
1.Illiterate/No Schooling	39	54.93	5	0.00	44	48.89
2. Upto Class VII	20	28.17	8	42.11	28	31.11
3.Class VIII-X	8	11.27	1	5.26	9	10.00
4. Class XI-Graduation	4	5.63	3	15.79	7	7.78
5. Post graduation	0		2		2	2.22
Occupation						
1. Attended domestic duties only	8	11.27	0	0	8	8.89

Table 2 Socio-economic characterisitcs of respondents

2. Self-employed agriculture						
(farmer)	14	19.72	4	21.05	18	20.00
3. Self-employed non-	10	14.08	1	5.26	11	12.22
agriculture (shopkeepers, small						
traders, drivers, small business)						
4. Casual laborer in agriculture	9	12.68	0	0.00	9	10.00
(agricultural laborer)						
5. Casual laborer in non-	1	1.41	1	5.26	2	2.22
agriculture (daily wage laborer)						
6 Regular wage and salary	8	11.27	5	26.32	13	14.44
(professional, technical,						
administrative, govt. jobs)						
7. not able to work due to	17	23.94	5	26.32	22	24.44
illness/old age/dependent						
8. Retired/ pensioners	4	5.63	3	15.79	7	7.78
Religion						
1. Christian	59	83.10	18	94.74	77	85.56
2. Indigenous religion	5	7.04	0	0.00	5	5.56
3. Indigenous religion blend	6	8.45	0	0.00	6	6.67
with Hinduism						
4. Others	1	1.41	1	5.26	2	2.22
Average annual income						
1. Not reported any income	25	35.21	5	26.32	30	33.33
2. Below 12,000	1	1.41	0	0.00	1	1.11
3.12,000-84000	15	21.13	0	0.00	15	16.67
4. 84001-100000	12	16.90	3	15.79	15	16.67
5. 100001- 300000	15	21.13	7	36.84	22	24.44
6. Above 300000	3	4.23	4	21.05	7	7.78
Socio-economic groups						
1. Above Poverty Line	27	38.03	10	52.63	37	41.11
2. Below Poverty Line	44	61.97	9	47.37	53	58.89
Number of Children						
1. No Children	1	1.41	2	10.53	3	3.33
2. 1-5	19	26.76	5	26.32	24	26.67
3. 6-10	47	66.20	9	47.37	56	62.22
4. More than 10	4	5.63	3	15.79	7	7.78
Years diagnosed with diagnosed with diabetes						
1. less than one year 2. 1-10 years	4	5.63 73.24	0	0.00	4	4.44
2. 1-10 years	5	7.04	0	0.00	5	5 56
4.21-30 years	2	2.82	1	5.26	3	3.33
5. more than 30 years	- 1	1.41	0	0.00	1	1.11
6. Cannot recall	7	9.86	1	5.26	8	8.89

Family History of diabetes						
1. Yes	8	11.27	3	15.79	11	12.22
2. No	27	38.03	8	42.11	35	38.89
3. Don't know	36	50.70	8	42.11	44	48.89

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

	Men (n=19)		Women (n=71)		Total (n=90)	
	n	%	n	%	n	%
Antidiabetic medicine was available from the last follow-up	9	47.37	32	45.07	41	45.56
Antidiabetic medicine purchased from Pharmacies	1	5.26	10	14.08	11	12.22
Stopped taking antidiabetic medicine and no dietary restriction	1	5.26	11	15.49	12	13.33
Blood sugar control only through diet and exercise	8	42.11	18	25.35	26	28.89
Total	19	100.00	71	100.00	90	100.00

Table 4 People from West Jaintia Hills District admnitted in the "UVW" private hospital, Shillong

Years	Admitted due to c with its complicat infected with CO	liabetes along ions but not VID19	g Infected with COVID19 along wi other complications such as chron 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, Shillong