

# Living with diabetes in Northeast India: An exploration of psychosocial factors in management

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## ABSTRACT

**Purpose:** India is the 'Diabetes Capital of the World' and accounts for one in seven adults living with diabetes worldwide. Psychosocial, economic, and cultural correlates of disease have important implications for disease management but are rarely explored in India. The purpose of this study is to address psychosocial and cultural factors in diabetes management in the northeastern region of India which has a high disease burden.

**Methods:** This study attempts to explore the psychosocial and lived experience of diabetes in the northeastern state of Meghalaya. The sample was selected from individuals attending an outpatient facility of a multi-speciality clinic. Semi-structured interviews were conducted with 25 individuals (13 women and 12 men), above the age of 40 years, who had been diagnosed with diabetes for at least 6 months. The narratives were analysed using thematic analysis.

**Results:** Using the social cognitive framework, themes were organized in terms of a thematic map linking knowledge of diabetes to the perception of diabetes as 'a silent killer', to coping, leading to self-efficacy. However high self-efficacy, over time, may lead to complacency, disrupting health behaviours and requiring re-establishment of those behaviours. Adequate knowledge along with cognitive adaptation and self-efficacy were important constructs that contributed to behaviour change and maintenance. Elements of the cultural context were observed in the spiritual aspects of adaptation, the socially isolating consequences of diabetes, as well as gender differences in social support and management.

**Conclusion:** Understanding the lived experiences of patients contributes to planning more effective interventions keeping the social and cultural context in mind for more effective management of diabetes. Additionally, acknowledging and supporting women's needs in diabetes management is called for.

## 1. Introduction

There has been a dramatic increase in the prevalence of adults with Type 2 Diabetes Mellitus (T2D), 75% of whom live in low- and middle-income countries. [1] India is the 'Diabetes Capital of the World' [2] and accounts for one in every seven adults living with T2D worldwide. [1] The onset of T2D for Asian Indians occurs at a younger age with a lower body-mass index, additionally, their predisposition to develop complications is also higher [3], stressing the importance of glycaemic control. Poor glycaemic control and the presence of cardiovascular complications among those with T2D are not only associated with higher levels of stress, and depression but also affect engagement in health behaviours and increase morbidity and mortality. [4]

Given the chronic nature of T2D, individuals tend to combine the doctor's advice with personal knowledge and experience. [5]

Sociocultural and religious factors influence T2D perception and management. [6,7] Therefore, social, political, and economic structures need to be considered in curtailing T2D onset and morbidity. [8] Exploration of these structures in urban [9–12] and rural [13] India highlights significant structural inequalities. However, these structures remain unexplored in the northeastern region of our country, even though it is a socially and culturally distinct region. [14] The northeastern region consists of multiple ethnic groups residing in eight states that include Arunachal Pradesh, Assam, Manipur, Meghalaya, Mizoram, Nagaland, Tripura, and Sikkim. Compared to the rest of the country, this region remains geographically and economically isolated. [15] Despite this, the prevalence of T2D and hypertension is quite high [16], while the prevalence of co-morbid hypertension among individuals with T2D or at risk of it, is highest in the country. [17] This high prevalence could be due to the consumption of a restricted diet consisting of white rice

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and non-vegetarian food. [14] In addition to the increased morbidity, healthcare is characterized by limited, under-trained, under-equipped healthcare facilities [18] and medical intervention is usually sought when morbidities become serious [19] or when traditional medicine and home remedies fail [20], further increasing the disease burden.

The aim is to study the psychosocial and cultural factors involved in T2D management among the population of adults living with T2D in Meghalaya.

## 2. Methodology

The Standards for Reporting Qualitative Research [21] and the Consolidated Criteria for Reporting Qualitative Research [22] checklists were used to authenticate the research protocol followed in this study and ensure rigour in reporting the themes. The protocol was also approved by the Institute Ethics Committee, Indian Institute of Technology, Bombay.

### 2.1. Theoretical model

The interviews were guided by the theoretical underpinnings of the Health Belief Model. [23] The Health Belief Model provides a useful lens to understand the experience of living with T2D as it focuses on the individuals' beliefs regarding a health threat along with health measures used to reduce this threat. [23]

### 2.2. Study design

To explore the psychosocial and cultural experience of T2D along with the factors that promoted and impeded management, a qualitative research design was used. Qualitative enquiry is effective in generating knowledge related to perceptions, social experiences, and cultural beliefs that significantly influence illness management. [13] Qualitative approaches are important in healthcare as they illuminate the underlying or latent meanings assigned to the lived experiences of individuals. [24] Through an enquiry of thoughts and feelings, such approaches aid in grasping how and why behaviours take place. [25] Understanding these lived experiences and the implicit meanings ascribed to them provides rich, diverse, and contextualized insights that contribute to knowledge and research. [26] Although experiences are studied in the present, yet recollections of the past and anticipations regarding the future form part of the lived experience. [27] These aspects thus emerge as global, cohesive, and unique experiences that are occurring in the subjective present [27] that could inform how T2D is perceived, understood, and managed.

A phenomenological research approach was used, given that the focus of the study was on the experience of T2D by the participants. The experience at diagnosis as well as coping with the condition cognitively, emotionally, and behaviourally, along with the barriers and facilitators in management were studied. Phenomenological research provides a subjective view [28] of a homogenous group of participants, who in our study, comprised of individuals diagnosed with T2D for at least 6 months, living in Meghalaya, who have similar experiences in terms of access to healthcare, as well as the influence of social and cultural norms and illness perceptions. Thus, our phenomenological investigation aimed at understanding the experiences of individuals with T2D who are subjected to a healthcare infrastructure characterized by constrained resources [18], along with a sociocultural context characterized by poor health knowledge, poor health-seeking behaviours [19,20] and consumption of a restricted diet. [14] Thus, emphasis was placed on grasping the ground reality through the participants' subjective experience of T2D, given that it is a chronic condition that is influenced by lifestyle and eating habits.

Our study adopted thematic analysis based on descriptive phenomenology which has been widely used to understand lived experiences and human phenomena. [24] Although the interviews were guided by

the theoretical foundations of the Health Belief Model [23], the researchers set aside knowledge that is not presented and focused on the descriptions presented by the participants, which was considered as knowledge that is observed and carefully analysed. [29] The researchers bracketed past knowledge and refrained from assuming an objective reality of the phenomenon and the participants' expressions were extracted and elaborated to construct the psychological meaning. [28] The researchers embraced the principles of descriptive phenomenology which include openness, bracketing pre-knowledge, adoption of a reflective attitude [24] and ensuring that probes did not reflect assumptions of the researchers. The study therefore attempted to provide a voice to an understudied population of individuals living with T2D in the northeastern region of India, exploring their perception of T2D along with the facilitators and obstacles, including the social and cultural attitudes, beliefs, and knowledge regarding T2D and its management. Following the interviews, participants' doubts and misconceptions were clarified and for participants expressing difficulties communicating with the treating team, an effort was made to communicate their concerns to the treating doctor.

### 2.3. Sample recruitment

Participants were recruited through a private, out-patient multi-speciality clinic, in the city of Shillong, in Meghalaya and included adults diagnosed with T2D for at least 6 months. Purposive sampling was used since it effectively explores lived experiences, through the selection of 'information-rich' cases [30], who are insightful about the phenomenon of interest. [31] To ensure a diverse sample, all individuals with T2D hailing from different socioeconomic backgrounds were potential participants. They were approached as they sat in the waiting room at the clinic and were informed about the objectives and procedure of the study. It was ensured that participation or refusal would not affect their treatment and a convenient time was set with them for the interviews. A total of 31 individuals agreed to participate in the study but four of them dropped out because of time constraints, leaving us with a sample of 27.

### 2.4. Interview guide

A semi-structured interview guide was prepared by the researchers. The guide included open-ended questions based on the research objectives and a review of literature. The following are representative of the questions asked, and discussions related to their experiences were encouraged.

- How did you feel when you found out that you had T2D?
- What sort of changes did you have to make in your life since the diagnosis?
- Do you find making the changes necessary for the management of your T2D difficult? (Blood glucose monitoring, dietary changes, exercise, medications, cost of treatment)
- Do you use any home remedies to treat your T2D?
- What do you think enabled or prevented you from making changes in your lifestyle?
- How does your spouse feel about your T2D?

### 2.5. Data collection

Interviews were conducted face-to-face by the first author (NK) in a private space at the clinic between May and June 2019. Written informed consent along with permission to audiotape was obtained from all participants before the commencement of the interviews. Depending on their preference, interviews were conducted in either English or in the native language (Khasi). All interviews were audio-recorded, field-notes were taken after each interview and the duration of each interview was about 45 to 75 mins. Data collection continued until no new

information was obtained from new participants [32].

### 2.6. Data analysis

Audio recordings were transcribed verbatim. Participants' names were replaced with codes to ensure anonymity. Interviews in Khasi were initially transcribed in the language and later translated into English by the first researcher (NK) who is fluent in both languages. To ensure accuracy, transcripts were checked against the original audio files. The English transcripts were then analysed, independently by both authors (NK and MK).

The interviews were analysed qualitatively using a six-phase thematic analysis technique. [33] Lived experiences have been successfully studied using thematic analysis as it contextually situates the participants' experiences, perspectives, and behaviours. [34] Both researchers independently familiarised themselves with the breadth and depth of the content of the interviews, through active and repeated readings of the transcripts. Notes assisted in understanding ideas and meanings, besides identifying patterns in the transcripts and the field notes. Initial codes were developed manually using 'post-it' notes, which were organized into meaningful groups. Codes were collated and themes were developed independently by both authors, improving intercoder agreement and coding reliability. [34] The authors (NK is a trained clinical psychologist, and MK is a health psychologist) met regularly to look for and identify similar codes, which were then combined to form overarching themes. [33] Themes were identified using a hybrid method of analysis [35] and were defined and refined to accurately represent the perceived meaning of the participants' responses. Transcripts were re-read and reviewed to confirm the content, scope, and 'essence' of each theme [33] and enhance reliability. [36] Each theme was then redefined and extracts from the transcripts that capture the 'essence' of a theme [33] are presented in Table 2.

**Table 1**  
Sociodemographic characteristics of the participants [N = 25]

		Percentage
Age	Mean ± SD	59 ± 6.13
	40–49	4
	50–59	40
	60–69	56
Gender	Male	48
	Female	52
Educational level	School	40
	College	48
Income group	Middle	84
	Lower	16
Residence	Rural	44
	Urban	56
Marital Status	Married	64
	Single/Widowed/Divorced	44
Occupation	Housewife	16
	Retired	16
	Business	36
	Government Service	36
Duration of illness	Farmer	4
	Mean ± SD	8.84 ± 5.59
	1 to 5 years	20
	5 to 10 years	44
Comorbidities	Above 10 years	36
	None	8
	1 comorbidity	48
Symptoms at diagnosis	> 1 comorbidity	44
	Diagnosed incidentally	68
	Symptoms present	32

### 3. Results

#### 3.1. Participants

The sociodemographic characteristics of the participants are presented in Table 1. Out of the 27 interviews, two interviews [aged 36 and 79 years] were removed from the analysis since their experiences would not be representative of the sample studied. Most participants (96%) were between the ages of 50 to 69 years (Mean ± SD = 59 ± 6.13), with almost equal representations of individuals identifying as men (48%) and women (52%), those with school (40%) and college (48%) education, and those from rural (44%) and urban (56%) areas. They mostly belonged to the middle-income group (84%) and most of them (92%) have at least one co-morbidity. Most of the participants (80%) have been living with T2D for more than five years and for most (68%), T2D was diagnosed incidentally.

Five main themes were identified and included knowledge of T2D, 'the silent killer', 'coping with T2D', 'self-efficacy', and 'becoming complacent'. The themes and sub-themes identified are presented in Table 2.

#### 3.2. Knowledge of diabetes

Knowledge determined participants' reaction to diagnosis, and perception of T2D, along with trust and compliance at the different stages of management. Having family members or friends with T2D led to concerns regarding the ability to manage, besides acceptance that it is a dangerous yet controllable disease.

*'Well, you have to control [T2D], so it is very, very hard, because if you don't – I've seen others getting worse'* (P7, Man aged 60).

Participants hailing from rural areas have 'not heard of T2D' before, and the diagnosis led to feelings of doom for some. For others, diagnosis contributed to initial denial and non-compliance with recommended health behaviours.

*'At that time, the doctor told me not to eat meat anymore, but I didn't know about this T2D, because in our village, no one has had it and we have never heard of it, so I did not listen and kept eating lots of meat.'* (P17, Woman aged 51).

Individuals with higher education reported better knowledge of T2D compared to their less educated counterparts, regardless of their area of residence. Additionally, communicating freely with health providers improved knowledge, trust, and compliance with the treatment, along with abstinence from alternative medicine and the use of home remedies. Whereas, use of alternative medicine, and/or unprescribed supplements to manage symptoms, besides non-compliance when better, were common among less educated participants hailing from rural areas, who also had poor knowledge and communication with health providers.

*'Before I would take those company medicines [unprescribed supplements]... Whatever people say, we listen, we are very gullible and people manipulate us. I trusted them and took those medicines, but I didn't feel like they helped me so I stopped, and only take medicines from here.'* (P17, Woman aged 51).

#### 3.3. 'The Silent Killer'

T2D was diagnosed mostly during a regular check-up or treatment of other problems, leaving participants 'shocked' since they did 'not feel anything' physically. T2D was generally perceived as 'something unwanted' and led to feelings of loss along with bitter-sweet reactions, particularly among those who experienced symptoms prior to diagnosis. Fear and anxiety were common reactions among participants who either had inadequate knowledge or witnessed others with complications due

**Table 2**  
Summary of themes and categories extracted from the interviews.

Theme	Quotes
Knowledge of T2D	Prior knowledge <i>'I have seen my other friends who have had it before I did, it is very problematic. From your diet to your exercise to everything else, even to be socially free is very difficult. I felt like everything is taken away from me'</i> (P3, Man aged 62) <i>'Initially I felt disgusted, I felt weird because we do not know about something like this...I was afraid because I thought they cannot help me; I cannot be treated.'</i> (P6, Man aged 55)
	Communication <i>'If I feel anything odd, I come back to meet doctor and tell him that it is like this and that. I tell him if there is any reaction and he helps, I do get help'</i> (P8, Man aged 47)  <i>'They tell me to drink the juice of passion fruit leaves, but I do not trust such things. Once I take treatment from one doctor, I trust completely, and from that trust, I get better'</i> (P22, Woman aged 52)
	<i>'We knew that my mother had T2D and she took the medicines and was better. The doctors then did not explain that she also needs to change her diet and, in our ignorance, we thought it was like any other illness, that once you are cured, it is alright'</i> (P18, Woman, aged 57)
'The Silent Killer'	'Not feeling anything' <i>'I was shocked. How was it possible, because I was very energetic, doing physical work and walking'</i> (P2, Man aged 64) <i>'If you have T2D, because it is related to your blood, there is no part of your body where blood does not go. So, it affects every part of your body, that's the worst part of T2D.'</i> (P19, Woman aged 64)
	Bitter-sweet <i>'I feel good because if I did not come to doctor, I would not have known'</i> (P7, Man aged 60)
	Why me? <i>'My sister's husband also has T2D. He is fine now, he is a doctor and takes his own medicines, but he eats everything and nothing happens to him. I am quite surprised'</i> (P7, Man aged 60)
	Reason for diabetes <i>'They told me that it is hereditary, that is my only understanding of it. My father had it, I also agree with what the doctors said that it is hereditary'</i> (P22, Woman aged 52)
	<i>'I wonder how I developed 'sugar' problem when I never use to take sugar from before... I am not sure, but it could be because of eating without thinking. Before, how will we measure, I used to eat almost half kg of meat a day along with a lot of rice'</i> (P3, Man aged 62)
	<i>'Natural thing, after 40 years. After 40 then if you do not control your diet then it will become T2D'</i> (P1, Man aged 69)
	<i>'Because of those stresses and strain, my T2D came, and I was losing weight, it was another sign, although I did not know that then. Fatigue was there, but then that was probably because of stress. The dual responsibility that I have been assigned to was stressful'</i> (P19, Woman aged 64)
	Accepting the challenge <i>'One has to live with T2D. You have to walk around you have to do physical exercise. No meaning, no worrying, you just go on. One has to live with it, I have to manage'</i> (P11, Man aged 57)
	<i>'God is very intelligent. He gives us humans different types of illnesses so that we are not full of pride... We must accept that we are here as per God's wishes and not as per our own'</i> (P3, Man aged 62)
	<i>'T2D is common nowadays. My wife also thinks that it has become a normal disease nowadays, because it is common to all, common disease.'</i> (P5, Man aged 52)
Coping with T2D	Regaining control <i>'The most important thing is food and my lifestyle, so I have avoided everything doctor told me to. I do not eat those things anymore'</i> (P18, Woman aged 57) <i>'We have to prepare ourselves and we have to accept that we are here as per God's wishes and not as per our own... God has put us here for a reason and certain goals for us to reach'</i> (P3 Man aged 62)
	Self-justifications <i>'Now that I am accustomed, I do not like meat and other things</i>

**Table 2 (continued)**

Theme	Quotes
Self-efficacy	<i>anymore. I don't eat, I don't like them anymore, especially sugar.'</i> (P18, Woman aged 57) <i>'I have seen others getting worse, because of that, I am particular with food, and I try to walk everywhere I go'</i> (P7, Man aged 60) Confidence Vs lack of confidence <i>'I know if I do this what happens to my body and when I do that what happens to my body, so one has to listen carefully'</i> (P20, Woman aged 69) <i>'These medicines have helped me a lot, my tiredness has gone down, I can go here and there'</i> (P10, Man aged 64) <i>'I can't understand, because sometimes I feel like it [T2D] is not there in my body anymore... but sometimes I feel it swelling, and I feel heavy... I cannot manage it. It has won'</i> (P16, Woman aged 52)
	Becoming complacent <i>'Sometimes when I forget to take medicines or too much tensions. When we are still humans, we can't avoid tensions, it goes up, but once I take medicines, it gets better.'</i> (P25, Woman aged 60) <i>'I did get some advice that I should walk for about 40 mins or 45 mins, but sometimes I feel lazy and I don't do that much'</i> (P8, Man aged 47)
Contextual factors	Gender and Social Support <u>Spousal support Vs lack of support:</u> <i>'She [wife] is very supportive. She helps in cooking, washing, cleaning, and many other things. Even to chop wood that we use at home also, she does it'</i> (P8, Man aged 47) <i>'He [husband] doesn't say anything, but he does try to control my food...I should be the one controlling. Whatever they say, if I don't want to listen, they can't do anything'</i> (P23, Woman aged 63) <u>Family support Vs lack of support:</u> <i>'We eat the same food, everyone, nothing different. I just avoid the fat part of the meat or anything that I don't feel good about, I just avoid. I feel happy, supported, and healthy, I feel stronger'</i> (P13, Woman aged 63) <i>'My family didn't say anything, if I have money, they tell me to get medicines. My friends didn't say anything, they ask me about my illness and I tell them... I'm all alone there's no one to help me, my sister is also poor my mother is also poor, so they can't help me, so I'm all alone. There is no one to help me'</i> (P15, Woman aged 52)
	Socioeconomic status <i>'If I have money, I send someone for medicines. It's been a long time since my last visit... I come once a year and when I have some money, I get the medicines and if I don't have, I just bear with it.'</i> (P15, Woman aged 52)
	Cultural context <i>'T2D affects socially also because sometimes we work together in our locality, and I can't help out when I don't feel strong. I feel bad when I can't be there with everyone, sometimes at other people's homes, funerals, here and there, they offer tea and it has sugar in it. I feel embarrassed to ask for tea without sugar, so I just taste a little and keep it away'</i> (P23, Woman aged 63) <i>'I cannot go out with my friends anymore, I cannot go to weddings and celebrations, I cannot go because they cook everything together, they add masala and all and I cannot eat'</i> (P4, Man aged 64)

to T2D. However, being better informed encouraged the perception of T2D as controllable, fostering hope in their ability to manage it.

*'Initially, I was afraid, but when I met a friend who also had similar problems, I realized that it was not too bad...because we do not know about something like this. I was afraid because I thought they could not help me. I cannot be treated'* (P6, Man aged 55).

T2D was generally perceived based on physical symptoms. It was therefore seen as a 'silent killer' that is unobservable yet 'dangerous' because of its potential to negatively affect other parts of the body.

*'T2D is like a silent killer. If we are not careful and regular with treatment, we can get stroke and we can die also, but now that I am taking care of myself, I am not scared anymore, I feel comfortable'* (P22, Woman aged 52).

Some participants expressed feelings of jealousy or 'why me' reactions when they compared themselves with others.

*'Even though he [brother] drinks heavily, alcohol, sprite, but till now he does not have T2D, nothing.'* (P1, Man aged 69).

Participants attributed T2D to genetic and lifestyle factors such as unhealthy diet, alcohol, and 'eating too much'. Women particularly, emphasised stressful situations as potential causes. Among those hailing from rural areas, T2D was even attributed to consumption of excess sugar since in the local language it is called '*pang shini*' which translates to 'sugar disease'.

### 3.4. Coping with T2D

#### 3.4.1. Accepting the challenge

Meanings and explanations regarding experiences were sought, which led to acceptance of responsibility to adjust and cope with T2D. While some considered T2D as 'a part of life', others considered it as a 'challenge given by God', which encouraged efforts towards management. Some participants even downplayed their emotions by considering T2D as 'common nowadays', that it is 'natural with age' or like any other illness, which facilitated acceptance and coping.

*'Well, it [T2D] has become a part of my life...I cannot put any more clearly – it is with you now– you have been diagnosed, so you live with it.'* (P 19, Woman aged 64).

*'It has been more than 2 years now that I have sought treatment and I thought that maybe God has given me this challenge, but how would I know.'* (P10, Man aged 62).

#### 3.4.2. Regaining control

Attempts to regain control were made through lifestyle changes like compliance with medication, physical activity, and dietary changes, along with alcohol and smoking cessation. Medication compliance was common and considered important. Regular check-ups ensured better management and reduced fear of hypoglycaemic episodes and potential side effects.

*'I have this fear that it might affect, maybe, if I take too many medicines. I regularly go for check-ups, but I don't know what happens inside. I come here regularly since it is still treatable right now'* (P18, Woman aged 57).

Exercise generally included walking, although it was irregular. Dietary changes were generally considered difficult. Since most participants had comorbid hypertension, changes included avoiding meat, potatoes, and sugar, while some also substituted chapatti for rice at least once a day. Men depended on their families to prepare their meals while women reported different strategies they used to cope with dietary changes.

*'I keep feeling hungry, every now and then, so I eat little by little, after every 2-3 hours... Wherever I travel, to far-off places, or the fields, I carry food with me and eat it.'* (P17, Woman aged 51).

Spirituality was another method used to regain control. Lifestyle changes were made with prayer, and surrender to God provided hope to those feeling helpless since 'illness and death is dependent on Him'.

*'I put my trust in God, whether he cures me or it ends here. Doctors have told me that there is no cure for this illness, only God can cure it because man can't... We need God and we also take medicines – but in their own time.'* (P4, Man aged 64).

#### 3.4.3. Self-justifications

Self-justifications like being 'accustomed to lifestyle changes', and preference in continuing them were also made to regain a sense of control, particularly among those belonging to the middle-income group.

*'I don't drink [alcohol] anymore, it's been a long time. I can't even bear the smell now. Even smoking, I can't take the smell'* (P10 Man aged 64).

Self-justifying evaluations that that they have 'had enough in the past' and/or that they are doing better than others who also have T2D, were made. This reinforced and encouraged further compliance with management.

*'There are a few friends of mine who also have T2D, they say that I am different from him [person with T2D]. I take good care of myself.'* (P8, Man aged 47).

Overall, accepting the challenge, regaining control and self-justifications contributed to the adoption and maintenance of health behaviours.

### 3.5. Self-efficacy

Confidence in ability to manage T2D was expressed by most and was dependent on the physical feedback received as lifestyle changes were made. Individuals with higher education reported higher levels of confidence, however confidence was also enhanced when participants 'felt better' with medication or behavioural changes. Experiencing persistent fluctuations like fatigue, weakness, irritation, and inability 'to work like before', particularly among those with more than one complication, led to feelings of helplessness.

*'Nothing is difficult. If you follow the [diet] chart then everything is normal, normal-like, and if you don't follow, if you eat more, if you eat sweet, if you drink then it becomes a problem.'* (P1, Man aged 69).

*'I just get disturbed by this T2D, because to cure it is also difficult. No matter how much I avoid certain foods, sometimes my sugar goes up and sometimes it goes down, it gives me a headache'* (P23, Woman aged 63).

### 3.6. Becoming complacent

Periods of complacency were reported either in terms of visitations to the clinic, or compliance with management. It was observed that T2D duration of >10 years without major complications, and/or stable glucose levels led to delayed follow-ups. Additionally, stressful situations, 'feeling better' and/or lack of time, especially among women, were the main reasons for non-compliance. Most were aware of the consequences of giving in to cravings related to restricted food but made justifications that medicines would normalize glucose levels.

*'In the morning, my sugar [glucose level] is usually normal, sometimes I skip the medicines intentionally, I test after 2 hours, and it increases a little, only 150-160, but if that happens then I take medicines the next day and I don't skip anymore.'* (P8, Man aged 47).

*'Sometimes I have a little, I know this is not for me, but I want to taste, then I suffer. This is true, sometimes they [family] purchase foods from Dominos and all, I would taste, then it increases my sugar and again I suffer'* (P5, Man aged 52).

Physical symptoms and overconfidence determined complacency and when physical symptoms were experienced again, they accepted the seriousness of treatment, resumed coping mechanisms, and made lifestyle changes again (Fig. 1).

### 3.7. Contextual factors

Gender, socioeconomic status, and the cultural context play important roles in T2D management.

#### 3.7.1. Gender

Gender was a vital determinant of social support. Men acknowledged the support they received from their wives and/or children, who helped

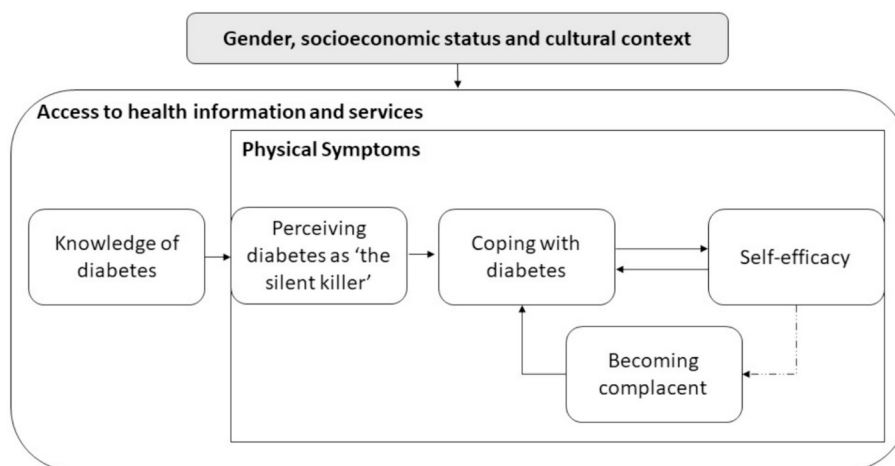


Fig. 1. Thematic map of the themes identified from the interviews.

them maintain their diet, medication, and lifestyle changes.

*‘My wife supports me, reminds me to take medicines, or prepares simple food, chapattis, and all. It is helpful, especially for us men. If no one prepares chapatti, then we have to eat rice.’ (P6, Man aged 55).*

Among women with a spouse, husbands were generally described as being uninvolved or that their involvement was unhelpful.

*‘He [husband] didn’t say anything, just that you ate too much, you did it to yourself. After I had this [T2D] and when I eat food that I’m not supposed to, he’d scold me and say don’t eat this, don’t do that, which annoys me.’ (P17, Woman aged 51).*

Women generally felt supported when family members adjusted to their diets. Having to cook separate food for themselves, and/or being employed, especially in a food stall, led to more cravings, and dietary violations, along with lack of time to eat healthy. Support from children included obtaining medicines, and giving dietary advice and/or reassurance. Poor support from extended family members among widowed women increased the burden of T2D.

*‘I really wish someone would cook because when I cook and I see, it is difficult for me to resist. I want my children to cook for me, but none of them can do that.’ (P17, Woman aged 51).*

### 3.7.2. Socioeconomic status

Expenditure on treatment comes from the participants’ own pocket, thus financial constraint was the main reason for non-compliance among those belonging to the lower income group. Access to trustworthy health services was non-existent in rural areas and having to travel long distances to reach the clinic added to the financial burden. Additionally, choosing fruits and healthier vegetables was difficult for those with lower income since they then to cost more than the ones restricted like pumpkins and potatoes.

*‘They [doctors] said I have T2D, then asked me to do an MRI. Someone told me that whatever you do, you’ll have to pay more than a lakh. Where will I get that money? ... I tried to get some money but couldn’t, so I didn’t go for a while’ (P9, Man aged 62).*

### 3.7.3. Cultural context

Food is an integral part of all community activities, and communal eating and solidarity are very important aspects of the Khasi culture. [37] Ceremonies involving major life events, religious functions and especially funerals, are observed communally with the extended family, friends, and neighbours. In such situations, refusing or asking for sugarless tea or food appropriate for a T2D diet becomes awkward.

Participants complained that T2D affected them socially since they now avoided attending such functions.

*‘I have avoided spending too much time with friends and attending functions, whether they are celebrations or something sad. If I can go for a short while, to a place nearby, then go back home to have tea and eat, then it is fine. Far-off places are not possible, because if my diet is a little different, my sugar level will increase.’ (P3, Man aged 62).*

*‘I cannot eat everything, I cannot do whatever I want. When others eat, it looks so delicious, but I am not allowed to eat anymore... I cannot go to funerals and I cannot go out to happy or sad events anymore... Everyone complains that I do not visit the sick or go to funerals anymore’ (P17, Woman aged 51).*

## 4. Discussion

Our results suggest a thematic map (Fig. 1) that links knowledge of T2D to the perception of T2D as ‘a silent killer’, to coping with T2D which leads to self-efficacy. High self-efficacy over time may lead to complacency, disrupting health behaviour and requiring them to re-establish those behaviours. Knowledge of T2D is influenced by access to health care and information. The role of gender, socioeconomic status, and the larger cultural context in influencing this model is also discussed.

Knowledge determines perception, with poor knowledge leading to denial or perceiving the diagnosis as a death sentence. This was especially true for the rural participants who were less educated however literature suggests that most Indians have inadequate knowledge. [38] Additionally, in rural India, T2D is sometimes believed to be fatal since awareness before diagnosis is uncommon. [13] Improvements in knowledge, however, lower the perceived threat and encourage acceptance. Good communication with and trust in health providers also improves management and encourages abstinence from alternative treatments. This is particularly significant in the Indian context where brusque healthcare providers and the fragmented healthcare system adversely affect T2D management. [10]

Consistent with the literature, diagnosis of T2D is ‘unwanted’ and associated with feelings of ‘loss’. [39] The absence of physical symptoms was shocking leading to a ‘why me’ reaction. Literature suggests that individuals with T2D tend to feel physically betrayed by their bodies [39], because they may not ‘look sick’. This adds to the perception of T2D as a ‘silent killer’ that is potentially ‘dangerous’, encouraging responsibility to manage it, even if they ‘don’t feel anything’. Supporting literature suggests that perceived threat leads to behavioural compli- [12]

According to the theory of cognitive adaptation [40], individuals try to cope with a threatening event by seeking meaning in their experience, trying to regain control over the situation and restoring their self-esteem. In this study, participants normalize T2D as being 'a part of life', 'a challenge given by God', and that it is 'common' or 'natural with age'. Literature suggests that such normalizations make T2D seem less threatening, besides negating self-blame; thereby reducing distress [11], validating experiences [39], and encouraging accountability. [41] Participants also make self-justifications like having 'had enough in the past', that they are 'accustomed to' lifestyle changes or are 'better' than others, and literature suggests that such justifications further reduce threat perception [40], and indicate lowered distress over time. [42]

When lifestyle changes result in 'lowered' glucose levels for participants, it provides evidence of the effectiveness of their changes thus promoting self-efficacy. According to the Social Cognitive Theory, belief in one's ability to exert control is critical in promoting personal agency. [43] While behaviours that maintain glucose levels encourage further engagement in them [44], beliefs regarding control encourage accountability. [45] Therefore, physical changes create a feedback loop to self-efficacy. Experiencing persistent physical fluctuations, however, leads to low self-efficacy and helplessness. Literature suggests that reinforcement along with self-efficacy determine behaviour change [43], whereas repeated unsuccessful efforts to control lead to helplessness. [46]

When management is effective in lowering glucose levels, it sometimes leads to complacency resulting in delayed follow-ups, irregular medication, and careless eating/skipping exercise, especially when stressed. Research suggests that busy lifestyles affect compliance, and given the chronic nature of T2D, there are fluctuations in motivation and self-management. [45] Sometimes, lifestyle changes are considered of little significance when individuals are on medication. Whereas, medication non-compliance could also indicate attempts to regain autonomy [13], or lessen dependency on medication. Additionally, consistent with research in India, financial constraint is a major barrier to compliance [10,45] and when access to medication is limited, adjustments are made to the medicine dosage based on physical symptoms. [10,12] Our study also highlights that residing in urban areas improves compliance and lowers expenditure on treatment since health services in the northeast are concentrated in urban centres. [18]

Cultural factors influence different aspects of management and consistent with research, T2D knowledge is combined with cultural beliefs. [6] Apart from T2D being attributed to genetics, it is also attributed to eating too much food or sugar, since 'sugar disease' is a cultural understanding and literal translation of T2D in most languages in India. [13] Regarding behavioural changes, exercise is irregular for most, consistent with the non-existent cultural importance placed on exercise for health or leisure in India. [13] Additionally, dietary restrictions that include avoiding sugar, meat, and especially rice, were difficult to follow since the traditional diet consumed in Meghalaya consists of rice and meat [47] with a side of vegetables. These dietary restrictions also had social consequences, given that food and communal eating are important aspects of the Khasi culture. [37] Participants report avoiding social events like funerals and weddings because of the awkwardness related to requesting a T2D-appropriate diet. Literature suggests that restrictions in the normative diet are associated with feelings of loss [39], additionally, refraining from social participation could potentially lead to social isolation and increase the risk of poorer quality of life [48]. While culture affects behavioural change, cultural/spiritual beliefs nevertheless aid in regaining control. Medication and lifestyle changes are done with prayer, while 'surrender to God' reduces anxiety and helplessness. Spiritual beliefs generally provide support to individuals, especially during difficult situations. [7,49]

Women in our study emphasise how T2D is associated with stressful situations, in terms of its onset and management. They also report having to manage multiple roles with minimal support from their spouse and extended family members. Supporting literature suggests that

women report higher levels of stress, depression, and guilt [50,51] since they tend to place more importance on their family's needs before their own. [9,10] The matrilineal system in Meghalaya potentially adds to this struggle, since women are expected to take care of the house and family besides contributing financially. [52] Additionally, while the women in our study report little or negative spousal support, men report good spousal support in various areas of management. Social support improves T2D management and is a valued source of information and practical support [53]. Support in India generally centres around the immediate family, particularly the spouse, however, this support is gendered, similar to findings reported elsewhere. [50,53]

Further, more than half the women in our study are either widowed or divorced, a common scenario in Meghalaya. [54] The women in our study often turn to their extended families for support and when they do not get the support they are looking for, they experience anxiety, and helplessness and report being unable to manage their health behaviours. Being widowed or divorced is generally associated with higher distress and poorer quality of life [55,56], which increases the burden of T2D for women. These findings therefore emphasise the need to further explore and address women's needs and support in management.

Socioeconomic status impacted knowledge, perception and coping with T2D. The lower socioeconomic status participants were disadvantaged in terms of knowledge because of lower education as well as poor access to information which led to either denial or perceiving it as a death sentence. Financial constraints made regular doctor's visits and blood tests a burden and impeded coping. The middle class with better education and financial resources were better positioned to cope with T2D.

## 5. Strengths of the study

The study provides a qualitative perspective of the experience of T2D and describes with richness and depth, the significance of social, cultural, and economic structures in T2D management in Meghalaya. The relationship between the constructs of knowledge, perception, coping, and self-efficacy are illustrated in a model that includes gender, socioeconomic status, and culture in explaining coping with T2D. It also identifies the effect of complacency in T2D management.

The study also uncovers the evidence of gender disparities in T2D management. For instance, women report lack of support from their spouses as opposed to the reported support men receive from their spouses, also women heads of households, mentioned how mental stress exacerbated their condition. The study also highlights the importance of attending community functions that include eating within the Khasi culture and the conflict experienced in attending these events for T2D patients. The influence of spirituality in coping was also seen.

## 6. Limitations

The study was limited to those seeking allopathic treatment from one private clinic in the state capital of Meghalaya. Glycaemic levels of the participants at the time the interviews were conducted, was not determined.

## 7. Conclusion and implications

Given the high burden of T2D and pre T2D in India, health behaviour change is essential. Our proposed model provides a blueprint for T2D health educators where specific cultural influences may be factored in. Overall, our findings suggest that effective and trustworthy Information, Education and Communication (IEC) material regarding T2D which includes physical symptoms are critical in its prevention and management.

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## CRedit authorship contribution statement

**Naphisabet Kharsati:** Writing – review & editing, Writing – original draft, Visualization, Validation, Resources, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Mrinmoyi Kulkarni:** Writing – review & editing, Visualization, Validation, Supervision, Methodology, Formal analysis, Conceptualization.

## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

## Data availability

The data used and analysed in the current study are available from the corresponding author upon reasonable request.

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