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Lived experience and perceived barriers to self-care among patients with type 2 diabetes mellitus in South Ethiopia: a descriptive phenomenological study

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In resource-limited settings like Ethiopia, managing type 2 diabetes mellitus (T2DM) depends heavily on patients' self-care. Yet, this process is often disrupted by a complex interplay of emotional, cultural, and systemic factors. Existing research has insufficiently captured how these forces shape the lived experiences of patients managing diabetes in such settings. Therefore, this study explored the lived experiences and perceived barriers of self-care practices among individuals with T2DM attending hospitals in the Wolaita Zone of South Ethiopia.A descriptive phenomenological approach grounded in Husserlian philosophy was employed. Data were collected through 12 in-depth interviews with T2DM patients and supplemented by two focus group discussions with additional 13 patients conducted between August and September 2024. Data were analysed manually using a five-step phenomenological approach, emphasizing meaning extraction and textual synthesis. Five interconnected themes emerged:1) Emotional disruptions following diagnosis, 2) Perceived disease severity and fear of complications, 3) Economic and infrastructural constraints, 4) Cultural and religious beliefs, and 5) systemic and interpersonal gaps in support. Patients described experiences of fear, hopelessness, and shock at diagnosis, compounded by medication inaccessibility, unaffordable diets, and traditional beliefs conflicting with biomedical guidance. Patients reported limited diabetes-specific knowledge and insufficient emotional and educational support from their families and the health system. Self-care practices among patients with T2DM in Ethiopia are shaped by deeply embedded emotional, socio-cultural, and systemic realities. Effective diabetes management requires interventions that extend beyond clinical knowledge provision, incorporating emotional support, culturally tailored education, and improved health system responsiveness. Multi-level collaboration between healthcare providers, policymakers, religious institutions, and community structure is critical for building sustainable, patient-centred self-care support systems.

Keywords Type 2 diabetes mellitus, Self-care, Barriers, Phenomenological approach, Ethiopia

Type 2 diabetes mellitus (T2DM) is a major contributor to morbidity and mortality worldwide, with a particularly profound impact on low- and middle-income countries[1]. Effective self-care practices are essential for managing T2DM, as they help control blood glucose levels, prevent complications, and reduce healthcare costs[2,3]. These practices include taking prescribed medications, maintaining healthy eating habits, engaging in regular physical

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activity, monitoring blood glucose levels, and foot care[4,5]. However, patients with T2DM often encounter various barriers that affect their capacity to perform these self-care activities effectively[6,7].

In Ethiopia, various studies have explored these challenges to effective diabetes self-care practices among T2DM patients such as limited access to healthcare services, economic constraints, cultural beliefs, and lack of diabetes education contribute to the poor management of diabetes[6,8]. A study conducted in Eastern Ethiopia among healthcare providers, identified barriers at multiple levels, including the lack of organized diabetes care services, limited collaborative care practices among healthcare providers, and patients' perceived lack of knowledge about self-care practices[9]. Studies in northern and central Ethiopia, focusing on T2DM patients, reported barriers such as inadequate diabetes-related education to cope with the condition, emotional disturbances, failure to adopt new lifestyles, lack of social support, and perceived behavioural control issues[10,11].

While these studies provide valuable insights into the what of these barriers, there is limited understanding of the how and why from the patients' own perspectives. A deep, qualitative exploration of the lived experience is needed to generate sociocultural specific evidence how these barriers interact and are perceived in the unique context of South Ethiopia, where unique cultural and economic challenges exist. This gap is significant, given the region's resource-constrained healthcare system and distinct sociocultural dynamics, which may shape perceptions and practices related to diabetes self-care.

Moreover, despite the general perceptions among Ethiopians that diabetes is a manageable disease, misconceptions persist about the importance of consistent monitoring and lifestyle modifications[12]. This has contributed to a high prevalence of complications such as retinopathy, neuropathy, and foot ulcers, which lead to increased hospitalization and financial hardship[13,14].

To address this gap, the current study seeks to explore the lived experiences and perceived barriers to effective self-care practices among patients with T2DM in South Ethiopia. The study grounded in the Health Belief Model (HBM), which emphasizes individuals' perceptions of health risks and the benefits of adopting preventive behaviours[15], HBM helps in systematically identifying and categorizing the psychological and practical barriers that T2DM patients face in self-care practices. Through a phenomenological approach to conduct in-depth interviews and focus group discussions, we aim to generate an in-depth understanding their lived experiences and the challenges faced in managing T2DM self-care. The findings are expected to inform the development of more effective programs tailored to their specific sociocultural and economic context of South Ethiopia, ultimately contributing to improved diabetes care outcomes.

Methods

Study design and setting

This study employed a descriptive phenomenological approach, grounded in the philosophical traditions of Edmund Husserl, to explore barriers to effective diabetes self-care practices among individuals living with T2DM. This approach was chosen because it allows for rich and in-depth understanding of the lived experiences of participants, as phenomena appear in their consciousness, free from preconceptions and theoretical assumptions[16]. The emphasis was on capturing the essence of participants' experiences in their natural contexts. The study was conducted in the outpatient departments of three hospitals in Wolaita Zone, South Ethiopia: two district hospitals and one comprehensive specialized hospital from August 1 to September 30, 2024.

Research team and reflexivity

The data were collected by the lead researcher and co-authors, all of whom have prior experience in qualitative research. The researchers had no prior relationship with participants. In line with Husserlian phenomenology, reflectivity was practiced throughout the study by maintaining reflective journals, engaging in team debriefing, and consciously bracketing personal beliefs and assumptions to reduce bias and remain open to the meaning expressed by participants.

Participant selection and eligibility criteria

A total of 25 participants were recruited: 12 for in-depth interviews (IDIs) and 13 for two focus group discussions (FGDs). Eligible patients were identified and invited to participate by the clinic staff. TA then provided detailed information about the study and obtained written consent. Eligibility criteria included: patients with T2DM aged 18–60 years. The age range was selected to focus on the working-age adult population, who face distinct socioeconomic and familial responsibilities that influence their self-care practices. Newly diagnosed T2DM patients (diagnosed within the last 6 months) were excluded to ensure participants had sufficient lived experiences with the condition and its management.

Data collection methods

An in-depth interview and focus group discussions, were conducted, guided by open-ended questions designed to explore the participants' experience from the moment of diagnosis to the present. The guides were developed using components of the Health Belief Model to explore perceptions of severity, susceptibility, benefits, barriers, cue to action, and self-efficacy[15]. The tools were initially prepared in English and translated into Amharic, the local language. They were pre-tested with two patients with T2DM in the facility not included in this study. The instrument was designed to elicit deep, reflective description aligned with phenomenological inquiry. A total of 10 interview items were prepared for T2DM patients (Supplementary 1 A) and the FGD (Supplementary 1B) was moderated by an experienced PhD candidate not affiliated with the research team and the duration approximately lasted 50–60 min[17].

Before data collection, the instruments were validated by a panel of five subject matter experts (a physician, a public health specialist, a nutritionist, a professional nurse, and a researcher). The Content Validity Index (CVI) was calculated to be 0.80, indicating strong relevance and comprehensiveness.

The IDI and FGD sessions were conducted face-to-face in private settings within the hospital premises to ensure comfort and confidentiality. Each IDI session lasted between 30 and 45 min, and each FGD lasted 50–70 min. The IDIs and FGDs were audio recorded with consent and transcribed verbatim in Amharic, then translated into English. Data saturation was achieved at 25 participants. Throughout data collection, probing and clarifying techniques were used to ensure depth and clarity of participants lived experience.

Data analysis

By Husserlian phenomenology, the analysis aimed to reveal the essence of participants' lived experiences, as described in their own words[18]. All interviews and FGDs were first transcribed verbatim in Amharic, then translated into English by the first author (TA), who is fluent in both languages. Data were manually coded using line-by-line inductive analysis in Microsoft Word and Excel.

The data analysis process followed phenomenological procedures outlined by Colaizzi(1978) and Moustakas (1994), including immersion, horizontalization, formulation of meaning units, clustering into themes, and synthesizing into a rich description of lived experience[18,19].

Coding and initial theme development were conducted by TA, EI and reviewed by CLN, EW, AW, and CS. Reliability was ensured through peer review by other authors and consensus coding, where two researchers independently coded the data, and discrepancies were resolved through discussion.

Triangulation of data from both IDIs and FGDs enriched the understanding of the phenomenon and ensured a more comprehensive portrayal of participants' experiences.

The study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines[20] to ensure rigor and transparency.

Results

Sociodemographic characteristics of participants

The study included a total of 25 participants: 12 in-depth interviews (IDIs) and 13 in two focus group discussions (FGDs). The age of these participants ranged from 38 to 59 years, with an average age of 51.5 years. The sample included both male and female participants. The duration of diabetes was 5–20 years. Two focus group discussions were conducted with 13 additional participants, including 7 males and 6 females. Each group included individuals managing type 2 diabetes and provided a range of perspectives on diabetes self-care practices. All FGD participants were unique individuals who did not take part in the IDIs (Table 1).

Findings from in-depth interviews and focus group discussion

The analysis of data from 12 in-depth interviews (IDIs) and two focus group discussion (FGDs) with 13 patients revealed a complex, multidimensional understanding of self-care practices in individuals living with type 2 diabetes mellitus(T2DM). Using a descriptive phenomenological approach, five main themes emerged, each reflecting the lived experiences, emotional journeys, and systemic challenges faced by participants. The themes and subthemes are presented below with illustration quotes to highlight the depth and diversity of participant's perspectives.

Theme 1: Emotional disrupts following diagnosis.

Subtheme 1.1 Fear and hopelessness:

The lived experiences of participants, as they encountered the moment of diagnosis, were characterized by profound emotional disruption. Participants described being suddenly confronted with a new reality that was both unfamiliar and unsettling. The moment of being told they had diabetes was not merely an informational

No	Participation type	Participants code	Age	Sex	Years diabetes
1	IDI-1	P01	49	F	9
2	IDI-2	P02	59	M	19
3	IDI-3	P03	48	F	5
4	IDI-4	P04	59	M	14
5	IDI-5	P05	58	F	12
6	IDI-6	P06	41	M	5
7	IDI-7	P07	38	M	5
8	IDI-8	P08	59	M	6
9	IDI-9	P09	48	M	6
10	IDI-10	P10	46	F	12
11	IDI-11	P11	55	M	10
12	IDI-12	P12	58	M	20
13	FGD1	NA		4 M, 2 F	
14	FGD2	NA		4 M, 3 F	
	Total	25	25		

Table 1. The sociodemographic characteristics of participants in the IDIs and FGDs of lived experience and perceived barriers to self-care of outpatients with type 2 diabetes mellitus outpatients in hospitals of Wolaita zone, Ethiopia. IDI- in-depth interview, FGD- focus group discussion, NA-not applicable.

exchange, but rather, a deep existential counter that provoked powerful emotional responses. As expressed by participants:

''I was shocked and hopeless when the doctors told me I had diabetes." (P01: IDI-1).

This moment of realization the "*I have diabetes*" moment surfaced feelings of disbelief, vulnerability, and loss of control. The experience was not limited to the physical implications of the illness, but extended to the emotional and existential reality, as reflected in the words of another participant:

"*When I was diagnosed with diabetes*, *I thought I wouldn't survive*, *and I cried.*" (P12; IDI-12).

The participants' narratives point to an overwhelming initial encounter with their condition, marked by a sense of despair and fear about the future. For them, the diagnosis represented not only a medical condition but a turning point in disrupting their sense of continuity and predictability in life. These emotional reactions such as shock, fear, anxiety, and hopelessness emerged as essential features of the phenomenon of being diagnosed with T2DM. For older participants, particularly those aged 49 and above, the moment of diagnosis was often accompanied by strong affective responses such as shock, fear, and hopelessness.

Subtheme 1.2: Lack of knowledge at initial diagnosis:

The participants often described encountering the term "*diabetes*" without any prior understanding of what it entailed, resulting in a disconnection between the diagnosis and the reality of their condition: The experience of not knowing was more than an absence of information, it was lived as a form of disorientation, where the body, once familiar, suddenly became the site of an unknown and potentially dangerous condition. This lack of knowledge influenced how the participants oriented themselves toward self-care. Many delayed engaging in dietary changes glucose monitoring, or medication adherence simply because the necessity of these actions was not part of their experiential world at that time.

> "As I am a farmer with no higher formal education, I did not understand the severity of diabetes at the time of diagnosis."

(P06: IDI-6).

> "The first time when doctors told me that I had diabetes, I felt nothing because I did not have any knowledge about diabetes.'

(Participant 1: FGD1).

For these individuals, the diagnosis was not immediately felt as threatening or urgent, but rather as an abstract piece of information. It was only in retrospect that after complications emerged or symptoms worsened, the full emotional and physical weight of the diagnosis began to be grasped.

The following narratives from participants aged 49 and above (P01-IDI (49, F), P02-IDI (59, M), P012-IDI, (58, M), P05-IDI (58, F), illustrated this shift from unawareness to emotional overwhelm. The realization that diabetes was not a temporary illness but a lifelong condition to be managed indefinitely brought a deep sense of vulnerability and despair.

However, overtime support from healthcare providers, family, and peers helped these patients adapt emotionally.

Theme 2: Perceived severity and complications.

Subtheme 2.1: Lived experience of diabetes-related complications: Encountering the phenomenon of diabetes, participants spoke not only the condition itself but of the *unpredictable and silent nature* through which it unfolds. The experience of living with T2DM was often described as one marked by *hidden danger*, a sense that something serious was happening inside the body without warning signs. As expressed by participants:

> "Diabetes is dangerous because it is silent killer; you don't know when it will happen…ended up in intensive care due to a stroke."

(P09: IDI-9).

This narrative underscores a world in which illness operates invisibly, where the body becomes unfamiliar, and trust in one's own physical states diminishes. Participants expressed a shared *vulnerability*, shaped by the realization that complications can emerge without notice, transforming everyday life into uncertainty.

These complications are not merely clinical events but also felt as interruptions, sudden disruptions that reorient patients' daily lives and identities. Another participant described the emotional and physical impact of living with dual diagnosis:

> "Thinking about the double burden (diabetes and hypertension), I was shocked by this news, and later that day, I suffered a stroke and was unconscious for four days. The stroke resulted in partial paralysis.'

(P04: IDI-4).

The experience of complications is not simply medical; it is embodied and transformative. Participants described how complications altered their sense of normalcy, introducing vulnerability and dependence into their lives. These moments are not only recalled merely as fact but as deeply felt events that reshaped their understanding of health time and risk.

Subtheme 2.2: Lived experience of comorbidity.

Living with comorbid conditions alongside diabetes was also a recurring theme. Participants mentioned accumulating diagnosis as a gradual burden, a layering of illness that compounded their challenges and complicated daily life.

"Over the years, I have developed other comorbidities, including hypertension and high cholesterol. I am on medication for both, in addition to my diabetes treatment." (P05: IDI-5).

The experience of comorbidity was described not only in terms of physical discomfort but also a growing sense of vulnerability and exhaustion. Many described the emotional fatigue of managing multiple illnesses and the way these conditions blurred into one another making it difficult to discern which symptoms belonged to which illness, and how best to respond.

Understanding the severity of diabetes and its complications influences patients' motivation to engage self-care practices: Those who recognize the potential risks of complications and comorbidity may be more likely to take preventive action, as mentioned by respondents. Thus, minimizing the perceived severity of diabetes is a dangerous misconception.

Theme 3: Economic and infrastructural constraints.

From the lived experiences shared by participants, the economic and structural realities surrounding diabetes care emerged as deeply embodied and persistent barriers. Participants did not merely describe financial hardship in abstract terms but lived it felt as a continued, constraining force in their daily management of diabetes. Their narratives reflect a world in which care is conditional upon means, and where the simple act of sustaining life becomes an economic negotiation.

Subtheme 3.1: Economic difficulties: Economic hardship appeared not as a distant or theoretical problem, but as an immediate, living condition that shaped every aspect of self-care. Participants conveyed how financial limitations altered the way they perceived and responded to the illness. The inability to afford medication, appropriate foods, or regular clinic visits was not only a logistical issue, but it was also an existential one. For many, diabetes was not just a disease of the body, but a daily confrontation with the limits of personnel and capacity.

''Economic constraints also make it difficult to manage my condition."

(P08: IDI-8).

"Managing diabetes requires low-carbohydrate foods, but these food items are expensive, and I cannot afford them due to my economic constraints." (Participant 2, FGD2).

These expressions unveil a recurring structure of experiences where health becomes contingent on financial ability. Participants often faced choices between essential needs such as food, medicine, and family obligations, where diabetes became a luxury rather than a right. The tensions between what is medically advised and what is financially possible gave rise to feelings of frustration, helplessness, and resignation.

The phenomenon of managing diabetes under economic constraint was not described as a background issue but a framework crisis, one that continually resurfaced in decision-making, emotion, and bodily experiences.

Subtheme 3.2 Medication unaffordability and supply issues: Participants mentioned how interruptions in drug supply systems translated directly into disruptions in their sense of control and well-being. The absence of essential medications is not merely an inconvenience, but it was a deeply unsettling rupture in their attempt to live with stability and hope.

''When there is a shortage of medication at the hospital, I discontinue taking my medication because I cannot afford to buy it from a private pharmacy.'' (Participant 6, FGD2).

This statement echoes a broader experiential pattern: the absence of access becomes an absence of possibility. For many, the lack of reliable medication created a rhythm of uncertainty and anxiety. Time and again, participants described a felt sense of vulnerability, not only to the diseases but to the system meant to support their care.

At the core of these experiences is the profound interplay between the economic realities and the *lived world* of diabetes. Financial limitations and medication shortages serve as significant perceived barriers that prevent patients from effectively managing their diabetes self-care, leading to poor consistency in self-care practices such as food choice and medication.

Theme 4: Cultural and social beliefs.

In the lived experience of individuals managing type 2 diabetes, cultural and religious beliefs surfaced as significant influence shaping how participants engage with or disengage from self-care practices. Through reflective descriptions, participants revealed experiences of tension between medical advice and ingrained cultural norms and religious convictions.

Subtheme 4.1: Cultural barriers: Participants described their experiences as shaped by societal expectations and traditional understandings of illness and healing. Cultural interpretations of medication, herbal remedies, and food choices are often intersected with internalized feelings of embarrassment of nonconformity when following biomedical recommendations. Participants shared the emotional discomfort associated with taking medication in public spaces, expressing an inner conflict between taking prescribed medication and maintaining cultural decorum:

''One main challenge in self-care for diabetes is the cultural belief within society. I know many diabetes patients who feel embarrassed to take their medication in front of others, so they skip the time of medication time."

(P05, IDI-5).

This reluctance reflects not merely a personal choice, but a deeper cultural embodiment that values discretion and conformity over visible signs of illness management. Others described a reliance on herbal remedies, rooted in tradition and familiarity, even in the face of medical advice:

‘’When I didn’t get my prescribed medication from hospital and I use herbal remedies, such as mango leaves.”

(Participant 3, FGD1).

These experiences reveal a world in which traditional healing is not just an alternative but a preferred and trusted mode of care. The lived experience is one of navigating between two paradigms, biomedical and cultural, each carrying its authority and significance.

Subtheme 4.2: Religious beliefs: Religious convictions were also deeply intertwined with participants’ understanding of illness and healing. Some recounted how the spiritual interpretation of diabetes led to the discontinuation of medication in favour of faith-based healing. For these individuals, managing diabetes became more than a physical task; it was situated within a larger spiritual framework that prioritized divine will over pharmacological treatment, Respondent, reflecting on his observations, stated:

“Some patients discard their medication based on religious beliefs, and I have seen some lose their sight, become paralyzed, or even die as a result.“

(P05, IDI-5).

Such experiences reveal how spiritual frameworks can either support or obstruct self-care, depending on how they are internalized and acted upon. The phenomenon how withholding medication is not simply a rejection of treatment but an affirmation of spiritual beliefs, perceived as more powerful or meaningful.

These descriptions highlight how cultural norms and religious beliefs function within participants’ consciousness as both barriers and potential motivators for action. In the language of the Health Belief Model, they may act as perceived barriers discouraging adherence to medical advice and alternatively cues to action, particularly when cultural or religious leaders endorse biomedical treatment. By focusing on these lived experiences, we begin to understand how individuals with type 2 diabetes inhabit a complex lifeworld where self-care is negotiated through personal meaning, cultural expectations and spiritual values.

Theme 5: Systemic and interpersonal gaps.

In the lived world of individuals managing T2DM, experiences of limited support both from healthcare systems and from close social relationships emerged as fundamental to their daily reality. Participants shared expressions of frustration, neglect, and disconnections, revealing how systemic and interpersonal barriers shaped their embodied experiences of illness and self-care.

Subtheme 5.1: Experiencing low support from healthcare providers: Participants recounted experiences of uncertainty, disheartenment, and emotional discomfort as they navigate healthcare settings. The perceived lack of compassion, delays in care, and inconsistent contact with healthcare providers were not simply logistical barriers but were deeply felt as forms of abandonment and invisibility.

The main challenge is that healthcare providers often lack compassion, and patients may experience discrimination and stigma from them.”

(P09, IDI-9).

‘’Another issue is that the doctor is not always available on time, and we don’t get sufficient care as we need to stay healthy.”

(Participant 6, FGD2).

‘’Those days doctors were better caring and so committed compared to today. Their role will never be forgotten in my life.‘’ (P02, IDI-2).

The quotes disclose a lived sense of being unsupported and unprioritized. The temporal delay in receiving care was not merely a delay; it became an existential weight, contributing to a sense of marginalization. Such experiences point to a deeply felt need for rational care, one marked not only by clinical presence but by genuine human attention.

Subtheme 5.2: Lack of family support: Participants described how the absence of family involvement contributed to emotional and practical isolation. Family members’ failure to understand or actively participate in dietary routines, medication schedules, and general support left many participants feeling alone in their management journey.

“Some family members are not supportive of preparing foods suitable for diabetes patients.”

(Participant 2, FGD1).

The lack of support shaped a felt experience of vulnerability. The home, ideally a space of comfort, became a site where self-care efforts were strained or even sabotaged by misunderstanding. The experience of this barrier was both practical and emotional, undermining motivation and instilling doubt in one’s capacity to manage the diseases alone.

A lack of support from healthcare providers and family can reduce motivation and self-efficacy, making it more difficult for patients to maintain self-care. On the other hand, strong support systems can act as cues to action, encouraging positive to self-care practices.

Main themes	Subthemes	Description
1. Emotional disruption following diagnosis	• Fear and hopelessness • Lack of initial knowledge at diagnosis	Initial reactions to diagnosis include fear, shock, anxiety, and despair. Many participants lacked understanding of diabetes at diagnosis, delaying effective engagement with self-care.
2. Perceived disease severity and fear of complications	• Experience of diabetes related complications • Comorbidity burden	Complications were described as unpredictable and frightening, disrupting normal life and highlighting the silent progression of the disease. Managing multiple illnesses such as hypertension intensified emotional and physical exhaustion, reinforcing the need for sustainable self-care.
3. Economic and infrastructural constraints	• Economic difficulties • Medication unaffordability and shortages	Financial limitations and systemic shortages hinder consistent medication use, dietary intake and clinical follow-up
4. Cultural and religious beliefs	• Cultural stigma and traditional practices • Religious influence on treatment intake	Cultural norms discouraged visible self-care, such as taking medication in public, and promoting herbal remedies over biomedical advice. Faith-based healing and belief in divine intervention led some to abandon medical treatment, with serious health consequences.
5. Systemic and interpersonal gaps6.	• Low support from healthcare providers • Inadequate family involvement • Limited patient health literacy	Participants reported lack of empathy from healthcare providers, compounded by delays in delivery service. The absence of emotional and practical support from family further undermines their ability to engage in self-care. Limited understanding of diabetes and self-care behaviors led to mistakes such as alcohol use and missed meals.

Table 2. Summary of Themes and Subthemes.

Subtheme 5. 3: Living with limited knowledge as a patient: For participants, knowledge was not only cognitive but existential-; it marked the boundary between agency and confusion. When knowledge was lacking, participants described a disjointed relationship with their conditions, marked by uncertainty, regret, and the repetition of harmful habits.

''Some of my friends died because of poor self-care practices."

(P11: IDI-11).

''Sometimes we diabetes patients make mistakes such as consuming alcohol, which is a great mistake, we make… forgetting a meal is another mistake we make."

(Participant 4, FGD1).

The forgetting and mistakes described are not merely lapses in behavior, but reflections of the larger struggle to internalize and live with chronic illness knowledge. The participants' voices reflect moments of disconnect from their own bodies and routines, revealing the fragile nature of self-efficacy when not continually reinforced. The analysis yielded five main themes and associated subthemes as summarized in Table 2.

Concluding the results, at the heart of these five themes lies a central existential truth: living with diabetes is not just a physical journey, but an emotional, social, and spiritual one. The barriers experienced are not merely external obstacles, but they are lived realities that affect how individuals relate to themselves, their bodies, their communities and their care systems. To support effective self-care interventions must move beyond clinical protocols to embrace empathy, education, cultural sensitivity, and relational support.

Discussion

This study explored the lived experiences and perceived barriers to effective self-care practices among outpatients with T2DM in three hospitals of Wolaita Zone, South Ethiopia. Through a descriptive phenomenological approach, participants revealed a range of individual, socio-cultural, economic, and systemic factors that hinder self-care engagement. The essence of these experiences was clustered into five major themes: emotional responses to diagnosis, perceived severity and complication, socioeconomic and resource barriers, cultural and social beliefs, and system and interpersonal barriers.

The initial moment of diagnosis was described by participants as a deeply distressing and disorienting experience. Feelings of fear, shock, hopelessness, and denial emerged as core constituents of their emotional response. These reactions, lived in the immediacy of being diagnosed, disrupted patients' engagement with self-care practices. The emotional weight of diagnosis was not merely a transient reaction but a persistent condition that shaped their relationship to the conditions. These findings align with the Health Belief Model (HBM) constructs of perceived susceptibility, where individuals internalize diabetes into a life-threating, irreversible condition[15,21]. Similarly, other studies suggest that unmanaged emotional stress can intensify glycemic control issues and hinder long-term diabetes management[22,23]. Participants' emotional experiences revealed a non-linear trajectory, often oscillating between acceptance and despair. This highlights the need for psychological support to be integrated into routine diabetes care. As emotional turmoil becomes embodied in the patients' day-to-day consciousness, supportive intervention tailored to the individuals' evolving psychological state are critical for improving self-care behaviors[24,25]. Therefore, recognizing and addressing emotional reactions to self-care practice is essential for effective diabetes care. By integrating psychological support into routine care, healthcare providers can help patients manage emotional challenges and improve their engagement with self-care practices.

The lived experience of disease severity and the anticipation of complications were prominent in participants' reflections. Narratives were imbued with references to irreversible outcomes such as blindness, stroke, or kidney failure. The invisible of early complications described metaphorically by participants as diabetes being a "silent killer" intensified their sense of vulnerability. The presence of comorbidity like hypertension added further complexity, reinforcing a state of continuous health uncertainty. These experiences resonate with the HBM's perceived severity and perceived susceptibility constructs, where an awareness of serious consequences can either prompt or paralyze health action[26–28]. Participants did not merely perceive complications intellectually,

they experienced them as a shadow over daily life, making future health seem uncertain and threatening. The constant negotiation with comorbidity adds to the psychological and physical burden, complicating both treatment regions and prospects for improvement.

The daily struggle to access medications, afford nutritious foods and maintain transport to healthcare facilities emerged as a critical barrier to self-care. Participants vividly described their inability to purchase necessary medications and dietary recommendations, even when aware of their importance. These experiences represent not only structural constraints but existential limitations, where one's agency in managing their health is restricted by forces beyond their control. Financial hardship was experienced as a fundamental disruption to self-care, directly aligning with the HBM's perceived barriers construct. The unavailability of medications in public hospitals further compounded this burden, forcing patients to seek unaffordable alternatives in private pharmacies. These findings are supported by studies in low-income settings, where systemic resource-constraints undermine consistent self-care[29,30]. For these individuals, economic hardship was not just a backdrop, but a lived reality interwoven with the experience of conditions. These findings align with studies conducted in low-income countries[31,32]. Policy action to strengthen the medication supply chain and reduce out-of-pocket expenses is essential to restoring continuity and dignity in diabetes care.

Participants' experiences were strongly shaped by prevailing cultural norms and social interpretations of diabetes. The tension between biomedical prescriptions and traditional or religious beliefs created internal conflict that undermined consistent self-care. Several participants expressed embarrassment in taking medication publicly, reflecting a stigma around chronic illness that is deeply rooted in community perceptions. These lived realities reflect how culture is not an external influence but an internal framework through which health is perceived and practiced. This finding aligns with evidence that stigma and cultural attitudes can discourage individuals from managing their condition openly, thereby compromising treatment consistency[33]. Others described the use of herbal remedies like mango leaves, influenced by generational knowledge and spiritual tradition. This aligns previous study in Ethiopia, traditional medicine can conflict with biomedical approaches[34]. Religious beliefs such as fasting, prayer as treatment, and beliefs in spiritual causation of illness were mentioned as alternative frameworks for understanding and managing diabetes. This phenomenon has been reported in previous studies that discussed the influence of spiritual and religious beliefs on health behaviors in Ethiopia and similar settings, where patients prioritize faith-based healing over medication treatment[35,36]. Incorporating culturally sensitive education, involving religious leaders, and harmonizing traditional beliefs with modern care practices may enhance cue to action and support a more coherent patient understanding of self-care.

Participants frequently described experiences of neglect, delay, and emotional detachment from healthcare providers. Reports of unavailable doctors, inconsistent follow-up, and perceived discrimination illuminated a healthcare environment that, in the participants' experience, lacked compassion. Similar findings from other studies have emphasized the role of psychological and structural support in enabling effective diabetes self-care[37,38]. These encounters shaped patients' self-conception and their motivation to persist with self-care. Similarly, lack of family support emerged as an obstacle. Participants shared how the absence of encouragement or dietary support at home weakened their ability to follow prescribed regimens. This finding is consistent with studies demonstrated that family involvement significantly impacts self-care behaviors, including diet and medication management[38,39]. Addressing these barriers requires a collaborative approach involving healthcare teams, family and community members to provide consistent and supportive care of diabetes, ultimately strengthening cues to action and improving self-care practices. Further compounding these issues was limited knowledge and inadequate training among healthcare providers. Despite receiving counseling patients often failed to retain essential self-care guidance. Providers, particularly community health workers, noted that their academic training excluded diabetes management, leaving them underprepared to support patients. These align findings are consistent with evidence showing that low health literacy and knowledge gaps hinder effective diabetes self-care practices and worsen outcomes[40,41]. Addressing these barriers requires a holistic and patient-centered approach. Strengthens training, improving communication, and involving families in diabetes care are essential steps to rebuilding trust, enhancing self-efficacy, and enabling consistent self-care.

Strengths and limitations of the study

This study has several strengths, including the use of Husserlian descriptive phenomenology, which enabled an in-depth exploration of the lived experiences of individuals with T2DM and focus group discussion, capturing rich, context-specific insights from patients. The inclusion of diverse perspectives of IDIs and FGDs, integration of findings with the Health Belief Model enhanced the depth and interpretative value of the analysis. However, the study also has limitations. The reliance on self-reported data introduces potential biases, as participants might overstate self-care engagement in recommended practices or underreport barriers due to social desirability. Additionally, while systemic and cultural barriers were mentioned, the study may place disproportionate emphasis on individual behaviors without fully exploring broader systemic inequities and policy-level challenges.

Conclusions and recommendations

This study provides the lived experience of patients with T2DM in Wolaita Zone, South Ethiopia. The study revealed that barriers to self-care are embedded in emotional, cultural, economic, and systemic dimensions of everyday life. These are not abstract challenges, but they are the lived, felt, and embodied realities of individuals navigating a chronic condition within complex societal contexts. A responsive healthcare approach must therefore move beyond clinical protocols to engage deeply within patients' experiences, beliefs, and environments. Patients with T2DM should seek continued education about self-care practices, including diet, medication intake and recognizing complications-; actively engaging in counseling sessions and peer support groups may enhance knowledge and emotional coping. Community and family members should foster support free from stigma, misinformation, and harmful cultural beliefs. Healthcare providers need to adopt a more

compassionate, consistent, and patient-centered approach. Hospitals should improve the availability of essential diabetes medications and ensure timely access to services. Investing in staff training and multidisciplinary care teams will enhance the quality of diabetes management. The regional health office should strengthen the supply chain for diabetes medication and support capacity-building initiatives for healthcare workers, especially those working in diabetes management. Integrating mental health support into diabetes care is essential. Policymakers should prioritize diabetes care by allocating sufficient resources, formulating culturally sensitive public health campaigns, and ensuring universal access to medication and diagnosis. Future studies should include broader and more diverse participants from policy and community levels using mixed-method approaches.

Data availability

All necessary data is included in the manuscript.

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Conceptualization: T. A., C. S, C.N.L, A.W and E.W.Data curation: T. A, C. S., C.N.L and A.WFormal analysis-T. A, C.S, and SA.I., J.J, S.S., N.T.Funding acquisition: T. A. and C.S.Investigation: T. A, E.W, N.T, and J.JMethodology: T. A., C. S, C.N.L, AW, SS, and E.WProject administration: C.S.Resources: T. A and C.S, Software: T. A. C. S, and J.JSupervision: C.S, C.N.L, E.W, S.S, and A.W, Validation: C. S, C.N.L, E.W, A.W and SA. IVisualization-T. A, C.N.L, SA. I, and E.WWriting-Original Draft Preparation: T.A, C.S, NT, and EWWriting Review and Editing-T. A, C.N.L, and A.WAll authors read, approved, and agreed to the publication.

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Declarations

Ethical approval

Ethical clearance was obtained from the Walailak University Ethics Committee, Thailand (approval no. WUEC-24-264-01) and permissions from Wolaita Sodo University (reference no. CHSM-4/3579/20/1). Written informed consent was obtained from all participants; Confidentiality was maintained through the study. The research in this study adhered to the principles of the Declaration of Helsinki on human research ethics of the 1964 standard[42].

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Additional information

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