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Illness Cognition and Treatment Delay in Patients with Diabetes Mellitus

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Abstract. *Introduction* Delayed treatment seeking among patients with diabetes mellitus remains a major challenge to effective disease management and complication prevention. *Aim* This study explored patients' perceptions of diabetes mellitus and factors contributing to treatment delay using the Common-Sense Model. Data were collected through in-depth interviews and analyzed using deductive thematic analysis. *Result* Findings revealed limited understanding of the causes, symptoms, and complications of diabetes mellitus. Early symptoms were often perceived as normal or non-serious, reducing timely healthcare seeking. Participants commonly believed the disease could be managed through dietary modification and traditional remedies, often prioritizing these approaches over medical treatment. Delayed treatment seeking was further influenced by low perceived severity and environmental factors.
Conclusion Patients delaying treatment hold an illness cognition defined by symptom normalization, a preference for traditional management, and a minimized perception of disease seriousness, highlighting the need for targeted health education to promote timely care.

Introduction

Diabetes mellitus (DM) remains a major public health issue. DM affects approximately 589 million adults aged 20–79 worldwide, equivalent to 1 in 9 adults. Of this number, around 252 million people are unaware that they have diabetes. Approximately 81% of people with diabetes live in low and middle-income countries, highlighting disparities in access to prevention and treatment. DM was also responsible for approximately 3.4 million deaths in 2024 and imposed a

substantial economic burden, with total global health expenditures reaching around USD 1 trillion. The number of people living with diabetes is projected to rise sharply to approximately 853 million by 2050, indicating an increasing trend and posing a major challenge to global public health (IDF, 2025). In East Nusa Tenggara Province, diabetes reached 35,180 reported cases in 2023 (East Nusa Tenggara Provincial Health Office, 2023). Kupang City had the highest number of diabetes cases, with figures continuing to increase each year. In 2022, there were 5,138 recorded cases of diabetes, which rose to 5,269 cases in 2023 (Kupang City Health Office, 2023).

DM requires continuous self-management, including medication adherence, lifestyle modification, dietary regulation, regular physical activity, and blood glucose monitoring. Patients often experience physical, psychological, and social challenges in integrating these demands into daily life, which may negatively affect their quality of life (Kahu et al, 2024). Inadequate disease management and delayed treatment-seeking behavior can further increase the risk of severe complications. These include macrovascular complications such as cardiovascular disease and stroke, as well as microvascular complications such as retinopathy, nephropathy, neuropathy, and diabetic foot ulcers (PERKENI, 2021). Although effective treatment is available, some individuals still delay seeking care, which may worsen disease progression and outcomes.

Despite similar symptoms and medical recommendations, individuals with diabetes show different responses to their illness. Some patients actively seek treatment and adhere to medical advice, while others delay or avoid treatment and rely on self-management strategies. These differences indicate that patients' interpretations of their illness play an important role in shaping treatment-seeking behavior (Broadbent et al., 2006).

Illness perception refers to the cognitive and emotional representations that individuals form regarding their illness or health condition, which influence how they understand, evaluate, and manage their disease (Broadbent et al., 2006). This perception affects how patients interpret their disease, make treatment-related

decisions, and adapt to their health condition, making it essential to understand these perceptions to design effective education and intervention strategies for patients (Leventhal et al., 1980). Illness perception plays a significant role in diabetes management and health outcomes. Patients who perceive diabetes as a serious and chronic condition are more likely to engage in self-care behaviors, adhere to treatment recommendations, and utilize healthcare services regularly. Conversely, maladaptive illness perceptions may contribute to poor disease management and unfavorable health outcomes.

The Common Sense Model (CSM) explains that patients' cognitive and emotional representations of illness influence coping responses and health-related behaviors, including treatment decisions and healthcare utilization (Leventhal et al., 1980). Previous research in Indonesia indicates that patients' perceptions of type 2 diabetes are shaped by personal experiences, social interactions, and sociocultural contexts. These perceptions influence how individuals interpret symptoms, respond to their illness, and manage their condition in daily life (Widayanti et al., 2020). However, existing studies have primarily focused on self-management and treatment adherence, while limited attention has been given to understanding how illness perceptions contribute to delays in seeking professional healthcare among patients with type 2 diabetes.

Despite these findings, most existing studies have been conducted using quantitative approaches focusing on associations between illness perception and outcomes such as self-care behavior, adherence, or glycemic control. Limited studies have explored how illness perceptions are constructed through lived experiences and how these perceptions contribute to delayed treatment-seeking behavior. Given that treatment decisions are influenced not only by clinical factors but also by patients' cognitive and emotional representations of illness, a deeper qualitative exploration is needed to understand how illness perceptions contribute to treatment delay among individuals with DM.

Method

This study employed a qualitative descriptive method to explore illness cognition and treatment delay in DM patients, as this approach is suitable for integrating existing theoretical frameworks into data analysis (Colorafi & Evans, 2016). The study was conducted in Kupang City from December 2025 to March 2026. Informants were selected through snowball sampling until data saturation was achieved, defined as the point when no new information is obtained (Moser & Korstjens, 2018).

Two groups of informants (key informants and supporting informants) were recruited based on specific criteria aligned with the research objectives. Key informants were individuals with DM who had discontinued diabetes care, defined as not receiving diabetes treatment or attending medical check-ups for at least two months before the study. Key informants were eligible if they had been diagnosed with DM by a healthcare professional and were aged 18 years or older. Individuals who were unable to participate in an in-depth interview due to acute illnesses or communication difficulties were excluded. Supporting informants were family members who were knowledgeable about the patient's illness history and treatment-related behavior. A total of six informants participated in this study, consisting of five key informants and a supporting informant.

Data were collected through semi-structured in-depth interviews using an interview guide developed based on the CSM. In alignment with COREQ guidelines for transparency and reflexivity, interviews were entirely conducted by the first author, with training in qualitative interviewing. The researcher had no prior relationship with any of the participants. The interviews were conducted at informants' houses based on mutual agreement to ensure comfort and privacy. The interviews lasted approximately 30–45 minutes, were digitally audio-recorded with participants' explicit written consent, and were subsequently transcribed verbatim.

Data were analyzed using deductive thematic analysis driven by the CSM as the theoretical framework (Braun & Clarke, 2006). This method was selected to map

the informants' illness perceptions directly against the pre-established dimensions of the CSM (Colorafi & Evans, 2016; Fife & Gossner, 2024). Transcripts were read repeatedly to gain an understanding of the narratives. The initial codes were organized into the five dimensions of the CSM: Identity, cause, timeline, consequences, and control, and were interpreted to identify patterns related to delayed treatment-seeking behavior.

Trustworthiness was established based on Lincoln and Guba's evaluative framework. Credibility was enhanced through source triangulation by cross-checking the patient's information with the data from a supporting informant. Furthermore, member checking was performed by allowing participants to review and verify the accuracy of the interview data (McKim, 2023). Dependability was maintained by ensuring a consistent data tracking process through digital audio recording and verbatim transcription of all interviews, minimizing data loss or alteration during the descriptive phase. Confirmability was attained by anchoring the analysis strictly within the textual data and the structured dimensions of the CSM framework, verifying that the interpretations emerged directly from the informants' statements rather than researchers' preconceptions. Ethical approval was obtained from the Health Research Ethics Committee, Faculty of Public Health, Universitas Nusa Cendana (No. 000636/KEPK FKM UNDANA/2026), and written informed consent was obtained from all participants.

Result

A total of six informants participated in this study, consisting of five key informants (patients) and one supporting informant (a family caregiver). The key informants were aged between 40 and 60 years and came from diverse occupational backgrounds, including a tailor, a fish vendor, a private sector worker, and housewives. At the time of the study, these patients had been diagnosed with DM for durations ranging from 1 to 4 years. All key informants experienced a delay in seeking medical treatment, which varied from 5 months to 1 year. To provide

insights into the patient's illness and treatment-related delay, a supporting informant was interviewed.

Illness Identity Representation

Interview findings indicated that most informants had only a general understanding of DM as a sugar disease but lacked in-depth knowledge regarding its mechanisms or specific clinical signs. Their understanding was primarily derived from stories shared by others or brief information provided by healthcare professionals, rather than from comprehensive knowledge.

> *"What I know is that it is a sugar disease that can make wounds difficult to heal" (IN, female, 46 years)*

While most informants reported experiencing early symptoms, these initial physical changes were not immediately linked to DM.

> *"I just thought I was normally tired because I sell goods at the market every day. I was also often thirsty, so I drank a lot of water and frequently consumed sweet drinks. I also often urinated at night, and I assumed it was because I drank too much. I never thought it was diabetes" (AL, female, 60 years).*

The supporting informant explained that the awareness of the illness developed after the patient underwent a medical examination and received an explanation from healthcare professionals.

> *"At first, I thought my mother was just normally tired, but later she complained about blurred vision and feeling fatigued easily. After she went to the public health center for a check-up, we found out that her blood sugar level was high" (NS, female, 20 years).*

Illness Cause Representation

Most informants associated DM with uncontrolled dietary habits, particularly the excessive consumption of sweet foods and beverages. This belief was consistently expressed by nearly all key informants.

> *"I do not have a family history of diabetes; I am the only one in my family with this disease. Maybe it is because of my eating habits and my routine of drinking tea in the morning, afternoon, and evening" (IN, female, 46 years).*

In addition to dietary factors, several informants linked their illness to family history.

> *"My mother had diabetes. So when the doctor told me that I had diabetes, I immediately thought of my mother. I believed that this disease was inherited from my family. From the beginning, I was already afraid of developing it, so I started exercising and trying to maintain my diet. However, sometimes my eating habits were still uncontrolled, and eventually I developed diabetes" (BB, female, 40 years).*

Some informants reported that after understanding the possible causes of their illness, they became more aware of the importance of lifestyle changes. They recognized that habits such as excessive sugar consumption, irregular eating patterns, and lack of physical activity contributed to their health condition. This awareness encouraged them to gradually reduce unhealthy behaviors, such as limiting sugar intake, engaging in light exercise, and paying closer attention to their diet, although these efforts were not always applied consistently.

Supporting informants also perceived that the illness experienced by their family members was largely influenced by daily dietary habits.

> *"My mother really likes eating cakes while drinking tea, so maybe her eating habits are what caused her blood sugar to rise" (NS, female, 20 years).*

Illness Consequences Representation

All informants were aware of the physical effects of their illness. They reported feeling physically weaker than before and more easily fatigued.

> *"Now I feel tired more quickly. In the past, I could work from morning until evening sewing clothes without any problem, but now my body gets tired faster, and my vision becomes blurred. So this illness really affects my work" (DS, female, 44 years).*

Interviews with key informants indicated that diabetes had a noticeable impact on patients' daily activities. This was further supported by statements from the supporting informant, explaining that the patient's health conditions had changed after being diagnosed with diabetes.

> *"My mother now spends more time resting at home. If she gets too tired, she usually starts feeling unwell immediately" (NS, female, 20 years)*

Some informants demonstrated an awareness of the severe long-term consequences of DM, yet the resulting fear led them to adopt avoidant coping strategies rather than continue to treatment.

> *"I am afraid that if a wound does not heal, it might lead to amputation. Many people say that, and it scares me. But I try not to think about it too much so that I do not become stressed" (DS, female, 44 years).*

In contrast, other participants delayed the treatment due to a work schedule that left little time for healthcare, particularly when symptoms felt minor. The heavy workload and low symptom severity resulted in a shift toward daily self-care habits instead of a clinic visit.

> *"I work in an office from Monday to Friday, so sometimes I do not have time to go for a check-up, especially if I feel that my condition is not too severe. My workload is already quite heavy, so I just try to control my diet, pray so I do not get sick, and usually go for morning walks at Nostalgia Park [a park in the city]" (BB, female, 40 years).*

Illness Timeline Representation

Most informants understood DM as a long-term disease. This understanding was generally developed after receiving explanations from healthcare professionals. However, although they recognized the chronic nature of the disease, this perception did not always correspond with consistent treatment behavior.

> *"At first... I assumed it was just a common illness that would eventually improve as long as I maintained my diet, but I began to feel the symptoms more frequently. So I started to think that maybe I needed regular treatment. The doctor told me that as well, but if I feel fine, then I do not go for treatment" (DS, female, 44 years)*

Illness Control/Cure Representation

Informants acknowledged that prescribed medical treatment lowered blood sugar levels. However, despite recognizing this effectiveness, individuals personally modified the regimen based on a belief that self-directed dietary management and alternative remedies could avoid long-term dependency on medication.

> *"When I take medicine, my blood sugar does go down, I admit that. But sometimes I feel that if I maintain my diet properly and avoid sweet drinks, maybe I do not need to keep taking medicine continuously. I also do not want to become dependent, so when my*

> *symptoms return, I usually boil leaves and drink it. But I do not drink it every day, only once a week" (IN, female, 46 years).*

The choice to seek medical care depended heavily on how noticeable the symptoms were. When the health condition felt minor, treatment-seeking was put off. A supporting informant confirmed this behavior, noting that a trip to the hospital happened only after the patient experienced worse physical decline.

> *"At first, my mother said it was nothing serious, just normal fatigue. So she did not immediately go for a check-up. She waited until her body felt much weaker before finally going to the hospital" (NS, female, 20 years).*

Discussion

Treatment Delay in Patients with Diabetes Mellitus

The findings of this study revealed that treatment delay among patients with DM manifests in two forms: postponement of regular medical check-ups and discontinuation of ongoing therapy. During the early stages of illness, delays appear to be driven by the normalization of symptoms. Patients frequently misinterpret early signs of DM (such as polydipsia, polyuria, blurred vision, and fatigue) as common fatigue resulting from daily activities. This tendency to trivialize initial symptoms suggests a low perception of disease severity, which may prevent timely healthcare-seeking behavior at healthcare facilities.

In addition to symptom misinterpretation, structural barriers, particularly work schedules, contribute substantially to delayed care. Patients with standard weekday working hours face difficulties in accessing healthcare facilities during regular operating hours, leading to postponed medical consultations.

The study also reveals that treatment delay extends to poor adherence among already-diagnosed patients. The tendency to discontinue medication once clinical symptoms subside indicates a limited understanding of chronic disease management. Instead of following medical recommendations, patients frequently rely on advice from their social networks to make treatment decisions.

These findings are consistent with previous studies indicating that low perceptions of disease severity, blood glucose levels, and insufficient knowledge can influence treatment-seeking behavior among patients with DM (Rosalinda, 2023). Similarly, non-adherence to treatment is also affected by inadequate knowledge and attitude regarding the importance of long-term therapy (Istiqomah et al, 2021). Interpreted through the Health Belief Model (HBM), treatment delay was driven by low perceived severity and susceptibility, as early symptoms were minimized and assumed manageable. Work obligations and time constraints served as perceived barriers, dampening perceived benefits until symptoms escalated. Thus, delayed care stems not merely from a knowledge deficit, but from underlying illness beliefs. Health education must therefore extend beyond increasing knowledge to actively reshaping patient perceptions, encouraging timely care-seeking and long-term treatment adherence.

Illness Cognition based on the Common-Sense Model (Leventhal)

Illness Identity Representation

Initial understanding of DM was limited to a lay concept of "sugar disease", preventing the recognition of clinical blood glucose levels and early symptoms, such as excessive thirst, frequent urination, and fatigue. This finding indicates that low clarity in illness identity representation contributes to delays in seeking treatment. Patients generally took action only when symptoms became severe or began to interfere with daily activities. This is consistent with previous studies stating that low treatment adherence can be predicted when illness perception is also low, and that illness perception was related to treatment adherence among DM patients (Bilondi et al., 2021). Although knowledge and illness perception influence self-care behavior, not all patients with good understanding are able to consistently implement behavioral changes (Kugbey et al., 2017). Thus, the issue is not merely a lack of information, but rather how symptoms are interpreted and understood within patients' everyday experiences.

The lack of symptom recognition related to disease identity directly aligns with low perceived susceptibility and severity as conceptualized in the Health Belief Model (HBM) (Rosenstock, 1974). Because the initial signs are misinterpreted as minor or non-serious, patients do not perceive an immediate threat to their health, which initiates the timeline for treatment delay

Illness Cause Representation

The causal representations of the illness were predominantly attributed to uncontrolled eating patterns, excessive consumption of sweet foods, and lack of physical activity. The perception also existed that DM was caused by hereditary factors or family history, reflecting a common belief that diabetes is an inherited condition. This finding is consistent with previous studies reporting that patients commonly perceive diabetes as being influenced by hereditary factors, stress, and lifestyle imbalance (Widayanti et al., 2020). Such perceptions may shape how individuals understand their susceptibility to diabetes and influence how they respond to the illness. Previous studies have also shown that although patients may possess knowledge regarding the causes of diabetes, this knowledge does not always translate into adherence to healthy behaviors such as dietary regulation and physical activity (Kugbey et al., 2017).

Similar patterns were observed in the present study, where a clear recognition of the role of unhealthy lifestyles in the development of diabetes did not lead to consistent behavioral changes. Therefore, it can be understood that understanding the causes of the disease alone is insufficient to drive behavioral change, as health-related actions are also influenced by psychological factors, personal habits, and the patient's social context.

Illness Timeline Representation

Although DM was predominantly recognized as a chronic and permanent disease, this realization did not ensure long-term treatment compliance. While DM was understood as chronic, treatment urgency was perceived based on the physical condition experienced at a given time. This suggests that the understanding of

chronicity remained cognitive and was not fully internalized into behavioral practice. Informants tended to believe that as long as there were no severe symptoms, their condition was still under control. These findings are consistent with previous research showing that timeline perception, or beliefs regarding the duration of illness, is one of the factors influencing treatment adherence among DM patients, where patients who perceive their illness as chronic are more likely to adhere to ongoing therapy (Kim et al., 2021).

Illness Consequence Representation

Awareness regarding severe complications, including non-healing wounds and amputation, was widespread; however, these outcomes were viewed merely as distant possibilities rather than urgent health threats. According to CSM, the greater an individual perceives the consequences of an illness, the higher the likelihood of engaging in protective actions. However, this study found that fear of complications did not consistently motivate adherence to treatment. As long as individuals felt capable of carrying out normal daily activities, the perceived urgency for treatment remained low.

These findings are consistent with previous studies indicating that illness perception, including perceptions of consequences, is associated with treatment adherence, but may not always serve as a strong motivating factor unless accompanied by a realistically perceived threat. This study also highlights that adherence can be improved through changes in perceptions of illness and treatment, demonstrating that the interpretation of illness consequences plays an important role in shaping health behavior (Broadbent et al., 2011).

Illness Control and Cure Representation

Understanding that DM is a lifelong disease does not automatically lead to consistent treatment adherence. There is a clear contradiction in how the disease is managed. While the effectiveness of medical treatment in lowering blood sugar is widely accepted, there is a strong reliance on personal control through independent strategies, such as dietary habits and herbal remedies.

These findings show that patients' control beliefs are shaped by their cultural environment. Within the Health Belief Model (HBM), these cultural views act as modifying factors that change how people evaluate health options (Rosenstock, 1974). Choosing herbal remedies over medical care is not just an individual decision; it is driven by shared community beliefs. As shown by Widayanti et al. (2020), many Indonesian patients prefer alternative treatments because they believe natural ingredients are safer than long-term medical drugs. From an HBM perspective, this cultural norm increases the perceived barriers of conventional medicine, such as fear of drug dependency, while increasing the perceived benefits of traditional herbs. As a result, the local culture modifies patients' thinking, leading them to choose traditional care and delay medical treatment.

According to CSM, control and cure representations reflect individuals' beliefs regarding the extent to which an illness can be managed through personal actions or medical treatment. These beliefs influence coping strategies and treatment-related decisions. In the present study, participants demonstrated strong beliefs in personal control, particularly through dietary modification and the use of herbal remedies, which influenced their perceptions regarding the necessity of professional medical care.

The findings suggest that perceptions of personal control were highly apparent, as the necessity of treatment was decided based on subjective physical conditions. Additionally, alternative treatments were sought as an extra form of control. The findings also suggest that illness control beliefs were shaped by social and sociocultural influences. Several informants reported using herbal remedies such as leaves or modifying their diet based on information obtained from family members, relatives, or people within their social environment. These findings indicate that perceptions regarding diabetes management are not formed solely through personal experiences but are also influenced by social interactions and community knowledge. Such sociocultural influences may strengthen patients'

confidence in self-management practices and contribute to decisions to delay professional medical treatment. This reflects an active search for coping strategies that align with their personal beliefs.

These findings are consistent with previous research showing that personal control is an important factor influencing the beliefs of individuals with diabetes in managing their illness. The stronger patients believe that diabetes can be controlled through personal effort or treatment, the greater their confidence in managing the condition. This emphasizes that perceptions of personal control play a major role in shaping diabetes management behavior, as patients who feel they have greater control tend to be more confident in their ability to cope with the disease (Kim et al, 2018).

In addition to personal control beliefs, previous studies have shown that individuals with DM often employ cognitive and spiritual strategies, such as normalizing their condition, surrendering to God, or believing that the disease can be managed through personal efforts (Widayanti et al., 2020). These coping strategies help individuals maintain psychological balance and continue their daily activities despite living with a chronic condition. Consistent with the findings, patients in the present study frequently relied on personal judgment regarding when treatment was necessary, and many believed that diabetes could still be controlled through self-management practices. Consequently, medical intervention was often perceived as unnecessary unless symptoms became worse.

This study sheds new insight on how treatment delay is driven by the internal dynamics of patients' illness representations and subsequent coping behaviors. Specifically, while patients acknowledge the clinical efficacy of medical treatment, they actively postpone care due to confidence in personal control, primarily through self-directed dietary modifications and alternative remedies. This study also uncovers that an awareness of severe long-term complications, such as amputation, triggers fear-driven avoidant coping rather than encouraging proactive healthcare-seeking behavior.

This study has several limitations. First, participants were selected using snowball sampling from a single geographic area, which may limit the diversity of perspectives and the transferability of the findings to other settings or populations. Second, the findings were based on self-reported experiences and may have been influenced by recall bias. Nevertheless, the study enabled an in-depth exploration of individuals who had discontinued diabetes care, providing insights into their illness cognition and how these were reflected in decisions regarding diabetes care.

Conclusion

Treatment delay among patients with DM generally occurs as patients tend to seek treatment only when symptoms become more severe, along with a tendency to rely on self-management approaches such as dietary regulation or the use of herbal remedies. Patients also perceived that their condition can still be controlled without medical intervention, further reinforcing the decision to postpone treatment. Treatment delay among DM patients relates to patients' interpretation and perception of their illness, which ultimately influences their decision-making in seeking and adhering to treatment.

Suggestion

Healthcare providers should implement patient-centered educational interventions to address misconceptions about DM, particularly regarding symptom recognition, disease severity, and the importance of timely medical treatment, and focus on reducing patients' tendency to rely on self-management practices. Future studies should evaluate the effectiveness of theory-based intervention targeting illness perception in improving treatment-seeking behavior and adherence among patients with DM.

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Author contribution

VAGL conceptualized the study, collected data, performed data analysis, and drafted the manuscript. HJNN and EZHB participated in the data analysis and critically reviewed and revised the manuscript. M provided feedback on the manuscript. All authors read and approved the final version of the manuscript.

Competing interest

No potential conflict of interest was reported by the authors.

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