

EXPERIENCES AND PERCEPTIONS OF DIABETES PATIENTS AND THEIR FAMILIES IN IMPLEMENTING DIABETIC SELF-CARE: A QUALITATIVE STUDY

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ABSTRACT

Diabetic patients experience numerous challenges in adhering to self-care practices such as glucose monitoring, diet management, and physical activity, all of which require a continuum of care. This study aimed to explore the experiences and perceptions of diabetic patients regarding self-care, as well as the factors influencing their adherence. The study employed a qualitative method with a phenomenological approach, involved five participants from South Kalimantan. Data were collected through semi-structured, in-depth interviews and analyzed using the Colaizzi method to identify key themes reflecting self-care experiences. The study showed that the participants' understanding of self-care varied, especially concerning glucose monitoring and physical activity. Family support emerged as a significant factor in improving adherence to self-care; however, the family's limited understanding of diabetes management sometimes impeded these efforts. Additional barriers included limited access to healthcare, high medication cost, and the expense of monitoring devices. While participants showed optimism about their future health, they also voiced concerns about the long-term sustainability of self-care practices. The findings underscore the importance of diabetes management programs that involve education for both patients and their families, as well as policies that support more affordable health access. A comprehensive approach to diabetes management, including family and community support, can improve patient adherence to self-care and enhance quality of life.

Keywords: *Diabetes; family support; self-care*



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BACKGROUND

Diabetes mellitus, a chronic non-communicable disease, poses significant challenges to global health due to its high prevalence and its association with severe complications such as cardiovascular disease, neuropathy, and nephropathy (Magliano et al, 2021). Recent data highlight an alarming increase in diabetes cases worldwide, particularly in Southeast Asia, where lifestyle factors and genetic predispositions combine to exacerbate the public health burden (Shrivastava et al., (2013); Magliano et al., (2021). Indonesia, for instance, ranks among the top five countries in terms of diabetes prevalence, with projections indicating a continued upward trend (1).

Diabetes management is multifaceted, involving pharmacological interventions, lifestyle modifications, and patient-centered care practices. Diabetes self-care, a cornerstone of effective management, encompasses various activities such as glucose monitoring, dietary adjustments, medication adherence, and physical activity (American Diabetes Association, 2017). However, diabetes self-care practices are often challenging for patients, as they are influenced by socioeconomic factors, health literacy, motivation, and family support (4). Research suggests that self-care practices can substantially reduce the incidence of complications when effectively integrated into daily routines, particularly for patients with type 2 diabetes (5).

Although diabetes self-care has been extensively studied in clinical and educational contexts, a significant gap remains in understanding how patients and their families personally experience and perceive self-care in their daily lives. Most existing research emphasizes outcomes, adherence, or biomedical aspects, often overlooking the emotional, cultural, and relational dimensions that profoundly influence self-management behavior (Nam et al., 2011; Johnson et al., 2024). This study addresses that gap by exploring the lived experiences and perceptions of both patients and their family members in implementing diabetic self-care. Using a qualitative phenomenological approach, the study uncovers how cultural beliefs, family dynamics, emotional responses, and perceived challenges shape the understanding and practice of self-care (Davoodi et al., 2022; Zhang et al., 2024). The novelty of this research lies in its dual focus on both patients and families, as well as its context-specific perspective, offering valuable insights into how self-care practices are influenced by the social and cultural environments. These findings provide a fresh and essential perspective for developing more empathetic, family-centered nursing interventions and support programs tailored to real-world experiences.

Despite the critical role of self-care in diabetes management, adherence remains suboptimal worldwide. Barriers to effective self-care include inadequate health literacy, financial constraints, limited access to healthcare, and a lack of family or social support. Studies have shown that patients who lack knowledge about diabetes and its management are less likely to adhere to self-care regimens, increasing their risk of acute and chronic complications (Jaam et al., 2018; Busebaia et al., 2023; Ferreira et al., 2024; Uly et al., 2022). Therefore, there is an urgent need to explore strategies that support diabetes self-care adherence, emphasizing patient education, social support, and healthcare interventions such as dietary management, physical exercise or sports, medication management, blood glucose monitoring, and foot care.

This study is original in its in-depth exploration of both patients' and family members' experiences and perceptions regarding the implementation of diabetic self-care. While previous research has often focused on clinical outcomes or educational interventions, few studies have concurrently examined the psychosocial, emotional, and cultural dimensions that influence the success of diabetes self-management from both patient and family perspectives.

Using a qualitative phenomenological approach, this study captures the lived experiences and subjective meanings associated with self-care practices in the daily lives of individuals affected by diabetes. The research is conducted in a local context with unique cultural and familial dynamics, offering new insights into the enabling and inhibiting factors of effective self-care.

METHOD

Study design

A qualitative research design utilizing a phenomenological approach was employed to capture the lived experiences and perceptions of diabetes patients and their families concerning diabetic self-care.

Participants

The study was conducted in South Kalimantan, Indonesia, where the prevalence of diabetes prevalence has been increasing, highlighting the need for greater insight into patient adherence and self-care challenges in this region. The

participants included individuals with diabetes and their family members.

Purposive sampling was employed to recruit participants selected based on their diabetes diagnosis and their ability to effectively communicate their experiences. Data saturation was achieved with five participants, as redundancy indicated that sufficient depth of information had been obtained.

The inclusion criteria for participants are individuals with diabetes who were accompanied by their families, were at least 18 years old, were able to communicate in Indonesian, and were willing to participate. The exclusion criteria included individuals with diabetes who were in poor health.

This study aims to examine the experiences and perceptions of diabetes patients and their families regarding the implementation of diabetic self-care. By understanding these perspectives, the research seeks to identify facilitators and barriers to self-care adherence and to suggest actionable insights for improving diabetes management strategies.

Data collection

Data were collected through in-depth, semi-structured interviews, with questions focusing on participants' understanding of diabetes, self-care practices, family support, and perceived barriers. The interviews lasted between 25 and 60 minutes and were audio-recorded with participants' consent. This study was conducted in Banjarbaru, South Kalimantan, in May 2024.

Data analysis

Data were analyzed using Colaizzi's phenomenological method, which involves transcribing interviews, extracting significant statements, and identifying emerging themes.

Trustworthiness

To ensure credibility, participants reviewed the findings to verify the accuracy of the interpretations. Dependability and confirmability were further established through peer debriefing and feedback from experts in qualitative research.

Ethical considerations

Ethics Permit: Research Ethics Committee, Faculty of Nursing, University of Indonesia (KET-164/UN2.F12 D1.2.1/PPM.00.02/2024).

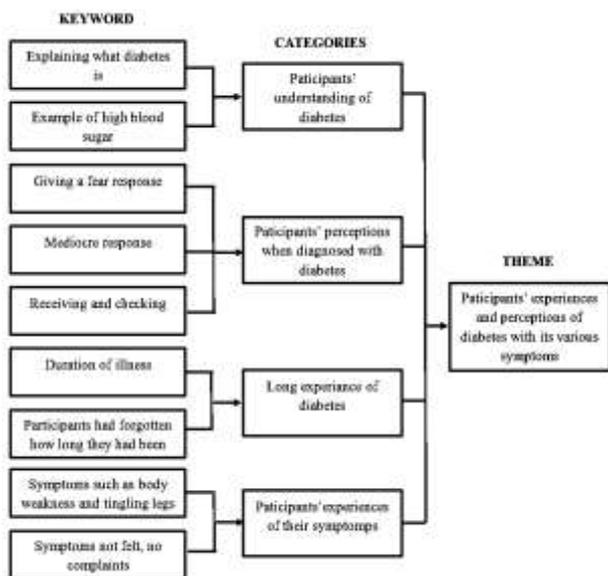
RESULT

This study identified five themes related to the experiences and perceptions of diabetic patients and their families in implementing diabetic self-care. The themes identified in this study are as follows: 1) Participants' experiences and perceptions of diabetes with various symptoms that appear; 2) Participants' ability to carry out diabetic self-care, encompassing medication, nutritional management, physical exercise, blood glucose monitoring, and foot care; 3) Obstacles encountered by participants in carrying out diabetic self-care; 4) Social support from the surrounding community and participants' families in managing diabetic self-care; 5) Participants' hopes and desires to maintain health and control their disease.

This study identified five primary themes related to diabetes self-care practices among participants: knowledge and perceptions of diabetes, self-care behaviors, challenges in adhering to self-care routines, family and social support, and future health expectations.

1. Participants' experiences and perceptions of diabetes and its symptoms.

This theme comprises of four categories. The theme tree is as follows:



Scheme 1. Theme Tree Scheme Experiences and Perceptions of Participants on Diabetes with Various Emerging Symptoms

Theme One (Scheme 1) consists of four categories. The first category addresses participants' understanding of diabetes. An example quote from a participant is: "...Doing blood sugar checks..." (P1). The second category relates to the participant's perception upon being diagnosed with diabetes. An example of a quote is: "... I was normal ... " (P3). The third category describes the duration of diabetes. An example of a quote is: "... It's been a long time, I can no longer remember it; if it's like that, it's estimated to be 10 years." (P2).

The participant's experience of the symptoms became the fourth category. An example of a quote from a participant is: "The body feels weak, the hands are often stiff, this leg, Mom, often tingles, and the legs are too heavy and too stiff ... (P1).

2. Participants' ability to perform diabetic self-care, which includes medication, nutritional management, physical exercise, blood glucose monitoring, and foot care.

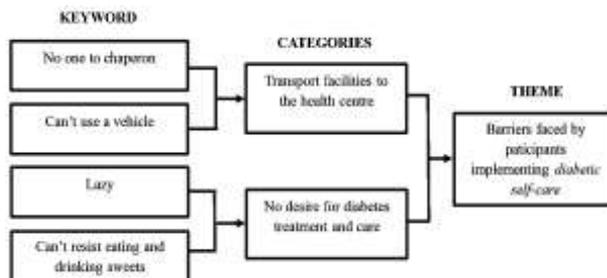
The second theme (Scheme 2) has five categories. The first category concern the care participants take regarding their disease. For Examples, one participants stated, "Just take treatment, yes, asked to go to the health centre to check, eat less" (P1). The second category addresses the care participants take with their food and drink is the second category. For instance, a participant said,; "... reduce eating sweet foods, only drink herbs, or only herbal drinks ..." (P3). The third category encompasses the care participants take regarding physical exercise or sports. For example, a participants stated,; "... every day just walking here around the house ..." (P1). The fourth category pertains to participant's ability to monitor their blood sugar levels at the health center. One e participant remarked: "No, I don't check my blood sugar; I rarely go to the health center ..." (P3). The fifth-to-last category is the participants' ability to inspect their feet and care for feet skin. An example quote from a participant is: "Yes, I don't do anything, Mum, I don't know what the medicine is" (P1). Theme Two consists of five categories. The theme tree is as follows:



Scheme 2. Theme Tree Scheme Participants' Ability to Perform Self-Care (Diabetic Self-Care) in Diabetes

3. Barriers faced by participants in implementing diabetic self-care.

This theme consists of two categories. The theme tree is outlined as follows:

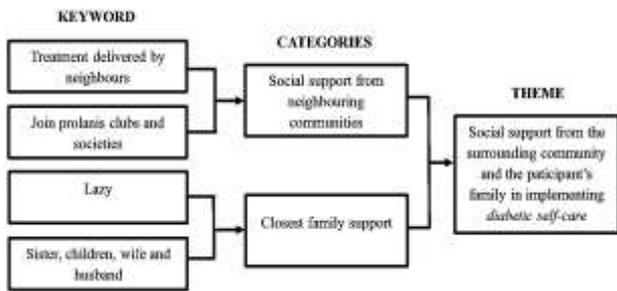


Scheme 3. Theme Tree Scheme Barriers Faced by Participants in Implementing Diabetic Self-Care

This theme (Scheme 3) own two categories. The first category is related to transportation facilities to the health center. An example quote from a participant is: "... I cannot use a vehicle..." (P1). The second category associates with the lack of desire to seek treatment and care for diabetes. Examples of quotes from participants include: "... Food cannot be controlled. Drinks are requested with ice. Asking for all kinds ..." (P5).

4. Social support from the surrounding community and the participant's family in implementing diabetic self-care.

This theme (Scheme 4) consists of two categories. The theme tree is as follows:

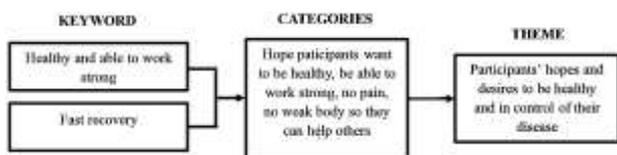


**Scheme 4. Theme Tree Scheme
Community and Family Social Support for Participants
in Implementing Diabetic Self-Care**

This theme comprises two categories. The first category concerns to social support from the surrounding community, which helps participants access health services. For example, one participant stated, “Taken by Mrs. Saiful, a neighbour, for treatment...” (P1). Another participant mentioned, “Joining a club or association, Prolanis” (P5). The second category involves support from close family members. For instance, a participant said, “... Reminding mum to restrict/abstain...” (P2).

5. Participants' hopes and desires to be maintain good health and control their illness.

This theme is just one category. The theme hierarchy is as follows:



**Scheme 5. Theme Tree Scheme
Participants' Hopes and Desires to be Healthy and able
to Control Their Disease**

This theme includes one category. This category is related to participants' expectations maintaining good health, being strong enough to work, experiencing no pain or weakness, and thereby being able to assist others. An example quote from a participant is: “My condition is healthy, mum, and I don't have any pain...” (P4). Another participant stated, “My condition is healthy, mum, and I can be strong to work, to help younger siblings” (P1).

DISCUSSION

The novelty of this study lies in its dual-perspective exploration of diabetic self-care—not only from the viewpoint of patients but also from the families who play a critical support role in daily disease management. While previous studies have highlighted the importance of family support in diabetes management, few have delved into the lived experiences and perceptions of both patients and their families. This research employs a qualitative phenomenological approach to uncover the emotional dynamics and cultural contexts that shape self-care practices. By capturing these in-depth narratives, the study provides a richer understanding of the real-life challenges and coping mechanisms encountered in home settings. Such insights are especially valuable for designing culturally sensitive, family-centered nursing interventions that go beyond standard education and truly resonate with patients' lived realities.

The first theme, knowledge and perceptions of diabetes, revealed a varied understanding of the disease, with most participants aware recognizing diabetes as a chronic

condition that requires lifestyle adjustments. However, misconceptions were evident, particularly concerning dietary control and the impact of glucose monitoring. These findings aligns with previous studies on diabetes awareness in developing countries (14).

Patients with diabetes mellitus have diverse experiences in managing their blood sugar levels. These experiences encompass knowledge about diabetes mellitus, the causes of elevated blood sugar, and, and strategies for blood sugar control. Research aimed at exploring the experiences of patients with diabetes mellitus in maintaining blood sugar levels revealed that patients possess varied insights. The key theme The key themes identified include understanding diabetes mellitus, recognizing factors that cause blood sugar to rise, and methods for controlling blood sugar (15).

The second theme, self-care behaviors, indicated that participants engaged in certain aspects of diabetes self-care, such as medication adherence and occasional dietary monitoring. However, participants reported challenges in consistently maintaining physical exercise and dietary restrictions. These findings align with previous studies, which attributed inconsistent adherence to self-care practices to a lack of structured guidance and motivation (16).

Diabetes Self-Management Education (DSME) can improve participants' ability to perform self-care and improve their knowledge and ability to manage diabetes independently. Diabetes Self-Management Education and support encompass various aspects of self-care, including medication adherence, nutrition management, physical exercise, blood glucose monitoring, and foot care. Studies have demonstrated that DSME and support significantly improve participants' knowledge and ability to manage diabetes independently (Ichsan et al., 2024). Similarly, self-management support has been shown to enhance these self-care skills and knowledge (Busebaia et al., 2023; Indriani et al., 2020).

Self-care significantly enhance the quality of life for patients with diabetes mellitus by encompassing medication adherence, nutritional management, physical exercise, blood glucose monitoring, and foot care. Research by Hasan et al. (2024) demonstrated that self-care improves participants' knowledge and their ability to manage diabetes independently. Educational interventions further enhance patients' capacity to perform self-care behaviors, including medication adherence, nutrition management, physical exercise, blood glucose monitoring, and foot care. Additionally, [NO_PRINTED_FORM] (18) highlight the importance of supporting who choose not only to use modern medicine but also scientifically proven alternative therapies, known as the holistic approach. This approach is increasingly favoured for improving the quality of care and, ultimately, the quality of life for patients with chronic diseases.

Challenges in adhering to self-care routines emerged as the third theme, highlighting both external and internal barriers. Participants noted limited access to healthcare facilities, transportation challenges, and economic constraints as significant obstacles to maintaining self-care adherence. Consistent with findings by [NO_PRINTED_FORM] (17), these socioeconomic barriers underscore the need for systemic support, particularly for rural populations. While self-management support can improve participants' ability to perform self-care, barriers such as insufficient knowledge and ability to manage their disease persist. To address these barriers, better education and support are essential to

empower participants in their self-care practice. Specifically, individuals with diabetes mellitus encounter multiple barriers related to dietary management, health monitoring, therapy adherence, and exercise. The lack of knowledge and skills in disease management remains a critical obstacle. Education can improve participants' capacity to engage in effective self-care behaviours; however persistent gaps in knowledge and management abilities continue to hinder optimal self-care (19).

The fourth theme, family and social support, was critical to participants' engagement in self-care activities. Family members often facilitated healthcare visits and encouraged adherence to treatment plans. Research corroborates the importance of familial support in managing chronic illnesses, demonstrating that social support can enhance self-efficacy and adherence to self-care (5). However, some participants indicated that family members lacked understanding of diabetes management, resulting in unintentional barriers, such as offering inappropriate foods. This finding aligns with the work of [NO_PRINTED_FORM] (20), which found that knowledge gaps within family units can hinder patient adherence to self-care. Family support is crucial in improving the quality of life for diabetic patients. Family support can increase participants' knowledge and ability to manage diabetes, as well as boost motivation and self-efficacy to carry out self-care (Indriani et al., 2020; Uly et al., 2022). Research by Setyowati et al. (2023) also confirms that family support has a major influence on the patients' self-care abilities to achieve planned care.

Social support for diabetes patients can significantly improve self-care behaviours. Social support can increase participants' knowledge and ability to manage diabetes, while also increasing motivation and self-efficacy to perform self-care activities. Additionally, social support contributes to an improved quality of life for diabetic patients. This underscores the importance of social support from the surrounding community and family in facilitating effective diabetes self-care. Social support is one of the key factors influencing the implementation of DMSM (Diabetes mellitus self-management), alongside individual patient factors (21). Patient self-care, supported by relationships and social structures, align with one of the three self-care practices — practices nurturing the internal self, practices nurturing the external self, and integrating practices — developed by Depner et al. (2021) (23). To promote lasting behavioral change and ensure that patient self-care is consistently maintained, the use of platform-based technology that educates and is easy to use across all age groups is recommended. Achieving this requires effective communication and support from family members, as not all individuals across different age groups possess the necessary skills or resources (Cheng et al., 2022).

Finally, the theme of future health expectations illustrated participants' desire to maintain their health and prevent further complications. Participants expressed hopes of regaining physical strength and alleviating symptoms, which they associated with better adherence to self-care practices. However, they also recognized that sustained improvements would require ongoing support and education, echoing the need for holistic diabetes management programs (Uly et al., 2022; Busebaia et al., 2023; Kurniawan et al., 2020). Participants with diabetes mellitus expressed hopes of keeping their blood sugar levels under control through dietary management and regular physical exercise. Conclusion: Participants with diabetes mellitus are hopeful about managing their blood sugar levels through dietary

adjustments and regular physical exercise. They aim to regulate their coping strategies by modifying their diet and engaging in physical activity to maintain blood sugar control. Additionally, patients with diabetes mellitus expect to receive strong family support, which they consider essential for effective self-care management.

Overall, these findings highlight the complexity of diabetes self-care adherence, which is influenced by personal motivation, health literacy, family involvement, and structural factors. The interplay of these factors underscores the importance of a multifaceted approach to diabetes management that combines education, social support, and policy-level interventions to mitigate socioeconomic barriers and enhance self-care adherence (Shrivastava et al., 2013). This study makes a significant contribution to nursing research by deepening the understanding of how patients with diabetes and their families perceive and experience self-care practices. It offers a nuanced perspective on the emotional, social, and cultural factors that influence patient behavior, aspects are often overlooked in biomedical-focused research. These insights are critical for advancing patient-centered care models in nursing science.

In clinical practice, these findings provide practical implications for nurses and other healthcare professionals. By recognizing the barriers and facilitators identified by patients and their families, healthcare providers can tailor self-care education, communication strategies, and support systems to be more culturally sensitive and family-oriented. This approach not only enhances patient engagement but also improves adherence to self-care routines, ultimately contributing to better health outcomes and a reduction in complications associated with diabetes.

Furthermore, the results support the integration of family members into diabetes management plans in both hospital and community health settings, reinforcing the essential role of family dynamics in chronic disease care. This alignment with holistic, family-centered nursing practices makes the study particularly relevant to clinical nursing development and chronic care planning.

This study has several limitations that should be considered when interpreting the findings. First, the use of a qualitative phenomenological approach, while effective for exploring lived experiences, may limit the generalizability of the results to broader populations. The insights obtained are context-specific and reflect the experiences of participants in a particular cultural and geographic setting (Banjar Baru, South Kalimantan), which may not be applicable to others regions or healthcare systems. Additionally, because the data collection relied on self-reported experiences during interviews, there is a potential for recall bias or social desirability bias, where participants might provide responses they perceive as acceptable rather than entirely accurate.

CONCLUSIONS

This study elucidates the challenges and facilitators of diabetic self-care adherence among patients and their families in South Kalimantan. The findings indicate that, although participants generally understand the importance of self-care, several barriers —including limited healthcare access, economic constraints, and knowledge gaps—impede effective adherence. Family and social support play a pivotal role in encouraging self-care; however, these efforts are often limited by a lack of diabetes-specific knowledge within families. To improve diabetes management in this context, comprehensive patient education programs and

community-based support structures are essential. Such initiatives should focus on enhancing patients' understanding of diabetes, equipping families with relevant knowledge, and providing accessible resources for self-care. Future research should expand on these findings by exploring interventions that address socioeconomic and educational barriers, thereby fostering a more supportive environment for diabetes self-management. Through targeted strategies that address the specific needs of diabetic patients, healthcare systems can make significant strides in reducing the burden of diabetes and improving patient outcomes.

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