Barriers to self-care among diabetes patients: A qualitative study

Odri Angnes[1], Chrismis Novalinda Ginting[2], Wienaldi[2]

Abstract

Diabetes Mellitus (DM) is a significant global health issue, with its prevalence continuing to rise in Indonesia. Self-care is a key component in managing DM, yet many patients face various obstacles in its implementation. This study aims to deeply explore the challenges faced by individuals with type 2 diabetes in managing their condition independently. Using a descriptive qualitative approach, the study analyzes the experiences of seven diabetes patients receiving care at Royal Prima Hospital. The social ecological model serves as the analytical framework to identify factors influencing self-care behavior, including individual internal factors, interpersonal relationships, healthcare systems, and the social environment. Data was collected through in-depth interviews and analyzed using thematic content analysis. The findings reveal several barriers to effective self-care in diabetes management. Firstly, at the individual level, a lack of knowledge, limited resources, non-adherence to medication, and financial constraints were major obstacles. Secondly, insufficient social support and misinformation about alternative treatments also influenced patient behavior. Thirdly, at the healthcare service level, long waiting times and inadequate social support were identified as challenges. Lastly, limited accessibility due to transportation issues and community resource constraints further hindered self-care. Patients require comprehensive education, easy access to medical tools, and psychological support to manage their condition effectively. Families and communities must be equipped with accurate knowledge about diabetes and trained to support patients. Healthcare providers should improve service quality by adopting a holistic approach and collaborating with communities to ensure optimal care. With collective efforts, it is hoped that the quality of life for diabetes patients can improve, and complications resulting from the disease can be prevented.

Keywords: type 2 diabetes mellitus, self-care, social-ecological model

Introduction

Diabetes melitus (DM, also known as diabetes, is a complex metabolic disorder characterized by hyperglycemia, an abnormal physiological condition represented by persistently high blood glucose levels.[1] Hyperglycemia results from anomalies in insulin secretion or insulin action, or both, and manifests chronically and heterogeneously as dysfunctions in carbohydrate, fat, and protein metabolism. Diabetes follows a progressive pattern with complex pathogenesis and varying presentations.[2] Diabetes, with its increasing global prevalence, has emerged as one of the most significant and challenging health issues facing the global population today. The rise in diabetes prevalence in many regions worldwide correlates with rapid economic development, which leads to urbanization and the adoption of modern lifestyle habits.[3] Diabetes during pregnancy affected more than 20 million live births (1 in 6 live births) in 2019.[4]

Published data on the incidence and prevalence of Type 2 Diabetes Mellitus (T2DM) in Indonesia is still limited. According to the International Diabetes Federation (IDF), the national prevalence of diabetes in Indonesia was estimated at 6.2% in 2019 and 10.8% in 2021, placing Indonesia among the top 10 countries with the highest prevalence of T2DM and the sharpest increase.[5] According to the 2018 Basic

Affiliation
[1]Master's Programme in Clinical Medicine, Universitas Prima Indonesia, Medan, Indonesia
[2]Department of Public Health and Community Medicine, Universitas Prima Indonesia, Medan, Indonesia

Correspondence
chrismis@unprimdn.ac.id

Health Research (Riskesdas) in Indonesia, 10.9% of the population aged ≥15 years had T2DM. [6,7] The majority of these patients also experienced acute or chronic complications. Hyperglycemia is associated with several potentially life-threatening microvascular and macrovascular complications, including heart failure, coronary artery disease (CAD), and chronic kidney disease (CKD).[7] Due to these complications, diabetes poses a risk to quality of life and leads to a high economic burden, making it a chronic disease that requires serious attention.

Given this huge disease burden, self-management is crucial to prevent complications and improve patients' quality of life. The healthcare system needs to accommodate changes to meet the growing demand for healthcare services. Evidence shows that improving the community's ability to care for themselves and involving patients in decision-making that affects their health will be beneficial, especially with the increasing number of primary healthcare consultations and pressure on the healthcare system.[8] A significant issue that needs to be addressed is how healthcare providers can support self-management in an evidence-based and structured manner and how the self-management process can be integrated into clinical practice as the patient-centered care model evolves. Patient participation is recommended to narrow the gap between the dichotomous roles of patients and healthcare providers. Patient participation involves engaging in care planning and exchanging knowledge, setting goals, and performing self-management activities.[9]

This partnership has been suggested as valuable in supporting management and symptom control, especially for patients with chronic health conditions.[10] Self-management strategies are increasingly recognized as essential components in managing chronic diseases and secondary prevention, individually tailored to the patient's preferences, knowledge, and previous conditions, thus supporting patient involvement in their care.[11,12] Self-care is a complex and natural decision-making process to maintain health, especially among chronic patients with T2DM. According to Riegel's theory, self-care behavior can influence actions aimed at maintaining physiological and emotional stability (i.e., self-maintenance), which facilitates the perception of specific signs and symptoms (i.e., self-monitoring) and is directed at managing them as they arise (i.e., self-management).[13,14] Overall, self-maintenance, monitoring, and management of self-care are influenced by self-efficacy, which is the level of confidence a person has in their ability to perform adequate self-care. [15,16]

Due to the strategic role of self-care behavior in influencing health outcomes for patients with chronic diseases, its significance is well-established.[17–19] Diabetes mellitus is a chronic medical condition that requires lifelong medical care, ongoing patient self-management, and multifactorial risk-reduction strategies beyond glycemic control. Twenty-one seven key self-care behaviors in diabetes patients contribute to good self-care outcomes, including eating healthy, being physically active, self-monitoring blood glucose, adhering to medication, having good problem-solving skills, coping skills to manage stress, and risk-reducing behaviors.[20,21] Various studies have shown that multiple factors influence diabetes self-care practices, including diabetes education, disease duration, presence of other illnesses, regular blood glucose checks, overweight status, lack of physical activity, dietary factors, foot care, and smoking, which are significant for Type 2 diabetes mellitus.[22–24].

Despite the importance of self-care, initial observations at Royal Prima Medan Hospital showed that only a small proportion of outpatient diabetic patients practiced it. Royal Prima Hospital is a type B hospital located in Medan City and serves as a referral hospital for the community, especially in Medan. From preliminary studies, the researcher found that 6 out of 13 diabetes patients receiving outpatient care were practicing self-care at home. Therefore, this study aims to deeply analyze the barriers faced by diabetic patients in practicing self-care.

Method

This study is descriptive qualitative research aimed at understanding the barriers diabetes patients face in managing self-care. The social-ecological model by McLeroy et al. (27) was used as a guide for the research. This model helped shape the interview questions, focusing on intrapersonal, interpersonal, institutional, and community factors. It assumes that health promotion operates at levels based on individual beliefs and understanding, family and social support, and institutional factors. Opportunities to

improve care are available at each model level through health education programs, counseling, and support from friends, coworkers, family, and organizations within the patient's environment.

The study was conducted at Royal Prima Hospital in Medan. It will take place over two months, from May 2024 to July 2024. The population of this study consists of all type 2 diabetes mellitus patients visiting Royal Prima Hospital. The sampling technique used was non-probability sampling, specifically purposive sampling. Seven diabetes patients were selected as informants. Inclusion criteria include individuals diagnosed with type 2 diabetes by a doctor for at least one year, aged 18 or older, able to communicate in Indonesian, and willing to participate in the study. In-depth interview guides were used to gather relevant information from the study informants. Pre-tested and modified open-ended questions were used throughout the interviews. This type of interview allows for follow-up questions to obtain the best data from informants. Through these interviews, participants could explain their life experiences and express the meaning associated with these experiences. The interviews were audio recorded with the participants' consent, and field notes were written after the researcher left the field. The researcher will take steps to build trust and establish a good relationship with participants to create a safe, non-threatening, and supportive environment for them to share their perspectives.

The researcher ensured that the individual interviews followed all qualitative interview protocols to ensure credibility. The audio recordings were transcribed verbatim and reviewed by participants to ensure data accuracy and proper representation of their views. Transferability was ensured by providing a detailed description of the study context and participants. The research process was conducted logically to ensure dependability, and all related documents were traceable. Confirmability was ensured by following up with participants to clarify issues that emerged during transcription, preventing the researcher from projecting their imagination.

Results
Informants' characteristics

Participants in this study were 14 type 2 diabetes patients who met the following criteria: had been diagnosed for at least one year, were of adult age (18 years and above), could communicate in Indonesian, and gave consent to participate. Most of the participants are over 45 years old, aged 47 to 64 years. This suggests that their relatively long life experiences may provide a more mature perspective on the research topic. In terms of education, most participants have a bachelor's degree, though some have a diploma or high school education. This indicates that the study includes participants with diverse educational backgrounds, which may influence how they understand and respond to the research questions.

Table 1. Informants' Characteristics

Code	Age	Duration of Illness	Education	Marital Status	Occupation
PD01	47 years	3	Senior High School	Married	Entrepreneur
PD02	55 years	2	Bachelor	Married	Housewife
PD03	47 years	3	Senior High School	Widowed	Housewife
PD04	57 years	5	Diploma	Married	Entrepreneur
PD05	52 years	8	Bachelor	Married	Civil Servant
PD06	64 years	10	Senior High School	Widowed	Retired
PD07	48 years	5	Bachelor	Married	Civil Servant

An interesting finding is the variation in the duration of illness among the participants, ranging from 2 to 10 years. This suggests that the participants have experienced the condition or issue being studied for a significant period. Such experiences could offer a richer perspective on the condition's progression. The participants' marital status also varies, with the majority being married. As for their occupations, the participants include entrepreneurs, housewives, civil servants, and retirees.

Overall, the participant profile reflects the socioeconomic and demographic diversity commonly found in people with type 2 diabetes. This suggests that type 2 diabetes is a health issue that can affect anyone, regardless of educational background, social status, or occupation. The selection of key informants for this study has resulted in a relatively homogeneous sample in terms of age and status as key informants. However, the variation in illness duration and education level indicates a diversity of experiences and perspectives among the participants. This diversity can enrich data analysis and lead to more comprehensive research findings.

Intrapersonal barriers

The participants in this study revealed several personal factors that act as barriers to managing type 2 diabetes. These individual factors are considered to affect their ability to engage in self-care. All participants stated that they understood the origins of their diabetes. This awareness of their health condition motivated them to seek medical treatment. After being diagnosed, the participants actively managed their condition, especially regarding dietary adjustments. The knowledge they gained about diabetes management formed the foundation of their efforts. However, some participants also mentioned challenges they faced in maintaining a healthy diet.

> *"Diabetes has many restrictions. I feel uncomfortable eating foods that are not suitable for my condition. That's why I've avoided all foods that could trigger symptoms. But I'm still unsure about the best food to eat right now."* (PD05, 52 years)

Although the participants' knowledge about a diabetic diet is limited, they can identify foods that trigger adverse reactions and independently avoid consuming them.

> *"I try to eat fruits and vegetables, but due to financial limitations, it's sometimes difficult."* (PD06, 64 years)

Regular blood sugar monitoring is a crucial part of diabetes management. However, this study found that many people with diabetes do not own a personal glucometer. This means they can only monitor their blood sugar levels during hospital visits, which limits their ability to manage the condition daily.

> *"… I don't have a glucometer at home. It's quite troublesome. Sometimes my blood sugar fluctuates suddenly."* (PD02, 55 years)

A personal glucometer allows people with diabetes to monitor their blood sugar levels independently, anytime and anywhere. This gives them more control over their condition and reduces reliance on healthcare facilities. Regular monitoring helps detect sudden changes in blood sugar levels early, allowing corrective action before serious complications arise.

The lack of access to a glucometer makes it difficult for participants in this study to actively monitor and manage their blood sugar levels daily. Yet, they remain consistent in following prescribed pharmacological therapy. Participants also only check their blood sugar at healthcare facilities like nearby clinics or leading hospitals. None of the participants reported using a personal glucometer.

> *"I regularly check my blood sugar every time I visit the doctor."* (PD02, 55 years)

The high cost of glucometers and test strips is a significant barrier for many people with diabetes, particularly those with financial constraints. A lack of knowledge about the importance of blood sugar monitoring and how to use a glucometer also poses challenges. Glucometers help people with diabetes understand how physical activity, diet, and stress affect their blood sugar levels. This enables them to make necessary adjustments to their lifestyle. With controlled blood sugar levels, people with diabetes can lead a more active and productive life while reducing the risk of long-term complications like heart disease, stroke, and kidney damage.

One of the main challenges in managing medication is forgetfulness. Several participants shared their difficulty in remembering to take their medication at the prescribed times, which impacts the effectiveness of their treatment.

> *"I have to take all my medication, usually after meals. The problem is, since I have to wake up very early for work, I often forget to take my medication on schedule."* (PD01, 47 years)

The participants acknowledged difficulties in consistently following their medication schedules. Particularly when they have to wake up early, they often forget to take their medication due to rushing or not having their medicine with them.

"It's tough sometimes; I forget to take my medicine. I forget and then remember. When I remember, it's already time for the next dose. So, I take the current one and skip the previous one. My wife often reminds me, but I still forget sometimes." (PD04, 57 years)

Although some participants occasionally forget to take their medication due to forgetfulness, they maintain medication consistency thanks to full support from their spouses. However, this remains a challenge in achieving independence in managing the illness.

Emotional support from spouses is often the biggest motivator for people with diabetes to keep fighting. The spouse plays a crucial role in reminding the patient about the importance of medication and maintaining a healthy lifestyle, especially when the patient feels tired or hopeless. The spouse can help monitor food intake, organize medication schedules, and accompany the patient to the doctor or pharmacy. Consistent supervision is essential to ensure treatment follows the plan. By creating a supportive home environment, such as providing healthy meals and scheduling physical activities together, the spouse contributes to the patient's health.

To achieve optimal self-care management in diabetes, access to various resources, including financial resources, is crucial. Based on the participants' accounts, their economic situation significantly impacts their self-care practices.

"Before, I used to eat three meals a day and take my medication after meals. But now, I often struggle to get three full meals." (PD06, 64 years)

Participants emphasized that an individual's financial situation greatly influences the success of their treatment. Since many medications need to be taken after meals, economic difficulties can make it hard to maintain a regular medication schedule. As a result, the healing process can be hindered or even worsened.

Interpersonal barriers

Most participants in this study stated that they did not feel they received significant benefits from the social support provided by colleagues in the context of self-care. However, some shared that they often exchanged ideas with their coworkers. Through these informal discussions, they found new approaches to maintain their well-being.

"I sometimes feel lonely and unsure about who to talk to. I tried sharing with a coworker before, but they didn't understand." (PD07, 48 years)

Some participants described experiences where fellow patients tried to convince them to switch from conventional medicine to herbal remedies. However, they stuck with their choice of traditional treatment.

"I've experienced being promised to heal through traditional medicine. Many people said they got better thanks to it. But from what I saw, it was the opposite. A lot of my friends' conditions worsened after trying alternative treatments." (PD02, 55 years)

Another participant said they only visited the hospital for treatment on scheduled days. They do not seem to discuss their treatments with other patients. This may be because they felt there was no need to share experiences or because of the lack of social interaction among them.

"It's strange; we're all fighting the same illness, but no one ever wants to talk about what it feels like. Everyone cares for their business, reports their condition, grabs their medicine, and leaves. Maybe because they fear looking weak or don't want to bother others? But maybe we could support each other and not feel so alone. It's just hard to start the conversation." (PD05, 52 years)

This suggests that despite shared experiences of managing a chronic condition like diabetes, participants struggle with establishing meaningful interpersonal connections that could provide emotional

support. The lack of open dialogue or willingness to discuss their condition with others highlights the isolation many experience, which could hinder their ability to cope effectively with the challenges of living with diabetes.

Organizational barriers

This theme delves deeper into the role of healthcare institutions and community organizations in assisting individuals with type 2 diabetes in managing their condition. The study examines how healthcare professionals and the environment influence patients' efforts to manage their illness. The role of healthcare providers as caregivers and sources of support is crucial, especially for those living with chronic diseases like diabetes.

However, the experiences of patients in receiving healthcare are not always positive. Many reported negative behaviors from staff that left them dissatisfied with the care they received. Some staff members preferred to chat or use their phones rather than promptly assist patients. As a result, patients often had to wait longer than expected to receive the care they needed.

> "After my check-up, I had to wait quite a while for my medication at the pharmacy. The pharmacy staff were chatting. There was no explanation about the delay. But the service has improved now." (PD07, 48 years)

One participant expressed concern about the potential health risks of the long wait times before their examination, especially since they often arrived at the hospital without breakfast. Long wait times at the hospital can pose a significant threat to the health of diabetes patients. Patients who arrive fasting for blood sugar tests are at risk of hypoglycemia due to delayed care.

> "Sometimes we had to wait a long time. We often didn't have time to eat breakfast because we were in a rush to get to the hospital. Then, once we got here, we had to wait even longer. That's not good for our health." (PD03, 47 years)

The role of the community in providing social support for participants in the study remains minimal. Participants highlighted the importance of community involvement in addressing health issues, particularly diabetes. The surrounding environment's lack of awareness and support was identified as a key barrier to managing the disease.

> "I'm puzzled why the community doesn't seem to care about diabetes. There are so many people like me in my area with this disease. If they were more active in providing education and creating special programs for diabetes patients, it could make a big impact. Imagine if every neighborhood had educational and support programs for diabetes patients or other illnesses. But, yeah, that's just my wish. The health centers could also be the ones to drive us; they have cadres who could help. If we start with the community, it could make a real difference." (PD05, 52 years)

The subject suggested that the government, through health centers, could facilitate educational and support programs for diabetes patients at the community level. This aligns with the concept of promotive-preventive healthcare, where the community plays an active role in maintaining its health.

Community-level barriers

A fundamental issue hindering the success of self-care management among participants is the community's limited infrastructure and human resources. Participants pointed to several challenges, including the lack of physical training facilities, adequate health clinics, and professional medical staff. In addition, the long distance to the nearest healthcare facility was a significant concern for some participants, especially in emergencies.

"In my area, the clinic or health center is quite far. If I need to check up or control my condition, I have to take a minibus, and even then, I have to wait a while. Just imagine what would happen in an emergency." (PD03, 47 years)

Participants complained about the lack of accessibility to healthcare services within their community. The absence of nearby clinics or health centers made it difficult for them to access medical care, particularly in urgent situations. This can be a serious issue, considering the risk of complications from diabetes.

"At first, I didn't realize that I had a serious health condition. I felt very weak and had trouble sleeping. I went to the nearest health center the next day, but the nurse was away for a training session. So, I had to go to a hospital in the city. After checking my blood sugar, I discovered my levels were dangerously high." (PD04, 57 years)

This highlights the critical barriers that individuals with diabetes face at the organizational and community levels. The lack of adequate healthcare infrastructure and professional medical support can exacerbate the challenges of managing diabetes, particularly when timely medical intervention is required.

Discussion
Intrapersonal barrier

This study's findings highlight significant challenges participants face in managing their diabetes independently. Although the participants possessed basic knowledge of diabetes, they lacked a deeper understanding of the recommended dietary practices and the long-term complications that can arise from uncontrolled diabetes.

Recent studies emphasize the ongoing challenges in the self-management of diabetes. Patients often struggle to control their blood glucose levels due to a limited understanding of the disease dynamics and self-care practices.[25] Despite diabetes education being a key component of self-management programs, the effectiveness of individual interventions remains inconclusive.[26] Cultural and language barriers further complicate self-management for specific populations, such as Spanish-speaking Hispanic immigrants, who face obstacles such as negative healthcare interactions and cultural stigma. [27] Health literacy limitations have also been linked to poor self-care behaviors in chronic diseases, which can contribute to disparities in diabetes outcomes. [28] These findings underline the need for better diabetes education strategies emphasizing problem-solving skills, decision-making, and cultural factors and addressing health literacy limitations to enhance patients' ability to manage their condition effectively. [25,27]

Limited educational background among several participants was another barrier to understanding the complexities of diabetes. Insufficient education led to participants' struggles in managing their health conditions. Patients with lower education levels tend to have a limited grasp of effective self-management methods for diabetes. Previous studies have shown that individuals with lower educational levels face significant challenges in managing diabetes. Patients with low health literacy often misunderstand diabetes management, exhibit passive behavior in seeking information, and struggle to obtain detailed guidance.[29] They tend to follow doctors' recommendations strictly, viewing diabetes management as a life whole of restrictions.[30] This group also struggles to understand prescription instructions, which can interfere with medication adherence.[31] Cultural beliefs, lack of resources, and mental health issues further complicate self-management in low-resource environments.[32] On the other hand, individuals with higher education levels seem more likely to develop their strategies for managing the disease.[30] These findings underscore the need for tailored diabetes education programs considering the patient's health literacy and socioeconomic background to improve self-management outcomes.[29,32]

The study also revealed that most participants faced difficulties adhering to dietary recommendations. Many struggled to prepare meals regularly at home, often consuming whatever food was available. Recent studies confirm that people with diabetes face significant challenges in maintaining the recommended diet. Food insecurity is a substantial barrier to healthy eating and blood glucose control, especially among lower socioeconomic groups. Limited access to nutritious food in low-income neighborhoods makes it even more challenging to adhere to diabetes management plans.[33,34] The complex

interaction between food, social life, and emotions makes sustained dietary changes difficult for many individuals.[35] Furthermore, stress from financial limitations and discrimination also contributes to poor eating habits and diabetes management. [3634]

The study found that some diabetes patients missed medication schedules due to forgetfulness. Several studies from the Middle East, North Africa, and Saudi Arabia consistently identify forgetfulness as a primary reason for non-adherence. [37,38] Similarly, a survey conducted in the United States between 2017 and 2019 revealed that simple forgetfulness was the most common reason for non-adherence over three years, although this resulted in fewer missed medication days.[39]

The research also showed that most participants did not own a personal blood glucose meter (glucometer). As a result, they could only measure their blood sugar levels when visiting the hospital for routine check-ups and could not monitor their glucose levels at home as recommended for diabetes management. Recent literature supports the finding that many diabetes patients lack personal glucometers for self-monitoring. A study in Pakistan found that only 59% of urban diabetes patients used a home glucometer, with socioeconomic status, education, and awareness being significant predictors.[40] Self-monitoring of blood glucose can improve blood glucose control, but its effectiveness is limited without proper education on interpreting results and adjusting medication. [41] The cost of glucometers is a significant barrier to adopting self-monitoring, particularly in developing countries. To address this issue, government subsidies and awareness programs can encourage using home glucose monitoring devices.[40]

Interpersonal barriers

The results of this study indicate that most participants did not perceive tangible benefits from the social support provided by coworkers in maintaining their well-being. Although some participants engaged in informal discussions with colleagues, which allowed them to explore new self-care methods, the social support provided was not sufficiently effective. Some participants stated that they preferred to continue following conventional treatments rather than combining them with herbal medicine, as suggested by their colleagues. Concerns about potential health complications from using both traditional and herbal medications simultaneously may be a key factor behind this decision.

Recent studies highlight the complex relationship between conventional and herbal treatments, particularly for patients with chronic conditions such as diabetes. While herbal medicine is widely used as a complementary therapy, there are still concerns about the side effects that may arise when combined with conventional treatments.[4243,44] A study in Malaysia[45] found that some diabetic patients altered their conventional medication doses to accommodate herbal treatment, while research in Jamaica showed that most patients believed that combining both types of treatment could be harmful.[42] Interestingly, many patients did not disclose their use of herbal medicine to healthcare providers, adding another layer of complexity to medication management.[42,44]

The study also shows that, while there is potential for support to be provided through social networks and online platforms, such as social media, this has not been fully utilized in diabetes self-management.[46] Some studies suggest that social media can offer emotional support and valuable information exchange between people with diabetes.[47] Facebook groups dedicated to diabetes management allow members to share experiences and receive guidance. However, these platforms also present challenges related to data privacy and the accuracy of information shared.[48] Additionally, the results of this study also reveal that the pattern of hospital visits tends to be individual and planned, with little interaction with other patients, which hampers the development of support networks among diabetes patients. Some patients prefer to remain separate and focus on their treatment, which reduces the potential for social support that might otherwise be expected.

This study found that the visiting patterns of participants were generally individual and planned, where they visited the hospital according to a predetermined schedule. They rarely interacted with other patients to share experiences or information related to their treatment. This may occur for several reasons, such as a lack of motivation to interact with others or limited opportunities for socializing with fellow patients in a medical care context.

The findings of this study are inconsistent with the conclusions drawn by McGowan et al.[49], who stated that peer support is highly beneficial. Studies have shown that patients often spend significant time separated from staff and other patients, with limited engagement in therapeutic activities. The hospital environment can induce stress factors, such as losing privacy and control while offering opportunities for fellow patients' support. Despite these challenges, most patients prefer rooms with multiple beds, where the presence of a roommate is seen as beneficial.[50]

Organization barriers

This study found that long waiting times at diabetes clinics were a significant barrier to patient satisfaction and treatment adherence. Perceived waiting times, rather than actual waiting times, have a stronger relationship with patient satisfaction. Studies have shown that patients who feel their waiting time is longer tend to be less satisfied with the medical services provided and are more likely to discontinue their treatment.[51,52] Perceived longer waiting times can significantly impact patient satisfaction more than the actual waiting times themselves.[51] To improve the patient experience, healthcare providers need to focus more on communicating with patients and managing their expectations.[52,53] Additionally, ensuring that patients feel valued and informed about delays or issues will significantly help in improving overall patient satisfaction.[53,54]

From a social perspective, the role of the community in providing social support to diabetes patients is still limited. Participants in this study emphasized the importance of community involvement in diabetes management but also noted that the lack of awareness and support from the surrounding community was a significant barrier. More excellent social support has been shown to improve blood glucose control, healthier lifestyle choices, and reduced diabetes complications.[5556] Other research has also demonstrated that participation in diabetes communities can improve diet adherence, physical activity, and overall health outcomes, reinforcing the importance of community involvement in effective diabetes management.[57]

Community-level barrier

The lack of adequate infrastructure and healthcare professionals in the community poses a barrier to implementing self-care management programs. Participants reported challenges like limited training facilities, insufficient comprehensive health clinics, and limited access to professional medical personnel. Additionally, the distance to the nearest healthcare facility has become a significant issue, especially in emergencies.

Recent research supports the challenges in implementing self-care management programs due to inadequate infrastructure and healthcare personnel shortages. A thematic synthesis revealed that communities and healthcare environments lacking resources hinder self-management for individuals with multimorbidities.[58] A qualitative study in Iran identified infrastructure challenges and inadequate resources as significant obstacles to mental health education programs in primary care.[59] In rural areas, barriers to implementing community-based chronic disease self-management programs remain, including low healthcare system involvement and fragmented funding.[60] These findings align with previous studies emphasizing the importance of integrating self-management education into primary care and involving healthcare professionals for successful implementation.[61]

Conclusion

This study reveals the complex challenges faced by individuals with diabetes in managing their condition. The main obstacles to achieving optimal glucose control are a lack of knowledge about diet and disease management, barriers to accessing healthcare resources, and limited social support. The findings highlight the need for improvements in the comprehensive diabetes healthcare system. There is a need to develop diabetes education programs tailored to participants' needs, involving community and religious leaders and utilizing various media. Additionally, improving access to primary healthcare facilities, providing affordable diabetes aid, and optimizing service wait times are necessary.

References

1. American Diabetes Association. Diagnosis and Classification of Diabetes Mellitus. Diabetes Care. 2014 Jan 1;37(Supplement_1):S81–90.
2. American Diabetes Association. Introduction: Standards of Medical Care in Diabetes—2018. Diabetes Care. 2018 Jan 1;41(Supplement_1):S1–2.
3. Khan MAB, Hashim MJ, King JK, Govender RD, Mustafa H, Al Kaabi J. Epidemiology of Type 2 Diabetes – Global Burden of Disease and Forecasted Trends. J Epidemiol Glob Health. 2019;10(1):107.
4. International Diabetes Federation. IDF Diabetes Atlas. 9th ed. Brussels: International Diabetes Federation; 2019.
5. International Diabetes Federation. IDF Diabetes Atlas. 10th ed. Brussels: International Diabetes Federation; 2021.
6. Kementerian Kesehatan. Riset Kesehatan Dasar 2018 (2018 Basic Health Research). Jakarta; 2018.
7. PERKENI. Pedoman Pengelolaan dan Pencegahan Diabetes melitus Tipe 2 Dewasa di Indonesia. Jakarta: PB PERKENI; 2021.
8. Bell J, Dziekan G, Pollack C, Mahachai V. Self-Care in the Twenty First Century: A Vital Role for the Pharmacist. Adv Ther. 2016 Oct 17;33(10):1691–703.
9. Thórarinsdóttir K, Kristjánsson K. Patients' perspectives on person-centred participation in healthcare. Nurs Ethics. 2014 Mar 27;21(2):129–47.
10. McWilliam CL. Patients, persons or partners? Involving those with chronic disease in their care. Chronic Illn. 2009 Dec 19;5(4):277–92.
11. Jordan JE, Briggs AM, Brand CA, Osborne RH. Enhancing patient engagement in chronic disease self-management support initiatives in Australia: the need for an integrated approach. Med J Aust. 2008 Nov 17;189(10).
12. Ekman I, Swedberg K, Taft C, Lindseth A, Norberg A, Brink E, et al. Person-Centered Care — Ready for Prime Time. Eur J Cardiovasc Nurs. 2011 Dec 1;10(4):248–51.
13. Riegel B, Jaarsma T, Strömberg A. A Middle-Range Theory of Self-Care of Chronic Illness. Adv Nurs Sci. 2012 Jul;35(3):194–204.
14. Riegel B, Dickson VV, Faulkner KM. The Situation-Specific Theory of Heart Failure Self-Care. J Cardiovasc Nurs. 2016 May;31(3):226–35.
15. Yu DS, De Maria M, Barbaranelli C, Vellone E, Matarese M, Ausili D, et al. Cross-cultural applicability of the Self-Care Self-Efficacy Scale in a multi-national study. J Adv Nurs. 2021 Feb 9;77(2):681–92.
16. Ausili D, Rossi E, Rebora P, Luciani M, Tonoli L, Ballerini E, et al. Socio-demographic and clinical determinants of self-care in adults with type 2 diabetes: a multicentre observational study. Acta Diabetol. 2018 Jul 5;55(7):691–702.
17. Baroni I, Arrigoni C, Caruso R, Magon A, Villa G, Manara DF, et al. Self-care and type 1 diabetes mellitus: systematic review of sex-related differences. Panminerva Med. 2023 Mar;65(1).
18. Dellafiore F, Arrigoni C, Pittella F, Conte G, Magon A, Caruso R. Paradox of self-care gender differences among Italian patients with chronic heart failure: findings from a real-world cross-sectional study. BMJ Open. 2018 Sep 28;8(9):e021966.
19. Riegel B, Jaarsma T. Recognizing the Complexity of Self-Care. Int J Nurs Stud. 2021 Apr;116:103908.
20. Hill-Briggs F, Gemmell L. Problem Solving in Diabetes Self-management and Control. Diabetes Educ. 2007 Nov 7;33(6):1032–50.
21. Fisher EB, Thorpe CT, McEvoy DeVellis B, DeVellis RF. Healthy Coping, Negative Emotions, and Diabetes Management. Diabetes Educ. 2007 Nov 7;33(6):1080–103.
22. Mogre V, Abanga ZO, Tzelepis F, Johnson NA, Paul C. Adherence to and factors associated with self-care behaviours in type 2 diabetes patients in Ghana. BMC Endocr Disord. 2017 Dec 24;17(1):20.
23. Istek N, Karakurt P. Effect of Activities of Daily Living on Self-Care Agency in Individuals with Type 2 Diabetes. J Diabetes Mellit. 2016;6(4):247–62.
24. Chen L, Magliano DJ, Zimmet PZ. The worldwide epidemiology of type 2 diabetes mellitus—present and future perspectives. Nat Rev Endocrinol. 2012 Apr 8;8(4):228–36.
25. Lippa KD, Klein HA. Portraits of patient cognition: how patients understand diabetes self-care. Can J Nurs Res. 2008 Sep;40(3):80–95.
26. Vas A, Devi ES, Vidyasagar S, Acharya R, Rau NR, George A, et al. Effectiveness of self-management programmes in diabetes management: A systematic review. Int J Nurs Pract. 2017 Oct 31;23(5).
27. Smith-Miller CA, Berry DC, Miller CT. Diabetes affects everything: Type 2 diabetes self-management among Spanish-speaking hispanic immigrants. Res Nurs Health. 2017 Dec 6;40(6):541–54.
28. Kim S, Love F, Quistberg DA, Shea JA. Association of Health Literacy With Self-Management Behavior in Patients With Diabetes. Diabetes Care. 2004 Dec 1;27(12):2980–2.
29. Kim S, Song Y, Park J, Utz S. Patients' Experiences of Diabetes Self-Management Education According to Health-Literacy Levels. Clin Nurs Res. 2020 Jun 9;29(5):285–92.
30. Fink A, Fach EM, Schröder SL. 'Learning to shape life' – a qualitative study on the challenges posed by a diagnosis of diabetes mellitus type 2. Int J Equity Health. 2019 Dec 24;18(1):19.
31. Singh S, Acharya SD, Kamath A, Ullal SD, Urval RP. Health Literacy Status and Understanding of the Prescription Instructions in Diabetic Patients. J Diabetes Res. 2018 Jun 11;2018:1–5.
32. Whittemore R, Vilar-Compte M, De La Cerda S, Marron D, Conover R, Delvy R, et al. Challenges to diabetes self-management for adults with type 2 diabetes in low-resource settings in Mexico City: a qualitative descriptive study. Int J Equity Health. 2019 Dec 23;18(1):133.
33. Flint KL, Davis GM, Umpierrez GE. Emerging trends and the clinical impact of food insecurity in patients with diabetes. J Diabetes. 2020 Mar 14;12(3):187–96.

34. Breland JY, McAndrew LM, Gross RL, Leventhal H, Horowitz CR. Challenges to Healthy Eating for People With Diabetes in a Low-Income, Minority Neighborhood. Diabetes Care. 2013 Oct 1;36(10):2895–901.

35. Al-Sahouri A, Merrell J, Snelgrove S. Barriers to good glycemic control levels and adherence to diabetes management plan in adults with Type-2 diabetes in Jordan: a literature review. Patient Prefer Adherence. 2019 May;13:675–93.

36. Vanstone M, Rewegan A, Brundisini F, Giacomini M, Kandasamy S, DeJean D. Diet modification challenges faced by marginalized and nonmarginalized adults with type 2 diabetes: A systematic review and qualitative meta-synthesis. Chronic Illn. 2017 Sep 24;13(3):217–35.

37. Jaam M, Mohamed Ibrahim MI, Kheir N, Hadi MA, Diab MI, Awaisu A. Assessing prevalence of and barriers to medication adherence in patients with uncontrolled diabetes attending primary healthcare clinics in Qatar. Prim Care Diabetes. 2018 Apr;12(2):116–25.

38. Ansari M. Barriers to Antidiabetic Medication Adherence among Patients with Diabetes Mellitus in Saudi Arabia: A Systematic Review. J Pharm Res Int. 2021 Feb 19;33(3):1–12.

39. Unni EJ, Gupta S, Sternbach N. Trends of self-reported non-adherence among type 2 diabetes medication users in the United States across three years using the self-reported Medication Adherence Reasons Scale. Nutr Metab Cardiovasc Dis. 2022 Jan;32(1):151–9.

40. Farhan SA, Shaikh AT, Zia M, Kahara BR, Muneer R, Rehman M, et al. Prevalence and Predictors of Home Use of Glucometers in Diabetic Patients. Cureus. 2017 Jun 10;9(6):e1330.

41. Clar C, Barnard K, Cummins E, Royle P, Waugh N. Self-monitoring of blood glucose in type 2 diabetes: systematic review. Health Technol Assess (Rockv). 2010 Mar;14(12).

42. Adeniyi O, Washington L, Glenn CJ, Franklin SG, Scott A, Aung M, et al. The use of complementary and alternative medicine among hypertensive and type 2 diabetic patients in Western Jamaica: A mixed methods study. Wilkinson J, editor. PLoS One. 2021 Feb 8;16(2):e0245163.

43. Jeong TY, Park BK, Cho JH, Kim YI, Ahn YC, Son CG. A prospective study on the safety of herbal medicines, used alone or with conventional medicines. J Ethnopharmacol. 2012 Oct;143(3):884–8.

44. Turkmenoglu FP, Kutsal YG, Dolgun AB, Diker Y, Baydar T. Evaluation of herbal product use and possible herb–drug interactions in Turkish elderly. Complement Ther Clin Pract. 2016 May;23:46–51.

45. Ithnain N, Panting AJ, Kassim R, Amirudin N, Krishnan M. Perception of Conventional Medicine and Herbal Medicine Usage Amongst Diabetic Patients: A Qualitative Study in Negeri Sembilan, Malaysia. Glob J Health Sci. 2020 Aug 19;12(10):122.

46. Elnaggar A, Ta Park V, Lee SJ, Bender M, Siegmund LA, Park LG. Patients' Use of Social Media for Diabetes Self-Care: Systematic Review. J Med Internet Res. 2020 Apr 24;22(4):e14209.

47. Spencer-Bonilla G, Ponce OJ, Rodriguez-Gutierrez R, Alvarez-Villalobos N, Erwin PJ, Larrea-Mantilla L, et al. A systematic review and meta-analysis of trials of social network interventions in type 2 diabetes. BMJ Open. 2017 Aug 21;7(8):e016506.

48. Greene JA, Choudhry NK, Kilabuk E, Shrank WH. Online Social Networking by Patients with Diabetes: A Qualitative Evaluation of Communication with Facebook. J Gen Intern Med. 2011 Mar 13;26(3):287–92.

49. Sharac J, McCrone P, Sabes-Figuera R, Csipke E, Wood A, Wykes T. Nurse and patient activities and interaction on psychiatric inpatients wards: A literature review. Int J Nurs Stud. 2010 Jul;47(7):909–17.

50. Larsen LS, Larsen BH, Birkelund R. A companionship between strangers – the hospital environment as a challenge in patient–patient interaction in oncology wards. J Adv Nurs. 2014 Feb 8;70(2):395–404.

51. Toga-Sato S, Tosaki T, Kondo M, Tsunekawa S, Kato Y, Nakamura J, et al. Impact of actual waiting time and perceived waiting time on treatment satisfaction in patients receiving outpatient diabetes care. Diabetol Int. 2021 Jul 2;12(3):293–300.

52. Sato S, Tosaki T, Oshiro C, Kudara A, Inagaki A, Kondo M, et al. The Influence of Outpatients' Wait Times and Health Care Professionals' Communication Behaviors on Treatment Satisfaction and the Intention to Drop Out. Diabetes. 2018 Jul 1;67(Supplement_1).

53. Xie Z, Or C. Associations Between Waiting Times, Service Times, and Patient Satisfaction in an Endocrinology Outpatient Department: A Time Study and Questionnaire Survey. Inq J Heal Care Organ Provision, Financ. 2017 Jan 1;54:004695801773952.

54. Nottingham QJ, Johnson DM, Russell RS. The Effect of Waiting Time on Patient Perceptions of Care Quality. Qual Manag J. 2018 Jan 2;25(1):32–45.

55. Ishak IA, Walls ML, Aronson BD. The Role of Social Support in the Management of Type 2 Diabetes Mellitus among American Indians: A Qualitative Study. Am Indian Alaska Nativ Ment Heal Res [Internet]. 2022 Mar;29(1):59–91. Available from: https://coloradosph.cuanschutz.edu/research-and-practice/centers-programs/caianh/journal/volume29

56. Miller CK, Davis MS. The Influential Role of Social Support in Diabetes Management. Top Clin Nutr. 2005 Apr;20(2):157–65.

57. Suhl S, Rost JB, Stoner KC, Gowen R, Florissi C, Wood R. 737-P: Positive Impact of Social Support and Diabetes Community Participation on Patient-Reported Outcomes. Diabetes. 2020 Jun 1;69(Supplement_1).

58. Younas A, Shahzad S, Tejada-Garrido CI, Monari EN, Durante A. Sociocultural and patient-health care professional related factors influencing self-management of multiethnic patients with multimorbidities: A thematic synthesis. George MS, editor. PLOS Glob Public Heal. 2023 Sep 21;3(9):e0002132.

59. Validabady Z, Memaryan N, Naserbakht M, Zandifar A, Lotfi M. Challenges of a Program for Public Mental Health Education with an Emphasis on Self-Care in Primary Health Care: A Qualitative Study. J Community Heal Res [Internet]. 2023 Jan 8;11(4):287–96. Available from: https://publish.kne-publishing.com/index.php/JCHR/article/view/11645

60. Pullyblank K, Brunner W, Wyckoff L, Krupa N, Scribani M, Strogatz D. Implementation of Evidence-Based Disease Self-Management Programs in a Rural Region: Leveraging and Linking Community and Health Care System Assets. Heal Educ Behav. 2022 Oct 18;49(5):894–903.

61. Jordan JE, Osborne RH. Chronic disease self-management education programs: challenges ahead. Med J Aust. 2007 Jan 15;186(2):84–7.