

Experience of diabetes patients in preventing its complications

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Abstract:

It is necessary to explore the experience of diabetes patients in preventing its complications since Indonesia has many cultural beliefs and practices that influence the prevention of DM complications. A limited number of studies have discussed it. The study aimed to explore the experiences of diabetes patients in preventing its complications. A descriptive qualitative study was conducted in Indonesia between December 2022 and April 2023. Fifteen participants with DM were included. Purposive sampling was used, and data were collected through in-depth interviews, observations, and the writing of field notes. The data were analyzed by thematic analysis using NVivo 12 software. Four themes emerged from the data analysis: (1) inadequate self-care practice related to misconception about DM and its complications; (2) self-awareness, intention, and motivation as basic to change the behaviors; (3) optimal holistic support is needed from family and health workers; (4) inadequate of education program provided by health workers to prevent DM complications. This is the first study to display that cultural beliefs and knowledge strongly influenced the experience of preventing DM complications. Internal and external environments also contributed to the experience of preventing DM complications. This study offers new insights for nurses in Indonesia and will assist them in designing a nursing intervention involving cultural aspects for diabetic patients.

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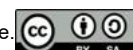
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INTRODUCTION

Diabetes Mellitus (DM) represents a significant global health challenge, a chronic metabolic disorder characterized by persistently elevated blood glucose levels (Dilworth et al., 2020). Its prevalence is escalating rapidly worldwide, presenting a substantial burden on healthcare systems and populations. This concerning trend is particularly evident in Indonesia, where the number of individuals diagnosed with DM continues to rise at an alarming rate (Hisni et al., 2023). Understanding the dynamics of this epidemic is crucial for developing effective public health strategies.

Accompanying this surge in DM prevalence is a parallel and equally troubling increase in the incidence of its debilitating complications. These complications are broadly categorized into macrovascular (affecting large blood vessels, e.g., cardiovascular disease, stroke) and microvascular (affecting small blood vessels, e.g., retinopathy, nephropathy, neuropathy) conditions (Hisni et al., 2023). The development of these complications significantly diminishes quality of life, increases healthcare costs, and is a major contributor to morbidity and mortality among people living with diabetes (Garg & Duggal, 2022).

Research indicates that physiological factors do not solely determine the path to complications. Psychological well-being plays a critical role, with studies reporting that psychological disorders and low motivation are significant risk factors associated with the development and progression of DM complications (Wong et al., 2019). These mental health aspects can profoundly impact a patient's

ability and willingness to engage in essential self-management behaviors necessary for complication prevention (Mangoulia et al., 2023).

Furthermore, patient cognition and perception significantly influence complication risk. A lack of self-awareness regarding the seriousness of DM, inadequate or inaccurate health beliefs about the disease and its management, and insufficient knowledge about effective self-care strategies have all been identified as contributing factors that foster the onset of complications (Jiang et al., 2021). These cognitive and perceptual barriers can hinder adherence to treatment plans and healthy lifestyle modifications (Alrasheeday et al., 2024).

Given the multifaceted nature of complication risk, proactive prevention through targeted nursing interventions is imperative. Nurses are pivotal in delivering education, support, and behavioral counseling to empower patients to manage their condition effectively and mitigate complications. However, the effectiveness of such interventions hinges on a deep understanding of the individual patient's lived reality and perspective (Dailah, 2023).

Nurses must recognize that every person with DM is unique, especially concerning their approach to preventing complications (Salihu, 2023). Patient experiences, beliefs, cultural backgrounds, and daily habits create diverse challenges and perspectives. For instance, some patients hold beliefs that consuming cold rice is more effective for blood sugar control than other methods, fear that medications inherently damage organs, struggle to adhere to dietary recommendations during cultural celebrations, or find it extremely difficult to abandon ingrained habits like drinking sweet tea in the morning (Salsabila & Sjaaf, 2022; Sari et al., 2022). These factors necessitate personalized care approaches.

While previous research has explored the general experiences of living with DM, there remains a notable scarcity of studies specifically focused on the nuanced experience of preventing complications (Christian & Nagar, 2021; Sari et al., 2022; Zhang et al., 2023). This gap is particularly concerning given that the majority of deaths among individuals with DM are directly attributable to its complications rather than the disease itself (Raghavan et al., 2019; Tomic et al., 2022). Understanding the specific barriers and facilitators patients encounter in actively preventing complications is therefore vital.

For multiple reasons, exploring patients' rich, detailed experiences in preventing complications is essential. It provides critical insights into current patient behaviors, decision-making processes, and the real-world challenges they face within their contexts. This deep understanding is foundational for developing patient-centered strategies and interventions that are evidence-based, culturally resonant, practical, and acceptable to the individuals they aim to serve, moving beyond generic advice to meaningful support (English, 2022).

This exploration holds particular significance in the Indonesian context, characterized by its immense cultural, normative, and ethnic diversity spread across thousands of islands. The interplay of local beliefs, traditions, and social norms significantly shapes health behaviors and perceptions of DM management (Salsabila & Sjaaf, 2022; Sari et al., 2022). Given the limited existing research on complication prevention experiences within such a diverse setting, and the authors' conviction that perspectives on this critical behavior vary significantly among individuals, this study aims to fill a crucial gap. By capturing these diverse patient voices, the findings will directly inform the development of more effective, culturally tailored nursing interventions to prevent DM complications in Indonesia.

METHOD

A qualitative descriptive study was carried out to describe the experiences of diabetes patients in preventing its complications. The study occurred in the Jakarta Public Health Center between December 2022 and April 2023. There were 15 patients with type 2 DM using purposive sampling. The participants were recruited from the Public Health Center in North Jakarta. The sample was recruited according to the following criteria: (a) the duration of DM was more than 1 year; (b) no complications, both macrovascular and microvascular; (c) consent for participation in the study. Collecting and analyzing the data were conducted concurrently until data saturation was obtained.

The data was collected using in-depth interviews, observation, and field notes. Interviews were carried out in a private room at the Public Health Center. To conduct interviews, the researcher was assisted by two research assistants who had been trained previously. Each interview was held for approximately 1 hr. Interviews were started with open-ended questions, for instance, "Please tell me why you came to the Public Health Center," and "Please tell me, do you know about DM complications?".

A semi-structured interview guide was created according to the literature reviews done by the study team. The interview guide asked questions about physical activity, medication, diet, blood sugar monitoring, foot care, and patient needs during the prevention of DM complications. Experts in the diabetes area have reviewed these questions, and then the questions were revised based on their references. They were then pilot tested on five patients before being used in the main study. Participants in the pilot study were excluded from the main study. The interview was conducted in Indonesian. Saturation was achieved at 15 participants. To gain an understanding of participants' culture, beliefs, and how diabetes management at home, observations were used. Researchers and research assistants used field notes to record the environment, thoughts, behaviors, and feelings during the research. Field notes are important because they provide rich content and increase the data for analysis.

During the interviews, the research assistants wrote notes with participants' permission. Transcripts were written in Bahasa Indonesia and then translated into English by the study investigators. They were checked by people who are fluent in Bahasa Indonesia. Interview transcripts and field notes were organized using NVivo 12 software. Deductive thematic analysis was used to analyze the data. All transcripts were read many times to get a sense of the whole, then reviewed using a deductive coding approach. Comparing transcripts and field notes was conducted to get extra context beyond the information written in the transcripts. The concept appearing from the data was coded and constantly compared, and then themes were developed. All researchers joined to compare their identified code and discuss the differences and similarities. When different opinions appeared, they continued to discuss until a consensus on the appearance of the themes and sub-themes was achieved.

Criteria used to confirm the rigorousness of the study included credibility, dependability, formability, and transferability. The researchers ensure the credibility by immersing themselves in the study field for a period of time. Methodological triangulation was also carried out, including deep interviews, participant observations, and field notes. A source of triangulation was used to collect data involving diabetic patients. Data triangulation was carried out by performing several interviews to validate the findings. To conduct a transferability run well, researchers provided comprehensive demographic and clinical indicators so that the relevance to other situations could be considered. To ensure dependability, researchers recorded the process of collecting and analyzing data. To ensure confirmability, methodological documentation and associated materials were kept as a backup for potential future research interpretations.

The study received ethical approval from the Institutional Review Board (IRB) of Universitas Nasional before it was conducted. In addition, participation was charitable; each participant signed informed consent after receiving an explanation of the study. Participants were sure of the confidentiality of the interviews. The transcribed and audiotaped interviews were kept in a locked cabinet and destroyed after the study finished.

RESULT

The characteristics of participants are seen in Table 1. There were 15 participants in the study. Most of the participants were females. Ages ranged from 45 to 64 years old. All participants had formal education; one had completed junior high school, six had completed senior high school, and eight had completed a bachelor's degree. Regarding the participants' jobs, 7 were homemakers, seven were retired, and 1 was a government employee. The mean DM duration was 5 years.

Table 1. Characteristics of participants (n=15)

Code	Gender (F/M)	Age	Marital status	Level of education	Job	Duration of DM
P1	F	64	Married	Senior high school	Housewife	4 years
P2	M	60	Married	Bachelor degree	Retired	10 years
P3	M	70	Married	Bachelor degree	Retired	15 years
P4	F	51	Married	Senior high school	Housewife	5 years
P5	F	59	Married	Junior high school	Housewife	4 years
P6	F	54	Married	Bachelor degree	Retired	10 years
P7	F	66	Married	Senior high school	Housewife	5 years
P8	F	50	Married	Senior high school	Housewife	3 years
P9	F	47	Married	Senior high school	Housewife	4 years
P10	F	48	Married	Senior high school	Housewife	5 years
P11	F	56	Married	Bachelor degree	Retired	10 years
P12	M	55	Married	Bachelor degree	Retired	5 years
P13	M	57	Married	Bachelor degree	Retired	2 years
P14	M	50	Married	Bachelor degree	Retired	2 years
P15	M	45	Married	Bachelor degree	Government employee	2 years

Table 2 explained the theme and categories. Four themes appeared from the data analysis: (1) inadequate self-care practice related to misconceptions about diabetes and its complications, (2) self-awareness, intention, and motivation are the basics to change the behaviors, (3) the need for optimal holistic support from the family and the health workers, and (4) an inadequate education program to prevent DM complications.

Table 2. Themes emerging from the data

Themes	Categories
Inadequate self-care practice related to misconceptions about DM and its complications	<ol style="list-style-type: none"> 1. Inadequate knowledge about the concept of DM and its complications 2. Patient's belief in herbs and medicinal plants for preventing DM complications 3. Inappropriate DM perception regarding medications
Self-awareness, intention, and motivation are fundamental to changing the behaviors.	<ol style="list-style-type: none"> 1. Inadequate self-awareness and intention to change behavior 2. Motivation is important to change behavior
Optimal holistic support is needed from family and health workers	<ol style="list-style-type: none"> 1. DM patients need support from a nurse and their family to change their behavior 2. DM patient needs spiritual support
Health workers provide inadequate education programs to prevent DM complications.	<ol style="list-style-type: none"> 1. Delivering education is too brief and not related to the participants' problems. 2. The educational content from another source is obvious.

Theme 1: Inadequate self-care practice related to misconceptions about DM and its complications

The first theme consists of three categories:

1. Inadequate knowledge about the concept of DM and its complications

According to the interviews and field notes. Participants explained that DM is a common disease and that they should not worry too much about it. There was no food restriction, and DM patients could eat any food because the food's calories would be burned through physical activity. Therefore, physical activity is more important than diet and medication. Furthermore, performing physical activity can prevent DM complications. Furthermore, there were two types of DM: dry sugar and wet sugar. Dry sugar is easier to recover when DM patients have a wound, as stated by one of the participants, who was male, 60 years old, and had been diagnosed 10 years ago with fasting blood glucose 159 mg/dl.

"I consider that DM is not a deadly disease. I eat everything, and there are no restrictions on food. I believe that calories from foods can be burned by conducting physical activity, which will decrease blood sugar and prevent its complications. So, I prefer to perform physical activities rather than diet and medication. I believe there are two types of DM: dry sugar and wet sugar. I also believe that dry sugar is easier to recover when I have wounds in my body".

2. The patient's belief in herbs and medicinal plants for preventing DM complications

Some patients believed that traditional plants such as the leaves of *Syzygium polyanthum*, *Zingiber officinale*, and *Cinnamomum verum* can reduce blood glucose and delay DM complications. Patients thought combining traditional treatments with modern medications would lower blood glucose levels more successfully than using only modern medications. These will benefit in preventing DM complications in the future. However, patients did not measure these conventional medications when taking them; instead, they based their quantities on their tastes, according to researchers' observations and interviews. It was stated by a participant who was 47 years old, who had been diagnosed for 4 years with fasting blood glucose 165 mg/dl.

*"I prefer to consume herbs rather than medicines from the doctor. It is proven by my own experiences that they can reduce blood glucose and delay DM complications. I consume herbs twice daily, in the morning and evening. Last week, I checked my blood glucose level, and the result was good. Furthermore, I remembered my parents taught me that it is more effective to reduce blood glucose when consuming medicine from a doctor, combined with some medicinal plants such as *Syzygium polyanthum*, *Zingiber officinale*, and *Cinnamomum verum*. I consume these plants once a day, and I feel healthier in my body. It means that these plants work to decrease blood glucose and delay DM complications in the future."*

3. Inappropriate DM perception regarding medications

Consuming medication from the doctor could increase body weight. Based on this perception, some participants take only half of their medicines to prevent body weight elevation. Other participants also stated that taking some cups of coffee with sugar is allowed rather than consuming modern medicines. Most of the participants' medication behaviors were not appropriate according to the doctor's prescription. They take some medicines when they have high blood glucose. These conditions were described by one of the participants who has been diagnosed with DM for 5 years, a male, 55 years old, with a fasting blood glucose of 150 mg/dl.

"I take medicines from the doctor only half, for example, half in the morning, half in the afternoon, and another half in the evening. I do this because I feel my body weight has increased due to the medicines prescribed by a doctor. Almost every morning, I drink coffee rather than medicine because I feel my body is getting healthy."

Theme 2: Self-awareness, intention, and motivation are fundamental to changing behaviors.

The second theme consists of two categories:

1. Inadequate self-awareness and intention to behavior change

Self-awareness is a basic knowledge for DM patients to perform behaviors to prevent DM complications. Patient reported that self-awareness comes from their own thinking, and it is tough to increase self-awareness regarding preventing DM complications. The patient with DM also believed that intention is necessary to prevent DM complications. Patients understand and know that management of DM diet, exercise, medication, and quitting smoking are important; however, they find it very hard to implement these behaviors. These were stated by a participant who was 70 years old, male, had been diagnosed with DM more than 10 years ago, and had a fasting blood glucose of 145 mg/dl.

"I know how to prevent DM complications, such as managing calorie intake, performing exercise, stopping smoking, and taking some medicines. However, increasing the intention and self-awareness is one of my weaknesses, because I have not had them until now".

2. Motivation is important to change the behaviors

Some participants explained that although they have good self-awareness and intention, they did not have internal and external motivation, and it was hard to change their behaviors. Therefore, self-awareness, intention, and motivation are necessary and cannot be separated. These were stated by a participant who was 48 years old, female, had been diagnosed with DM more than 4 years ago, and had fasting blood glucose of 136 mg/dl.

"I believe that without motivation, we cannot do anything right. For example, I want to eat some DM foods; however, nobody cares to tell me how to prepare DM foods, appetizers for DM patients, etc. I am a DM patient who was diagnosed with DM more than 3 years ago. I must also increase my motivation from myself; it will be useless if there is a good external motivation, but internal motivation is worse. Therefore, motivation is important as a basic need for behavior change, and it will impact delaying DM complications".

Theme 3: Optimal holistic support is needed from family and health workers.

This theme consists of two categories:

1. DM patients need support from a nurse and their family to change their behavior

Participants stated that support was needed to change their behavior. They were unable to prepare some pills, food, blood glucose checks, and take some candies before exercise by themselves. Participants also reported that nurses had a necessary role to support the DM patient, such as giving information regarding how to choose DM food correctly, the benefits of DM food, the time to consume, and the side effects of some medicines, preparing for exercise, and managing psychological problems. Besides these, the DM patient wants to receive education regarding how to build social relationships properly when they have a diabetic foot ulcer. Thus, the DM patient needs holistic support to prevent complications. These statements are fit with a participant who is 54 years old, female, and has been diagnosed with DM more than 7 years ago, with fasting blood glucose of 230 mg/dl.

"Support from husband and children is required, for example, to accompany me when I go to the Public Health Centre for a monthly check-up. Furthermore, support from nurses is also critical, they have to give me some information regarding how to prevent DM complications and to be obedient in performing DM management in daily life".

2. The DM patient needs spiritual support

Participants reported that spiritual support was also necessary in performing DM management. When problems affected their blood glucose, they had to return to their God by performing prayer and other spiritual activities. Some participants also stated that spiritual support is crucial, as it encourages open conversations about patients' beliefs, offers to connect with a spiritual leader or counselor, and ensures a compassionate and understanding presence during patients' journey. Hence, DM patient needs spiritual support to improve their behavior in preventing DM complications. These reports are suitable with a participant who is 56 years old, female, and has been diagnosed with DM more than 8 years ago, with a fasting blood glucose level of 180 mg/dl.

"I am always careful about what I eat, as our religion teaches us to eat before you are hungry and stop eating before you are full. In addition, our faith teaches that you should beware of your stomach, because it can make you pray and make you sick. And you should eat in moderation, because it prevents sickness and encourages obedience. Therefore, I think it is relevant that spiritual support is important for patients in maintaining their main diet".

Theme 4: Inadequacy of the education program provided by health workers to prevent DM complications.

This theme has two categories:

1. Delivering education is too brief and not related to the participants' problems

Education was given by health workers such as nurses and doctors when participants came to "Prolanis", a health program initiated by the Indonesian government to prevent DM,

hypertension, and their complications. However, education was concise and not tailored to the participants' needs. Thus, participants need to control their disease in poor condition. These phenomena occurred because health workers have other responsibilities and cannot handle DM patients appropriately. Furthermore, participants also stated that they need information on how to build self-awareness and self-motivation to change behavior to prevent DM complications. These statements were reported by a participant who had been diagnosed with DM for 2 years, was 45 years old, and had a fasting blood glucose 139 mg/dl.

"Education from the public health center is very short and fast. When I arrived home, I forgot the information nurses and doctors gave me. Health workers' education should only be tailored to patients' needs. I cannot remember anything in detail. The important thing is that health workers must give information regarding how to appear self-aware and self-motivated to change behavior so that DM complications can be delayed."

2. Education content from another source is obvious

Not only was the inadequacy of the education program fundamental, but the content of the education was also significant. The participant explained that the educational content was comprehensive and sometimes incomprehensible. Participants followed and joined another DM community to get detailed information on preventing DM complications. Finally, they invite other participants to join that community. These were stated by a participant who had been diagnosed with DM for 3 years, 50 years old. Her blood glucose was 121 mg/dl.

"I chose another DM community to get some information regarding how to prevent DM complications because if I had only joined the education program from the "prolanis" program, I would not have understood it deeply. When I joined a DM community, I realized I got new information unavailable in the "Prolanis" program. Education in the "Prolanis" program focused on delivering information regarding DM medication only."

DISCUSSION

Our study is the first to prove that Indonesian culture, beliefs, and practices had a strong influence on preventing DM complications behaviors, especially in Javanese diabetic patients. Four themes appeared from our study they were inadequate self-care practice related to misconceptions about DM and its complications; self-awareness, intention, and motivation as basic to change the behaviors; optimal holistic support is needed from family and health workers; and inadequacies of education programs provided by health workers to prevent DM complications.

Several misunderstandings of self-care practices about diabetes and its complications were revealed in this study. Participants reported that dry sugar was more favorable than wet sugar because dry sugar was not at high risk of diabetic ulcers. These concepts have been rooted in the Javanese people for a long time. However, the idea may have originated from how ulcers appear on the skin (Sari et al., 2022). They also explained that physical activity is important than DM diet and medication for DM because performing physical activity can burn calories, which can help lower blood glucose and delay its complications. ADA (2023) recommended that a person with DM should perform 150 minutes or more of moderate-to-intense aerobic activity per week, spaced out across at least three days, and refrain from inactivity for no more than two days in a row, for younger and more physically fit people, shorter, high-intensity or interval training (minimum 75 minutes/week) may be adequate. Types of physical activities for patients with DM include walking briskly, doing housework, swimming, bicycling, and playing sports. These depend on the patients' condition and their ability to perform.

Some participants reported consuming herbs as a primary or secondary therapy to decrease blood glucose and make them healthy. A DM patient in Indonesia used herbs to prevent DM complications. However, the use of herbs as therapy to lower blood glucose levels and prevent DM complications must be scientifically supported (Yedjou et al., 2023). Some herbs that can be consumed for DM patients include garlic (*Allium sativum*), bitter melon (*Momordica charantia*), rosella flowers (*Hibiscus sabdariffa* L.), and ginger (*Zingiber officinale* Rosc), which are proven to be

able to reduce blood glucose levels due to the content of phytochemicals as antioxidants, anti-inflammatories, and anti-diabetes and prevent cancer (Mao et al., 2019; Yedjou et al., 2023). Thus, herbs can be considered complementary therapy for DM patients as long as they have proven efficacy and are safe for consumption. They also need consultation with health workers prior to consuming the herbs.

Participants also realized that self-awareness and intention are important assets for adherence to prevent DM complications behaviors (Rajkumar et al., 2023). However, these are very difficult to implement because patients with DM need support and motivation from their family and nurses. In addition, the existing program at the Public Health Center is not optimized to enhance self-awareness and intention to change the behaviors. These conditions are proven by increasing HbA1c levels of the participants. Therefore, a nursing intervention should be delivered to the patient with DM for increasing their awareness and intention by performing coaching because it can increase an individual's self-awareness through the mechanism of activating the parasympathetic nervous system which works to reduce heart rate and relax the body's muscles so that individuals are more able to accept and be open to new ideas as well as motivated to achieve goals. In addition, coaching also activates networks and parts of the brain that encourage individuals to focus on achieving goals (Carden et al., 2022).

Patients with DM also need holistic support, including bio-psycho-social-spiritual. Holistic care should help DM patients feel better mentally, emotionally, and behaviorally, leading to better blood glucose regulation and an enhanced quality of life (Juanamasta et al., 2021). The response and repercussions of the disease experienced by individuals, families, groups, communities, and populations are examined from the perspective of holistic nursing, which takes into account the whole human experience and condition on the physical, emotional, social, cultural, and spiritual levels (Frisch & Rabinowitsch, 2019). Holistic support also comes from family and the nurse. A study conducted by Yuliastuti et al. (2022) stated that support for type 2 diabetes provided by families can improve psychosocial status, motivation, enthusiasm, and growth since these supports are seen as beneficial and significant for families in establishing routine DM management practices that improve quality of life and avoid DM complications. Family support given to instrumental, emotional, and informational DM patients will encourage excellent behaviour in implementing diabetes self-care to prevent DM complications. In addition, family can influence attitudes and become aware of the requirements of individuals with DM by refusing or providing help on a physical, psychological, emotional, and social level. DM patient will have a better attitude toward learning about DM if their families support them and participate in health education about the disease. Besides family support, nurses are crucial in promoting the prevention of diabetes complications. In addition to giving patients medical attention and education, nurses are responsible for ensuring that patients are managing their diabetes properly by using effective communication and problem-solving techniques (Primanda & Herviani, 2021).

Another experience of DM patients was an inadequate education program in primary health care. Education was brief because nurses had many administrative activities, so they could not properly manage the education method. As a result, some of the DM patients come to the health care center in worse condition. Some patients also seek other sources to get information about managing DM and preventing complications. These findings were consistent with a previous study that reported education in the "Prolanis" program was ineffective in improving clinical outcomes in patients with DM (Alkaff et al., 2021). Actually, this program offered more benefits for DM patient through some regular activities as follow; 1) monthly regular meeting form medical consultation; 2) peer group education by healthcare professionals; 3) healthcare visit reminder; 4) peer-club activities; 5) home visit; 6) regular health status monitoring; and 7) laboratory check for clinical outcomes every 6 months. However, these activities did not work well due to the limited time for doctors to provide consultation, and the education provided was minimal because there was much administrative work that nurses must complete. Not all DM patients come to the monthly meeting.

CONCLUSION

This study provides new insight into how DM patients in Indonesia implement the management of DM to prevent its complications. It has been revealed that some misconceptions exist about DM and its complications. Results show that DM patients find DM management difficult and are influenced by their culture, practices, and beliefs. In addition, results show that self-awareness, intention, and motivation are basic needs to prevent DM complications. This study also provides important information that nurses in Indonesia should pay attention to regarding culturally sensitive education programs for DM patients to improve their behavior and prevent complications. Future studies are needed to investigate the effect of nursing interventions that involve cultural elements for patients on improving the prevention of DM complications behaviors.

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