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RESEARCH

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Perception and Educational Needs in the Self-Management Type 2 Diabetes Mellitus Patients: A Phenomenological Study Based on Local Wisdom

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Abstract

Lack of knowledge, misperceptions, and the absence of a diabetes management culture pose challenges to providing social support, particularly within families. This is a qualitative phenomenological study aimed at identifying factors contributing to self-management, unearthing the influence of a patrilineal culture, and uncovering the educational needs for local wisdom-based diabetes mellitus self-management in type 2 patients. Data were collected through in-depth interviews and analyzed thematically. The study population consisted of type 2 diabetes mellitus patients living within patrilineal families. The sample size was 10 female individuals aged between 40 and 60 years. The duration of type 2 DM ranged from 6 to 15 years. Four themes emerged from the research: (1) Insufficiency in self-management, (2) Beliefs and perceptions about type 2 diabetes mellitus, (3) The influence of patrilineal families on self-management, and (4) The need for the development of educational programs for self-management type 2 DM management rooted in local culture. According to the results, people with Type 2 Diabetes Mellitus may not be capable of managing their health. Though there are many different opinions and views regarding Type 2 DM, there are frequently gaps in our knowledge. The management of diabetes is greatly impacted by patrilineal family systems. Participants express a significant need for educational programs that are culturally sensitive and improve their ability to control their diabetes.

Keywords: Education, Local Wisdom, Self-Management.

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1. INTRODUCTION

The height of Diabetes Mellitus (DM) incidents impacts everyone in various aspects of a patient's life. It has profound effects on health, the economy, and mortality. Out of a total of 4.25 million deaths attributable to diabetes mellitus (DM) between 2006 and 2021, there was a notable increase of almost 30% in mortality rates during the pandemic. Specifically, the mortality rate rose from 106.8 per 100,000 individuals in 2019 to 144.1 in 2020 and further to 148.3 in 2021 (Lv et al., 2022). The cost of DM treatment reached 673 trillion in the same year (IDF, 2015). Therefore, effective management of DM is crucial. The primary focus in DM management includes lifestyle changes. Lifestyle management is fundamental in DM treatment and encompasses self-study, support care, physical activity, smoking counseling, and psychosocial care (American Diabetes Association, 2022). It is expected that glycemic control can be improved by changing lifestyle patterns, reducing complications and deaths.

Indicators for glycemic control include fasting blood glucose, blood glucose levels two hours after eating, blood pressure, blood lipid levels, and HbA1C (PERKENI, 2021). However, many DM patients still struggle to achieve optimal glycemic control. According to the National Health and Nutrition Examination Survey (NHANES), only 50% of adult DM patients in America achieved HbA1C levels below 7.0. Previous study with intervention of Diabetes Self-Management Education (DSME) showed 21% of DM achieved HbA1C levels below 7.0 (Emara et al., 2021). The Riskesdas results showed that 10.5% of individuals over 15 years old experienced hyperglycemia (Kementerian Kesehatan Republik Indonesia, 2018). Self-management by Type 2 Diabetes Mellitus (DM) patients is crucial for effective DM management. The success of DM management is significantly influenced by the family's role in supporting self-management. Currently, most educational material focuses only on dietary management for Type 2 DM patients and does not address the role of the family and cultural aspects in maintenance, even though culture plays a vital role in the education and care process for Type 2 DM patients and their families (Sohal et al., 2015).

Lack of knowledge, perceptual errors, and a failure to adapt to cultural aspects in diabetes management are obstacles faced in providing social support, including family support. Improving patient and family knowledge is influenced by several factors, including the family function and educational methods used (Pamungkas et al., 2021a; Sohal et al., 2015). Indonesia adheres to a patrilineal social structure. Culture and religion exert a significant influence on this phenomenon, as traditions are imparted through both formal and informal educational channels (Pamungkas et al., 2021a). The former study found patrilineal system impacts problem-solving skills, ineffective communication and burden, compliance and poor behavior control (Pamungkas et al., 2021a).

Educational models and media significantly impact patients' and families' understanding of DM treatment (Beck et al., 2018). Educating family members about the importance of DM treatment can help them provide better care in the treatment process (Pesantes et al., 2018). Knowledge about the disease, strategies for changing family routines, and optimal ways to address emotional aspects of the disease are essential components of DM self-management that family members need to understand (Bennich et al., 2017). Additionally, the choice of media used for education can influence information acceptance. Audiovisual media in the form of digital video discs (DVDs) is considered more effective than leaflets or booklets for educating DM patients and their families (Estacio et al., 2015; Pamungkas et al., 2017).

Providing education to families and DM patients is an ongoing process and requires repeated efforts. Therefore, a comprehensive educational model that is engaging and incorporates local Balinese patrilineal wisdom is needed. Based on these considerations, the researchers have developed an educational model for fostering self-management based on local wisdom to improve glycemic control and self-efficacy in Type 2 Diabetes Mellitus patients.

2. RESEARCH METHOD

This study utilized hermeneutic phenomenology to explore the experiences of their ability to maintain self-management, the influence of patrilineal culture, and the development of locally based educational models for Type 2 Diabetes Mellitus patients (Spence, 2017; Todres & Wheeler, 2001). Phenomenology seeks to comprehend the human experience through the interpretation of daily encountered phenomena. This study employs Heidegger's philosophical approach, which highlights the influence of an individual's temporal existence on their interpretation of experiences. Heidegger's concept of Dasein, which pertains to human existence, is crucial for contemplating the nature of being (Todres & Wheeler, 2001). Individuals partake in inter-subjectivity, a process wherein they subjectively engage with the objective aspects of the world, in order to contemplate their own existence. This phenomenon aligns with the philosophical notion of Dasein. The philosophical approach employed in this study aligns more closely with individuals' life-world and their everyday interactions (Lamb et al., 2019). This is crucial for comprehending the experiences of patients diagnosed with Type 2 Diabetes Mellitus.

The respondents were selected from one area at Mengwi 1 Public Health Center. The sample was recruited with purposive sampling with criteria: receiving regular treatment, effective communication skills, at least a high school education, and aged between 40 and 60 years (1 May 2021– 31 August 2022). Throughout the course of the study, a total of five participants declined to disclose information for a variety of reasons, including personal unease with the subject matter, apprehension regarding potential consequences, and a sense of insecurity. Ultimately, a total of ten participants were incorporated into the study. The determination of the sample size was made based on the point of data saturation, which occurs when no new codes are identified. The researchers conducted data analysis following each interview.

The interviews were administered in accordance with the patient's temporal and spatial context. The interviews, analysis, and interpretation in this study were conducted using the Bahasa Indonesia language. The primary author conducted individual interviews with each participant, lasting approximately one hour, predominantly within the confines of the patient's residence. A semi-structured interview guide was developed, with the initial query being, "Kindly provide an account of your self-management practices in order to uphold your condition." The interviews conducted exhibited a dialogical nature, wherein particular attention was given to the topics of self-management, patrilineal culture, and locally based educational models for individuals diagnosed with Type 2 Diabetes Mellitus. The interviewer utilized the responses to the main question as a basis for posing additional exploratory inquiries regarding the patient's self-management practices, drawing upon local knowledge. This was achieved by requesting further elaboration with the prompt, "Could you provide additional details?" Could you kindly provide an illustrative example, please?

The research team consisted of three individuals, namely the lead investigator and two researchers. The study's progress and conclusions were monitored by the research team members through the utilization of online meetings. Each member possesses a background in nursing research. This study did not involve conducting multiple interviews with the participants, and it is important to acknowledge that there were no pre-existing relationships between the researchers and participants that could have potentially influenced the responses.

To better grasp the significance of the individuals' lived experiences, the researchers employed Van Manen's approach (van Manen, 2016), which provides four levels of analysis. In order to extract thematic descriptions, one must first identify thematic aspects (Ritruethai et al., 2018), then extract thematic statements (Ritruethai et al., 2018), and finally create linguistic transformations (Ritruethai et al., 2018). Multiple readings of the interview transcripts were

done to ensure a thorough understanding of the material. Codes were placed on all of the pivotal components. The first and second authors performed the initial Bahasa Indonesia coding, and then they organized the collected data into overarching themes and their respective subthemes. The findings were originally written in Bahasa and translated into English by the first two authors, who were then checked for accuracy by the third pair. The team finally reached consensus on the underlying concepts and overarching themes.

The researchers employed rigorous criteria and specific rules to ensure the methodological soundness and trustworthiness of the study. The utilization of established phenomenological research method ensured rigor (van Manen, 2016). The study employed evaluation methods which involved maintaining long-term contact with participants, being transparent about the study's focus, conducting thorough data analysis, discussing emerging themes with participants, and adjusting themes based on participant input (Polit & Beck, 2017). The processes were recorded in Excel files to ensure the reliability and validity of the study. The final report included participant descriptions to demonstrate the relevance of the study's findings. Participants were provided with a process summary and diagram to enhance the study's credibility, and member checks were performed. Qualitative research and diabetes mellitus experts were consulted to enhance the accuracy of the study. Transferability was ensured by comprehensively explaining the study's context, background, and stage in the introduction and selecting participants with a wide range of characteristics.

This study has received ethical approval from the Health Polytechnic Ministry of Health Denpasar's Ethics Study Commission, registered as LB.02.03/EA/KEPK/0440/2023, dated May 8, 2023. Participants received both written and verbal information about the study's purpose and methods prior to their participation. Participants had the option to withdraw from the study at any time prior to the completion of data collection, after signing the consent form and arranging the interview details. To maintain confidentiality and safeguard the privacy of participants, each interview was assigned a code instead of using personal names or institutional affiliations. Consequently, their identities and information were maintained in strict confidentiality.

3. RESULTS AND DISCUSSION

The study involved ten female participants aged between 40 and 60 years, with diabetes mellitus (DM) duration ranging from 6 to 15 years. Four themes emerged from the data analysis:

Table 1. Themes overview

Quotes	Subthemes	Themes
"I am not able to check my blood sugar by myself.. I don't understand the procedure, and I'm afraid of making mistakes." (P2)	Inactive self-glucose check	Insufficiency in self-management
"I don't know how much my blood sugar should be... I don't understand whether it's normal or not." (P3)		
"I don't know the right glucose....I suddenly knew my glucose was high."(P5)		

"I can't check it [blood glucose] by myself...it is difficult to do." (P9)

"I find it difficult to manage my diet... it's complicated." (P5) Poor diet management

"I think it is difficult to manage diet, moreover choosing the right food." (P6)

"I can eat, but I can't manage it...I is messy, I can't eat this one, that one." (P10)

"I can't take care of my foot.....I don't know how to do it."(P1) Unknown foot treatment

"I don't know if my foot needs special care." (P3)

"I don't understand that even foot have to be cared for properly." (P5)

"I don't understand how to take care of my foot, sir. All I do is take a shower and wash my foot, sir." (P6)

"I also don't know if my feet need to be treated." (P7)

"I think exercise is good for my health, but I'm not sure if it can lower my blood sugar." (P1) Doubt about exercise

Walking would make me healthier, but they say it can lower blood sugar, sir. Is that true? (P7)

Does walking affect my sugar? (P9)

"I just know that diabetes is caused by many things like excessive eating." (P3) Negative perception Beliefs and Perceptions About Type 2 Diabetes Mellitus

"I don't understand about the cause... some say obesity, some say it's because of eating too much." (P8)

My knowledge of the cause is very limited, but I do know that genetics, obesity, and inactivity are contributing factors (P10)

"My husband decides where I should get treatment." (P4) Authoritarian man

<p>"If my husband doesn't agree, then I have to cancel it... I wait for his decision." (P7)</p> <p>"It's up to my husband to determine that. I'll just go along with it." (P9)</p> <p>"When my husband and I have different opinions, my husband's decision prevails." (P5)</p> <p>"Sometimes we argue first... in the end, yes, follow my husband" (P10)</p>		<p>The Influence of Patrilineal Family Structures on Self-Management</p>
<p>"My spouse is attentive to me as well, but it can be challenging at times to be left behind." (P6)</p> <p>"Yes, sir, my husband will definitely pay attention." (P9)</p> <p>"When I need something to treat my pain, call my husband" (P10)</p>	<p>Spouse caring</p>	
<p>"I want to study carefully about how to manage my diabetes independently." (P3)</p> <p>"I need comprehensive guidance to be able to manage it myself." (P5)</p> <p>"I want to start from the beginning with good guidance." (P9)</p>	<p>Independent learning</p>	<p>Hope for the Development of Educational Programs</p>
<p>"I want the explanations to use Balinese language." (P2)</p> <p>"Teach us using methods that are adapted to our daily lives." (P5)</p> <p>"The language and approach should be easy to understand." (P9)</p>	<p>Local wisdom</p>	

Theme 1. Insufficiency in self-management

Participants expressed their inability to manage diabetes mellitus independently. They lacked the skills and knowledge required for self-care management. This theme encompassed categories such as the inability to self-monitor blood glucose, set glycemic control targets, manage dietary choices, and provide adequate foot care and regular exercise. The statements revealed a lack of understanding and capability in critical aspects of diabetes self-care management.

Theme 2. Beliefs and Perceptions About Type 2 Diabetes Mellitus

Participants held diverse and often limited beliefs and perceptions about Type 2 DM, including its causes, treatments, and complications. They mentioned causes like excessive eating, obesity, and heredity. Their perceptions of dietary management were also unclear, and they expressed uncertainty about the benefits of physical activity. The statements in Table 1 highlighted a need for better education on the causes and management of diabetes.

Theme 3. The Influence of Patrilineal Family Structures on Self-Management

Participants revealed the influential role of patrilineal family structures in diabetes management. Husbands, as heads of the family, played a dominant role in decision-making and care for diabetes patients. Categories within this theme included decision-making, family support during complaints, and conflict resolution. The statements highlighted the dominant role husbands played in diabetes management decisions. This reflected the cultural context of patrilineal family structures in Bali.

Theme 4. Hope for the Development of Educational Programs

Participants expressed a strong desire for structured and culturally sensitive educational programs to enhance their ability to manage diabetes independently. They hoped for programs that incorporated local Balinese culture, including language and terminology. The statements underscored the need for culturally tailored educational programs to improve diabetes self-care management.

DISCUSSION

This study has identified four significant themes related to self-management based on local wisdom in Type 2 Diabetes Mellitus patients, which will be discussed below:

Insufficiency in self-management. Participants in this study exhibited inactive self-glucose checks, poor diet management, unknown foot treatment, and doubt about exercise in managing diabetes mellitus. They expressed their inability to fully engage in self-care management for diabetes. This overarching theme emerged from various participant statements that can be categorized into several sub-themes.

The research findings align with previous studies on self-care management, indicating that participants struggle to perform all self-management activities according to guidelines. While some can manage their diet and avoid excessive carbohydrate intake, they still face challenges in adhering to health recommendations fully. Other aspects of self-care tend to rely more heavily on medication for blood glucose control (Bhandari & Kim, 2016).

The sub-themes within this theme encompass diet management, physical activity, foot care, and glucose monitoring, all performed independently to some degree. However, participants admitted that they were not yet fully proficient in these areas (Mikhael et al., 2019). Other research suggests that only a small fraction of participants can perform some aspects of self-care, and even fewer can do so independently. Some individuals rely on recommendations from healthcare professionals, such as doctors or nurses, rather than being fully autonomous in self-care management (Murphy et al., 2015).

It's essential to recognize that self-care management is an ongoing developmental process for individuals with diabetes mellitus. This process involves mastering seven crucial activities: monitoring blood glucose levels, dietary management, taking medication as prescribed, problem-solving, coping, engaging in physical activity, and behavior modification (Shrivastava et al., 2013). Successful self-care management necessitates adequate knowledge and skills to perform these activities effectively and independently. This theme also underscores the prevalence of skill deficits, problem-solving difficulties, and challenges in behavior management among participants (Pamungkas et al., 2021b).

Beliefs and Perceptions Regarding Type 2 Diabetes Mellitus. Participants held diverse beliefs and perceptions about type 2 diabetes mellitus. However, these beliefs were often incomplete and marked by limited knowledge. Their perceptions encompassed various aspects,

including the causes, management, and consequences of diabetes mellitus. This theme emerged from participant statements related to their beliefs and perceptions.

It is important to note that self-care management depends on having positive beliefs and perceptions regarding diabetes. These beliefs significantly influence patients' self-care skills. Confidence serves as a motivating factor for effective self-care management, including accepting the illness and having the desire to improve one's health (Shakibazadeh et al., 2011).

Perceptions concerning physical activity, particularly sports, were generally unfavorable and highlighted a lack of understanding of its importance in managing diabetes. Participants attributed this lack of engagement in physical activity to a dislike of exercise and a shortage of time (Tewahido & Berhane, 2017). Additionally, perceptions related to diabetes mellitus were often underdeveloped, with some participants not considering diabetes a serious disease and having difficulty recognizing the importance of self-care management (Tan et al., 2018).

Influence of Patrilineal Family Structures on Self-Management. The influence of patrilineal family structures on the independence of diabetes mellitus patients was a prominent theme. Participants revealed that their husbands, as heads of the family, played a dominant role in decision-making and the management of their diabetes. This theme is based on several categories, including decision-making, family support during health complaints, and conflict resolution.

Balinese culture is deeply rooted in Hinduism (Juanamasta et al., 2020), emphasizing patriarchy and the central role of men in family dynamics (Sudarta, 2017). The patrilineal system places men in a more important position than women, as evident in Balinese wedding ceremonies that adhere to the "purusa" concept, signifying the male head of the family (Rahmawati, 2016).

Within this patriarchy, men are viewed as the leaders and organizers of the household and primary breadwinners, while women take on dual roles as mothers and contributors to the family's. Consequently, husbands actively influence decisions and rule-making within the family, including healthcare decisions (Omodara et al., 2022).

Hope for the Development of Culturally Tailored Educational Programs. Participants expressed a strong desire for structured and culturally sensitive educational programs to enhance their ability to manage diabetes independently. They sought programs that incorporated local Balinese culture, including language and terminology. This theme emerged from participant statements related to their educational needs and preferences.

Participants emphasized the need for culturally adapted educational programs that provide comprehensive guidance. They expressed a desire to start from the basics and receive clear instructions to enable them to manage diabetes independently (Pamungkas et al., 2021a).

Cultural adaptation is crucial to improving participants' understanding of diabetes mellitus and its management. This adaptation encompasses language, terminology, environmental context, and the availability of locally relevant dietary options (Alaofè et al., 2021). Culturally sensitive educational programs can positively impact participants' comprehension and empower them to take charge of their self-care (Stone, 2006).

Sensitivity to local culture in diabetes educational programs also opens up alternative approaches, methods, and educational materials that can alleviate learning constraints (Omodara et al., 2022). The focus on cultural adaptation extends to the entire education team, emphasizing the importance of understanding local culture, selecting appropriate teaching materials, and delivering education in a manner that resonates with the local context (Juanamasta et al., 2021; Lamptey et al., 2022; Suardana et al., 2023).

Studying has several limitations. First, related to the sample size, the findings may not be easily generalizable to populations outside of the specific cultural and geographical context of the study. Second, participants' responses can be subject to bias. They might provide socially desirable responses or unintentionally misrepresent their experiences. Last but not least, the

study is based on the experiences of individuals with diabetes mellitus in a specific cultural context (Balinese culture), the findings may not fully apply to individuals from different cultural backgrounds. It's crucial to acknowledge this cultural bias.

4. CONCLUSION

In conclusion, the study involved participants aged 40-60 years, all of whom were women. The findings suggest that there is a lack of ability in self-management among Type 2 Diabetes Mellitus patients. Beliefs and perceptions about Type 2 DM are diverse but often limited by knowledge gaps. The influence of patrilineal family structures is significant in diabetes management. Participants strongly desire culturally adapted educational programs to enhance their diabetes management skills.

Based on these findings, it is recommended that diabetes education teams consider cultural adaptation in their programs to enhance acceptance, understanding, and implementation by patients. Future research should explore local culture more deeply to develop materials, media, and educational content for independent diabetes management programs. This will help bridge the gap between cultural context and effective diabetes care.

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