

Experiences of Newly Diagnosed Diabetes Mellitus Patients in the Adaptation Process of Self-Management

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ABSTRACT

OBJECTIVE: To explore the experiences of individuals newly diagnosed with diabetes mellitus while adapting to self-management.

METHODOLOGY: This qualitative interpretative phenomenology design study was conducted at a Primary Health Centre in East Java, Indonesia. Data were collected through in-depth interviews with twenty-four patients newly diagnosed with DM during the last five years. Data were analyzed using Braun and Thematic Analytic.

RESULTS: Six themes emerged from this research: emotional distress after diagnosis, adaptation processes of DM, adaptation challenges, adaptation support, and the needs of newly diagnosed DM. Themes related to the reaction to the initial diagnosis, lifestyle adjustments, and the establishment of support networks were identified.

CONCLUSION: This study provides valuable insights into the existing literature on diabetes management, shedding light on the multifaceted nature of the adaptation process in newly diagnosed patients. Implications for healthcare practices and interventions to enhance support systems for these individuals are also discussed.

KEYWORDS: Adaptation Process, Diabetes Mellitus, lived experience, new diagnosis, self-management.

INTRODUCTION

Diabetes, a chronic condition characterized by high blood sugar levels, is a reality faced by millions of people worldwide¹. Whether diagnosed with type 1 or type 2 diabetes, individuals find themselves thrust into a world of health management in ways that they may not have anticipated². The experience of a newly diagnosed patient with diabetes mellitus is a complex and often challenging journey marked by a range of emotions, lifestyle adjustments, and a learning curve³. The International Diabetes Federation (IDF) estimated that approximately 537 million adults (aged 20-79 years) will have diabetes globally in 2021. This number is expected to rise, reaching 643 million by 2030 and 783 million by 2045, if current trends continue^{4,5}.

Patients with type 2 diabetes who have received a diagnosis may experience psychological and physical problems⁶. Financial and psychosocial issues, such as stress and depression, are the primary issues⁷. Challenges and issues raised by patients with diabetes include awareness of the disease, lack of social support, and food and activity adjustments following diagnosis⁸. For newly diagnosed, the journey

begins with motions, uncertainty, fear, and desire for clarity^{2,9}. Understanding the intricacies of blood sugar control, dietary adjustments, and the importance of regular monitoring is daunting and essential¹⁰. The learning curve is steep, but with appropriate guidance and support, individuals can gain the knowledge and skills necessary to lead fulfilling lives while managing diabetes effectively⁸. The experience of being a new diabetes patient often involves a series of adjustments¹¹. From learning to administer insulin injections, navigating oral medications, and grasping the significance of carbohydrate counting, the daily routine transforms into a mindful self-care process. Dietary choices have a new relevance, and regular exercise is paramount in maintaining a healthy lifestyle¹². Patients face stress from changing their behavior and managing their diabetes. There are difficulties in adjusting when one's health deteriorates suddenly. Transitions are dynamic and rely on how the patient feels about the illness and how they handle self-management. An individual will try to employ adaptive techniques to create, situationally, and transition diabetes treatments¹³. Adaptation is a crucial component of DM management¹⁴.

The landscape of diabetes management is continually evolving, with advancements in technology-providing tools, such as continuous glucose monitors and insulin pumps. These innovations offer new possibilities for improving blood sugar control and enhancing the quality of life. During this journey, resilience and adaptability become virtues. With time, patience, and a proactive approach, individuals with diabetes can not only manage their condition but thrive in their daily

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lives. The goal is not just glycemic control but also about embracing a holistic approach to health, well-being, and a future filled with possibilities. This study explored the adaptation experiences of patients newly diagnosed with diabetes mellitus.

METHODOLOGY

Research design

This qualitative interpretative phenomenology design study was conducted at a Primary Health Centre in East Java, Indonesia. This method aims to understand the participants' thoughts and feelings, allowing researchers to explore complex phenomena in depth.

Participant and setting

This research was conducted at a Primary Health Centre in East Java, Indonesia. The sampling technique used in this research was purposive sampling. The number of samples or participants in this research was not determined initially but was based on achieving data saturation during the research process. The number of participants in this study was 24 DM patients who met the inclusion criteria, namely type 2 DM patients diagnosed with DM within the last five years, willing to be patient, physically and cognitively aware to participate.

Instruments

The study tool includes six interview guidelines describing the adaptation process in DM patients undergoing self-management. These guidelines were developed based on a literature review. The interview guide created will be tested on one of the patients who have just been diagnosed with type 2 DM. An example of an interview question is, "Does asking you to tell me about your experience when you were diagnosed with diabetes mellitus help or not help you adapt to diabetes self-management?". Developing questions is necessary if the questions created cannot yet explore the research objectives.

Data collection

The data collection method used in this research is in-depth or open-ended. An open-ended interview is conducted in a semi-structured manner using open questions to allow participants to provide answers freely¹⁵. During the interview process, the researcher will record it so that, in the future, it can be carried out verbatim. Interviews were conducted at a location agreed between the researcher and the participant (participant's home, hospital or according to agreement). Interviews were conducted for 30 - 60 minutes.

Data analysis

The data analysis used in this research is Braun and Clarke's thematic analysis. The thematic data analysis stages consist of six stages, namely familiarizing yourself with your data (getting to know the data by reading them repeatedly and marking notes on essential words), generating initial codes (coding the data), looking for themes (looking for themes from the codes that have been generated), reviewing the theme (reviewing the theme that has been generated to ensure the theme that will be raised), defining and

naming the theme (defining and naming the theme), and making a report (writing down the results)¹⁶. Research data will be analyzed with the help of NVIVO software.

Ethical considerations

This qualitative investigation complies with nursing research guidelines. An ethical test involving volunteers and humans has to be carried out for this research. The Ethics Committee has given its approval for this project. Participants were asked to complete a written informed consent form. Data collection procedures from this research can be carried out after being declared to have passed and be worthy of the ethical test from the Health Research Ethics Commission, Faculty of Nursing, Airlangga University No 2874-KEPK.

RESULTS

This study was conducted on 24 patients with diabetes mellitus. Most of the participants were female (79.17%) and had a duration of being a DM patient of 1-5 years. Most participants had no history of DM in the family, with the therapy used being primarily oral medication (87.5%) (Table I).

Table I: Demographic data of participants (n=24)

Characteristics	Frequency	Percentage (%)
Gender		
Male	5	20.83
Female	19	79.17
Duration of DM		
≤ 1 year	10	41.67
1 – 5 years	14	58.33
History DM in Family		
Yes	10	41.67
No	14	58.33
Age		
Young	4	16.67
Middle aged	11	45.83
Elderly	9	37.5
Medication		
Oral	21	87.5
Insulin	0	0
Oral and Insulin	3	12.5

Table II shows the adaptation process that DM patients go through in carrying out self-management. This theme describes the challenges and challenges experienced, as well as the needs and hopes of newly diagnosed DM patients. The themes resulting from this study are emotional distress after getting diagnosed, the adaptation process of DM patients, adaptation challenges, adaptation support, needs of newly diagnosed DM, and expectations of DM patients.

Table II: Themes Emerging from Research "Experiences of Newly Diagnosed Diabetes Mellitus Patients in the Adaptation Process of Self-Management"

Theme	Subtheme
Emotional distress after getting diagnosed	Feeling anxiety
	Afraid to do new activities
	Feeling of untrust
Adaptation process of DM patients	Diet control
	Emotion control
	Self-motivation
	Glucose monitoring
	Surrender life to God.
Adaptation challenges	Difficulties in changing habits
	Difficulties in adapting physical alteration
	Financial issues
	Unclear information
Adaptation support	Support from a health professional
	Family support
	Peer support
	Social support
	Governmental support
Needs of newly diagnosed DM	Need for information
	Support to control DM
	Health Access
Expectations of DM patients	Life as healthy people
	New condition

Emotional distress after getting diagnosed.

Legal Information Institute defined emotional distress as mental pain brought on by memories or the repercussions of a specific event, occurrence, pattern of occurrences, or circumstance. Patients diagnosed with DM can experience emotional distress. Patients feel anxious and distrustful and tend to be afraid to carry out daily activities. Patients are so scared of their illness and the choice of appropriate activities. They feel that the activities they undertake will hurt their illness. *I feel scared, sis; this is the most dangerous disease. Most people die from this disease (P4).*

Someone who feels young and lives a healthy lifestyle will feel shocked or in disbelief when diagnosed with DM. This emotional reaction can occur in some patients with minimal medical background or history. *The first time I hit you, I was shocked; I was young; why did you hit me like that? It's true that I used to eat like this, ma'am, when I'm lazy at night, that's what I eat, it's like fried rice, noodles, fast food, fast food, fast food, that's it. This is the worst. I often have dinner. It's*

the best, but my brother hit all of them, just a little bit (P7).

Adaptation process of DM patients

An adaptation process simulates how the human visual system adjusts by gradually adjusting the tone operator to correspond with changes in the scene's luminance, eventually converging to the new average luminance value¹⁵. Being a DM patient brings about changes in one's life process that require adjustments in several areas, both mentally and physically. Patients must learn to control their emotions, monitor their blood sugar, adjust to the foods they eat, become self-motivated, and surrender to God.

One crucial component of managing diabetes is diet. Blood sugar levels will rise as a result of an unregulated diet. Patients with diabetes mellitus frequently struggle to regulate their nutrition, including meal timing, variety, and quantity. *Often twice, I never have lunch; I have breakfast at nine o'clock when I work. It's just after maghrib; it's like eating twice. It's just that eating here is possible if there is fruit; it's like fruit; if there's fried food, it's like fried food. The problem is that it is difficult to get rid of fried food (P10).* The patients must also be able to motivate themselves, another adaptation phase they must go through. Motivating factors might come from outside sources, such as the existing circumstances revealed by test findings or the desire or hope to heal. *I hope to get better because people want to get better; I don't want to do anything, and I don't like to keep taking medicine; it's not good anyway. It's good to eat, you don't have to worry about it. Actually, you want to get well, but diabetes cannot be cured; you have to be careful (P7).*

Adaptation challenges for managing DM

Diagnosing DM requires significant lifestyle changes in patients and their family members. Patients face several challenges in changing their behavior and self-management to manage their disease¹⁶. Patients will find it difficult to adjust to new circumstances, such as receiving a DM diagnosis. Patients confront several difficulties, such as the inability to modify behavior, adapt to physical limitations, financial challenges, and ambiguous information.

Patients with diabetes mellitus need to adhere to self-management principles, which may require them to modify their regular routines. Patients will also see changes in their physical state as a sign of the disease that results from the pathophysiological process. *Alhamdulillah, but when you return, you feel a tingling sensation (back of the neck). It turns out that I didn't do this yesterday; I'm really tired, and my sister-in-law and my nephew keep thinking about it. I'm exhausted, and I keep taking medicine irregularly. He eats irregularly, and eventually, he drops. Blood sugar rose three hundred and four Nine. If the blood is high, it's usually low. Ninety, one hundred, if it's over one hundred thirty, one hundred forty, I'm not strong, ma'am. It's crazy (P4).*

Patients with diabetes can face financial difficulties.

Since diabetes is a chronic condition, long-term care is needed. Despite the availability of government programs for the treatment of chronic illnesses, financial limitations can make it difficult for some patients to practice appropriate self-management. *I'm not a burden because it's like an injury; my activities are still the same. I don't want to have to control it to find out if it's diabetes. I often go to the pharmacy first; yes, once in a while, I check there. Initially, I often had a complete lab here, but the fee was three hundred, so the economic condition was somewhat saved. So once a month, you have to be controlled and checked, and then the ratio is every three months to record your heartbeat* (P10).

Patients with diabetes mellitus frequently obtain information from several sources that may not align with the guidelines for managing their condition. Social media or those close to the patient are the sources of unreferenced scientific knowledge. *I know that people with diabetes can't get it, they can't sleep in the morning, let's eat, they can't sleep, but they don't admit it, let's eat, you must be sleepy, it's a struggle against sleepiness, but Javanese people say let's eat when we're sleepy, that's true. But I'm against it in my heart. If I'm not healthy now, I'm going to get older; if I'm healthy, isn't it healthy? Age is indeed in God's hands, but we have to be able to do it* (P20)

Adaptation support

Every person involved in adjusting to diabetes should have support systems in place. This system refers to an individual's resources and environmental background¹⁷. Support from health professionals, family, peers, social support, and governmental support are the subthemes that support this central theme. Family support is the key to patients' ability to adjust to changes in their health state. This might come in instrumental, emotional, or informational form. *Especially the wife. There is no more because of the effect on this meal. It is obvious from myself how to reduce the amount of food because the rice tends to have high blood sugar; how can I reduce the carbohydrates? Maybe there is a boiled banana to cover the rice or three boiled bananas* (P10).

Healthcare is responsible for helping newly diagnosed DM patients adapt to the changes they will go through. Health professionals must educate patients about the illness and its management. *That's what the nurse was wearing. It's less sweet; drink regular water. What do you give? Like corn? What sugar is that? There is a picture of the corn* (P5). The government also has established a chronic illness control program (prolanis) in health centres to assist patients with diabetes mellitus. This program is one way the government helps people with diabetes mellitus (DM) so they can effectively practice self-management. *Regularly to PROLANIS, never absent. I was told there is a prolanis tomorrow, so I can't be late. I just do it regularly because it's free. It's OK. The two of them were treated together, right? I was told that if you get worse, you won't get better* (P24).

Needs of patients newly diagnosed with DM

Diabetes mellitus (DM) is a metabolic disease with various disorders due to chronic hyperglycemia characterized by complex self-management tasks¹⁸. Patients have numerous requirements, including support, knowledge, and access to medical care. Patients will be able to adjust if these demands are met. Information about the disease and its treatment is the primary need of DM patients when they are first diagnosed. Patients need clear and detailed information. *My blood glucose used to go up and down; it's usually more than a hundred when it's normal. Check blood every three months, but if you need to take medicine every month, it used to be one month, now it's three months. If you want to pay thirty-six thousand once a month, and if you don't have to pay for three months, use health insurance or BPJS* (P26).

Expectations of DM patients

A critical factor in lifestyle control in DM patients is that patients have hope and the ability to find the power to control life¹⁹. Living a healthy life and being able to adjust to changing circumstances is what DM patients aim for. This theme is supported by two subthemes: life as healthy people and adaptation to new conditions. *I hope the sugar is always under control; I can continue to exercise, keep my blood sugar under control, and do normal activities like a normal person* (P2). *Keep up the spirit, keep getting treatment, and ask the powerful so that nothing like this happens to me. It's just that sometimes children and grandchildren don't act like that when they buy cake. Yes, the illness has not been detected yet; the midwife said that's it. It's OK, ma'am, it's OK; I'm so excited from the old food. Then I thought that if you have diabetes, you shouldn't like to work, you're lazy, and I'm not good at it. Sometimes it's like this at home. But later, if you're dizzy, you can't be forced to take a nap. After sleeping, it's good again* (P4).

DISCUSSION

Self-management is the implementation of tasks that a person must strive to live well with one or more chronic conditions²⁰. Diabetes self-management is a set of behaviors undertaken by individuals with diabetes to manage their condition, including taking medication, managing the diet, performing physical exercise, self-monitoring blood glucose, and maintaining foot care²¹. Self-management in diabetes is also defined as self-management behaviors that include diet, exercise, self-monitoring of blood glucose, and taking medication, which is associated with significant improvements in controlling metabolic status¹².

Diabetes self-management is essential to a patient's life to have a better and healthier lifestyle²¹. This is related to increasing diabetes knowledge and disciplined behavior to comply with diet and physical activity recommendations, resulting in better outcomes²². Therefore, all resources must be integrated to

achieve the benefits associated with self-management. Another study's conceptual model provides a framework for integrating resources and support for self-management with key components of clinical care in a diabetes chronic care model²³.

The physiological adaptations of DM patients are various kinds of physiological changes due to the body's reaction to hormonal changes that occur in the body. Signs and symptoms that commonly occur in DM sufferers include urinating a lot (polyuria), drinking a lot (polydipsia), eating a lot (polyphagia), weight loss and feeling weak. Other complaints that can arise are tingling, visual disturbances, itching or ulcers, erectile problems and vaginal discharge²⁴. In this study, these signs and symptoms were also found; however, the signs and symptoms experienced by everyone were different.

The self-concept adaptation experienced by DM patients is a psychological response that occurs because of everyone's reaction to the diagnosis given or as a reaction to the treatment therapy being undertaken. This psychological response may or may not happen; this depends on everyone's ability to cope with the problem. Psychological responses that can occur in participants who experience diabetes mellitus include fear and stress. Interestingly, while many DM patients experience adverse psychological reactions, some studies have found positive psychological responses as well. For example, one study reported that DM patients exhibited resilience and optimism and received social support from family and close relatives despite also experiencing low self-esteem and anxiety²⁵. Another study found that emotional intelligence was related to quality of life in type 2 DM patients, with lower emotional intelligence associated with worse quality of life²⁶.

Psychological factors, such as stress, can exacerbate blood glucose fluctuations, particularly in individuals at risk of or diagnosed with diabetes mellitus²⁷. This study's findings suggest that individuals who perceive their illness as an overwhelming obstacle may experience heightened psychological stress, potentially impacting their glucose control. Conversely, those who view their condition as a manageable challenge and maintain a positive outlook are less likely to experience intense psychological distress related to their illness.

Effective diabetes management hinges on addressing patients' views and beliefs about their condition. Healthcare professionals can significantly contribute by implementing specific interventions to shift patients' perspectives towards seeing diabetes as a controllable illness²⁸. Offering mental health support can help alleviate stress and anxiety, factors known to influence blood sugar levels. Furthermore, providing educational materials can enhance patients' autonomy over their health. By promoting positive coping mechanisms and self-care techniques, healthcare providers can equip individuals with tools to navigate the complexities of diabetes, build resilience, and

enhance overall outcomes in managing their condition.

CONCLUSION

Patients with newly diagnosed diabetes mellitus are facing numerous problems and challenges. They have reported crucial issues that need to be solved to achieve better outcomes for the disease. In addition, patients need support significantly. Support from families, peers, health professionals, and social care helps patients adapt faster to their condition. Further research should investigate the role of peers and health professionals in understanding the patient's needs.

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AUTHOR CONTRIBUTION

Qona'ah A: Conceptualization, Investigation, Methodology, Validation, Review & Editing
 Dewi LC: Conceptualization, Data Curation, Formal Analysis, Methodology, Validation, Visualization, Writing – Original Draft, Review & Editing
 Pradipta RO: Conceptualization, Methodology, Formal Analysis, Validation, and Writing Original Draft, Review & Editing
 Nursalam N: Methodology, Visualization, Writing – Review & Editing, and Supervision
 Mukhtar M: Data analysis

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