

Psychosocial Experience of Patients with Diabetes Mellitus: An Interpretative Phenomenological Analysis

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ABSTRACT

Psychological problems experienced by diabetic patients need to be known and handled properly by health workers because distress will have a negative impact on the patient's diabetes management behavior. This study aims to capture and describe in detail the psychosocial experience of diabetes patients. This research is qualitative research with a phenomenological approach. Purposive sampling was used to select participants who had an experience following the phenomenon and research objectives. The number of participants in this study was 10 participants. This research was conducted in the Malang City Ciptomulyo Health Center area from March to May 2021. The analysis of this research was interpretative psychological analysis (IPA). The four themes of the psychosocial experience found in people with diabetes mellitus are fear and worry when diagnosed with diabetes, sad and disturbed by changes in body appearance and function, social support providing appeasement and self-awareness and support of others for diabetes management. Living with diabetes can be a difficult and overwhelming experience that often leads to fear and anxiety. Furthermore, the physical changes caused by diabetes can disrupt daily routines and affect mental health. Health workers should address both the physical and psychological effects of diabetes and encourage patients to take responsibility for their treatment to improve overall health.

Keywords: Diabetes, fear, psychosocial, self-awareness, social support, stress

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INTRODUCTION

Diabetes mellitus is a metabolic disorder in which the body lacks insulin or experiences resistance to insulin so that the body's ability to utilize glucose, fat, and protein

is disrupted (Dunning, 2013). Currently, diabetes affects many people worldwide as a chronic disease. The International Diabetes Federation (2019) states that the number of diabetics worldwide currently reaches 463 million people. In Indonesia, there is 1 in 16 people aged 20 to 79 years suffer from diabetes. The high prevalence of diabetes has made the Indonesian government stipulate that diabetes is one of the four priority non-communicable diseases in Indonesia (Ministry of Health Republic Indonesia, 2019)

Diabetics are not only at risk of experiencing physical disorders related to diseases such as retinopathy (Mikki et al., 2017), but they are also prone to psychological disorders (Gillani et al., 2017). Several studies show that people with diabetes generally have distress related to their disease (Aljuaid et al., 2018; Bo et al., 2020; Sankar et al., 2018). In addition to experiencing distress, individuals with diabetes are also more susceptible to developing depression (Bădescu et al., 2016). In various studies, such as in the European region, a cross-sectional study conducted on 216 individuals aged 20–45 years with type 2 diabetes in Denmark stated that 24% of participants had high diabetic distress (Bo et al., 2020). Meanwhile, in Spain, out of 3,443 patients with diabetes mellitus, 592 patients (20.03%) experienced depression (Salinero-Fort et al., 2018). Apart from Europe, depression in diabetics is also commonly found in Asia. A study of 893 people in China who suffered from diabetes showed that 56.1% of them

suffered from depressive symptoms (Sun et al., 2016). Another study in South Korea showed that 28.8% of 3540 diabetics as research participants experienced depression (Park et al., 2015). These data indicate that psychological problems such as distress and depression are common in people with diabetes mellitus.

Psychological problems such as distress experienced by diabetic patients need to be known and handled properly by health workers because distress will have a negative impact on the patient's diabetes management behavior. The distress experienced by diabetic patients will reduce the low level of adherence to medication, diet control, physical activity, and overall self-management (Kumar et al., 2017; Quek et al., 2019). Changes in managing this disease will impact controlling blood sugar levels in diabetic patients (Wong et al., 2015). These various factors will then impact the patient's health-related quality of life (Jannoo et al., 2017). Therefore, the worse the emotional distress diabetic patients feel, the lower their quality of life (Gómez-Pimienta et al., 2019)

The impact of diabetes distress on patients' quality of life highlights the need for nurses, particularly psychiatric nurses, to comprehend the psychosocial challenges faced by diabetic patients. One of the responsibilities of psychiatric nurses is to address the psychosocial issues of patients with physical illnesses (Austin & Kunyk, 2019). It is commonly referred to as a liaison (Townsend & Morgan, 2018). Liaison is a psychiatric service that integrates mental

health services into general health services so patients receive holistic care from a physical and psychological perspective (Harrison, 2007). A good understanding of the psychological problems diabetics face will help health workers improve the quality of the interventions provided (Berry et al., 2015).

Existing quantitative research has provided explanations regarding several aspects related to and influencing diabetes distress, such as emotional burden, distress related to treatment regimens, distress related to complications, and distress related to the level of health facilities (Aljuaid et al., 2018; Arifin et al., 2019; Bădescu et al., 2016; Berry et al., 2015; Bo et al., 2020). Previous quantitative research only used a questionnaire to measure physical problems and diabetes-related distress. It may have overlooked the nuanced and personal emotional experiences of individuals. These studies may not fully represent the depth and complexity of these issues, particularly in how they affect patients' daily lives and emotional well-being. Furthermore, there is still a lack of qualitative studies that delve into the psychosocial dimensions of diabetes.

This study used a qualitative approach that could explore these emotional and psychosocial dimensions more deeply by capturing patients' voices and lived experiences. This approach would help to understand the personal and emotional aspects of diabetes-related distress that are not easily quantified, providing a more comprehensive understanding of the issue. By focusing on patient narratives, this

research could uncover underlying themes and patterns that have been underrepresented in previous research, thus addressing a critical gap in the literature.

METHODS

Design

This research is qualitative research with a phenomenological approach. Phenomenology is a method used to understand a phenomenon from the perspective of the participants (Maltby et al., 2010). Therefore, a phenomenological approach is used to comprehensively understand the psychosocial experience of diabetic participants.

The researcher conducted literature reviews to formulate interview questions. The interviewer guide was counter-checked with a mental health nursing expert; thus, it can be considered effective in extracting information from the respondents. In the next step, for interview skills, we studied deep interview techniques, observed interview videos, and practiced the interview skills before starting the research.

Participants and Setting

Purposive sampling selects participants with experience following the phenomenon and research objectives. The number of participants in a qualitative study is determined by data saturation (Creswell, 2012). Data reaches saturation if previous participants repeat and confirm the information, even with different wording (Speziale et al., 2011).

The number of participants in this study was 10. Information was repeated starting from the eighth participant, so the researcher added two additional participants to ensure data saturation. The researcher confirmed that data saturation was achieved with 10 participants.

The study inclusion criteria were as follows: (1) over 18 years old (2) diagnosed with type 2 diabetes mellitus (3) willing to become a participant by signing a consent letter as a participant; (4) physically and mentally healthy; (5) able to communicate well. The exclusion criterion of this study was having more than three complications of diabetes mellitus. This research was conducted in one of the Health Centre areas of Malang City. The research was conducted from March to May of 2021.

Ethical Consideration

Researchers have obtained a permit from the ethical committee of the Faculty of Medicine, University of Brawijaya, with letter number 93/EC>KEPK-S2/03/2021.

The researcher ensures the confidentiality and security of the data by not providing the participants with their names. In addition, the researcher replaced the participant's identity with the initials P1 for participant number one, P2 for participant number two, and so on in the transcript and research report. The researcher will store data in the form of recordings, analysis results, or reports in a safe place for five years, and then the data will be destroyed by deleting each recording result. The researcher provided

a password to open each file containing participant data.

Data Collection

Researchers asked for permission from the Malang City Health Office and the Ciptomulyo Health Center to ask permission to conduct research in the health center area. After obtaining permission from the Community Health Center, the researchers identified potential participants whom Community Health Center nurses and cadres assisted. Then, the researcher determines whether the participants fit the research inclusion criteria. When potential participants meet the inclusion criteria and are willing to participate in the research process, the researcher then explains the intent and purpose of conducting the research in more detail and answers questions from potential participants about the research. After the participants agreed to participate in the study, the researchers submitted informed consent to the participants to be signed. Then, the researcher made an interview contract with the participants.

The research participants decided the time and place of the research interview. The researcher conducted interviews in a semi-structured manner by exploring the participants' psychosocial experiences in depth and recording all the client's conversations with a tape recorder. Researchers use field notes to record non-verbal expressions expressed by respondents. Interviews were conducted in person by implementing health protocols,

namely wearing masks and maintaining distance. The interview ended after the participants answered all the questions according to the interview guidelines. The researcher agreed with the participant to ask permission if the researcher had to contact the participant again by telephone or meet the participant in person if there were important data from the interview that might not be clear. Research interviews were conducted for approximately 60 minutes for each participant.

Data Analysis

The analysis used in this research is Interpretative Psychological Analysis (IPA). IPA is an analytical method to describe one's experience of a particular phenomenon (Smith et al., 2009). So, this method is used to describe the psychosocial experience of people with diabetes mellitus with in-depth interpretation.

The first step in the science analysis is for the researcher to read the research transcript repeatedly. It is done so that the researcher can understand the participant's point of view and ensure that the participant's statement becomes the focus of the analysis. The second stage is the initial recording, in which the researcher looks for the meaning in the participant's sentence. This note includes three things: The first is descriptive comments that focus on the descriptions that participants have submitted. The second is linguistic comments, namely notes on using certain words conveyed by participants. The third is a conceptual comment, an interpretive record of participant statements.

The third stage of the IPA analysis is theme development. The researcher carries out this stage by looking for the essence and important things from the participant's statements and uniting them into something meaningful. These are the themes in the research. The next step is for the researcher to move on to the transcript of the next participant and start analyzing the data as was done with the previous participant.

Trustworthiness

The validity of this research data is carried out in four ways: credibility, dependability, confirmability, and transferability. The credibility of this research was achieved by clarifying the findings of meaningful sentences from the interview results that the researcher perceived to the participants. It is to validate whether the researcher's perceptions of the interview results are based on what the participants expressed. Research dependability is to carry out structured data analysis to interpret the results of this research correctly. Confirmability of this research is achieved by auditing the research data to ensure that it has reached saturation. Transferability in this study was carried out by applying the bracketing principle; researchers set aside all personal interpretations of the phenomenon to be studied, especially when collecting and analyzing data. The researcher fully uses the participant's point of view so that the description of the phenomenon observed is purely from the participant's point of view without any intervention from the researcher.

RESULTS

The characteristics of the participants in this study included age, gender, education, and occupation. The ages of the participants in this study were 30 to 40 years (1 person), 41 to 50 years (3 people), 51 to 60 years (1 person), 61 to 70 years (3 people) and 71 to 80 years (2 people). The gender of participants in this study is two men and eight women. The education of most participants was not graduating from elementary school. Most participants did not have a job. The participant's demographic data are described in Table 1.

Findings from the study were detailed into four themes. Table 2 provides an overview of this research's main theme and sub-themes. The first theme is fear and worry when diagnosed with diabetes. The categories of this theme are fear of fatality from diabetes and fear of having to undergo an amputation due to diabetes. The second theme pertains to feeling sad and disturbed due to changes in one's body appearance and function. It consists of two sub-themes: (1) being sad and disturbed about the change in appearance and (2) being disturbed by changes in body function. The sub-theme of dissatisfaction

Table 1
Participant's demographic data

Code	Age	Gender	Education	Job
P1	65	Man	High School	Pensionary
P2	61	Woman	Undergraduate	Unemployed
P3	74	Woman	Undergraduate	Unemployed
P4	77	Woman	Undergraduate	Unemployed
P5	45	Woman	Junior high school	Unemployed
P6	52	Woman	Undergraduate	Factory workers
P7	43	Woman	Elementary School	Maid
P8	66	Woman	Undergraduate	Unemployed
P9	32	Woman	Elementary School	Unemployed
P10	46	Man	High School	Bank Employee

Source: Authors' work

Table 2
Theme's distribution

Theme	Sub-Theme
Fear and worry when diagnosed with diabetes.	-
Feeling sad and disturbed due to changes in one's body appearance and function.	Being sad and disturbed by changes in appearance
-	Being disturbed by changes in body function
Social support provides appeasement	-
Self-awareness and support of others for diabetes management	Self-awareness Social support for treatment

Source: Authors' work

with changes in appearance was related to looking older and confused about weight loss; the sub-theme disturbed by changes in body function was created under the category of “Disturbed” as it is common to feel tired and disturbed while sleeping due to frequent urination. The third theme is that social support provides appeasement. The theme falls under the category of uplifting conversations with family members, which can boost the mood of the participants and spending time with friends can distract participants from thoughts about diabetes. The fourth theme is self-awareness and support of others for diabetes management, with sub-themes of self-awareness and social support for treatment. The sub-theme category of self-awareness involves efforts to heal oneself and take responsibility for treatment. The sub-theme category of support of others for diabetes management involves the social environment, which encourages participants to seek treatment and family members who accompany them to check their blood sugar levels.

Fear and Worry when Diagnosed with Diabetes

Participants expressed feelings of fear and worry after learning that they had diabetes. Many expressed a fear of mortality, believing that those with diabetes were at a higher risk of death. Some of the other participants shared their concerns about the potential complications of diabetes. The following are participant statements:

“Yes, I’m afraid it’s prone to death. I know diabetes is prone to death....”

I still love to eat delicious food; how come I die.” (P1)

“Yes, I have a little anxiety... For example, I would be like my mother who suffers from diabetes. She can’t walk, now...” (P5)

Sad and Disturbed by Changes in Body Appearance and Function

The theme derived from the participants’ experiences of the changes they faced due to diabetes.

Being Sad and Disturb about the Change in Appearance

Participants stated that they felt sad about changing their appearance after suffering from diabetes. These changes included losing weight and aging.

“What I thought was, it’s sad that my body is small and looks old. My head is wrinkled like an old man. I became skinny. And I used to feel like I had no energy. My body looks so thin and unhealthy.” (P1)

“It turns out that I’m suddenly skinny. My weight suddenly dropped from 58 to 57 and continues to decrease by 1 kilo every month. I’m confused about why this is happening.” (P8)

Being Disturbed by Changes in Body Function

Additionally, the study revealed that participants expressed feelings of sadness and disturbance due to the physical changes

and body functions they experienced as a result of diabetes. Below are some quotes from interviews with the participants:

“If you’re a diabetic, you will get tired easily... When I get tired, I will leave all my housework. That’s how my laundry gets piled up like that. What else can I do? I can’t do it alone.” (P2)

“I keep feeling like my body is losing weight. I’m thirsty, and I keep drinking. I always eat. get hungry easily.” (P10)

“Suddenly, my head began to ache and feel heavy, causing dizziness. It was very unsettling for me.” (P3)

Social Support Provides Appeasement

Participants stated that they felt calm when they received support from their family members and friends. Some notable quotes from participants include:

“My husband was the source of my strength and calmness.... My husband said it was okay, the important thing was treatment. Insyallah, it will be okay....” (P5)

“Yes, my entertainment is when I’m at work. If you’re at the office, you can still talk to your friends, you know.” (P6)

Self-awareness and Support of Others for Diabetes Management

This theme was obtained from participants’ experiences in managing diabetes.

Self-awareness

The participants’ self-awareness is evident in their efforts to recover from diabetes. Here are interview excerpts:

“In the past, while at work, I used to drink Nutrisari with ice when I was thirsty. It used to be refreshing and delicious, but now I only drink water because I prioritize my health.” (P7)

“No, miss. I will just take my medicine myself. I don’t need any reminders. It’s my own responsibility, right?” (P9)

Social Support for Treatment

The social environment, including family and friends, supports proper diabetes management. Excerpts from participant’s interviews:

“Yes, my friend gave me a suggestion. My leader supports my treatment. My wife always reminds me to get regular medication and check-ups so we can monitor my blood sugar level.” (P1)

“Yes, my son-in-law drives me to the hospital every month for check-ups and to pick up my medicine.” (P2)

DISCUSSION

The results obtained in this study show that diabetics have feelings of fear and anxiety due to their diabetes. This feeling can arise from the belief that participants have that diabetics are vulnerable to death. Diabetics experience

emotional burdens such as feelings of anxiety and fear, especially those who do not have a family history of type 2 diabetes mellitus (Arifin et al., 2019). This feeling can arise from the negative perception of diabetics about the dangers of diabetes (Purewal & Fisher, 2018). Besides that, feelings of fear and anxiety that exist in participants can also arise due to the possibility of complications that can arise because of suffering from diabetes. It is in line with previous research that diabetic patients experience anxiety and fear associated with long-term negative consequences such as complications of diabetes and disability due to amputation (Tanenbaum et al., 2016). It shows that intervention is needed to improve coping skills and change the cognitive abilities of diabetics related to their illness. Mental health support, such as stress management skills, is needed by people with diabetes. Studies have shown that diabetes patients who undergo stress management training have lower levels of hemoglobin A1c (HbA1c; Wagner et al., 2016). The HbA1c measures the average blood sugar levels over the past two to three months (Sherwani et al., 2016). Therefore, optimal glycemic control in people with diabetes mellitus occurs when their HbA1c levels are within the normal range (Sherwani et al., 2016). It is important because optimal glycemic control can reduce the risk of microvascular complications in diabetics (Torkamani et al., 2020). Therefore, mental health interventions like this can reduce distress (Fisher et al., 2019) and improve glycemic control in diabetics (Perrin et al., 2019).

Other results of this study indicate that the participants expressed feelings of sadness and disturbance due to experiencing physical changes and body functions after suffering from diabetes. It is in line with previous research, which stated that patients with diabetes mellitus can feel physical pain, weakness, dizziness, and other physical problems due to diabetes, which can cause anxiety and fear (Tanenbaum et al., 2016). It shows that physical disorders that arise in diabetics need to get attention and treatment from health workers. Healthcare professionals should provide exercise education to diabetic patients, as research indicates it can improve their physical health (Cadore & Izquierdo, 2015).

Social support is needed for diabetics. Participants in this study stated that social support provides a feeling of calm and reduces the distress felt due to diabetes. It is consistent with research showing that adequate social support can reduce the emotional distress felt by people with diabetes (Ramkisson et al., 2017). In addition, the social support obtained from the family will provide the patient with practical assistance that can help the patient overcome the distress of living with the disease (Miller & Dimatteo, 2013). Thus, better social support is associated with better patient self-efficacy, improving medical adherence and glycemic control (Shao et al., 2017). It shows that health workers need to involve their family or those closest to the patient in the diabetes management process so that they can provide support in the treatment process.

The results of this study indicate that self-awareness in diabetics, such as their desire to recover and feelings of responsibility, triggers them to take diabetes medication regularly. Previous studies show that self-awareness like this contributes to diabetes medication adherence behavior (Ranjbaran et al., 2020). The results of this study indicate that it is important for health workers to build self-awareness in patients with diabetes mellitus to manage diabetes optimally.

Regimen-related distress is a critical area of diabetes distress that focuses on disease management in everyday life (Hessler et al., 2014). Distress related to regimen is one of the most common distresses found in patients with diabetes mellitus (da Silva et al., 2018). Regimen in diabetes is related to regular use of diabetes drugs or insulin, lifestyle changes, and dietary patterns that need to be followed to control the disease (Dunning, 2013). Therefore, social support is also needed for diabetics to manage diabetes (Dunning, 2013). Participants in this study stated

that the social environment helped them manage diabetes. The support received by participants can be in the form of emotional support, suggestions, reminders of diabetes management adherence, and involvement in the diabetes management process (Dunning, 2013). Such support leads to better diabetes self-efficacy, better medical compliance and, ultimately, better glycemic control (Shao et al., 2017).

The results of this study indicate that people with diabetes feel fear and are disturbed by physical and physiological changes caused by diabetes. Social support and self-awareness in managing diabetes can help overcome these problems. Figure 1 presents a diagram of the relationship between themes in this study.

CONCLUSION

Living with diabetes can be a challenging experience that causes fear and anxiety for many sufferers. They worry about the fatalities of diabetes and the potential complications of the disease, including paralysis and amputation. Additionally,

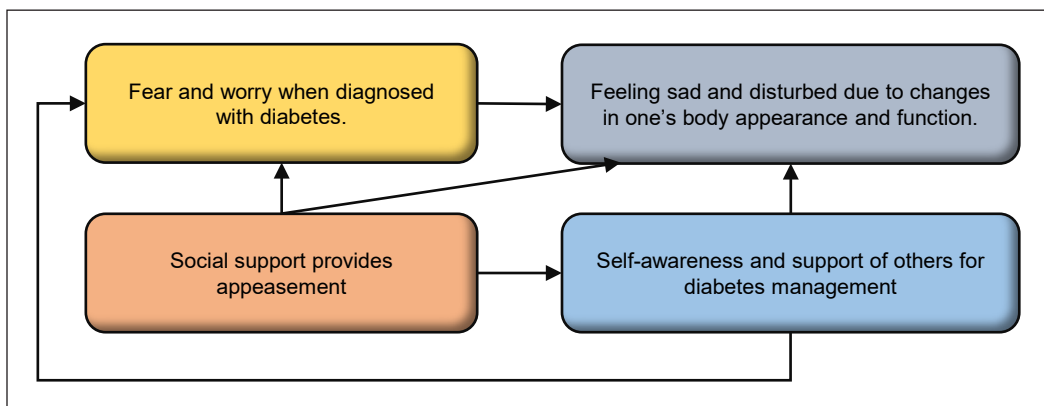


Figure 1. Diagram of the relationship between themes
Source: Authors' work

physical changes brought on by diabetes can disrupt daily activities and impact mental health.

Managing diabetes requires a complex set of behaviors that must be followed daily. However, some people feel a sense of responsibility for managing their condition and are more likely to follow recommended lifestyle changes and take medications. Health workers must provide interventions that address the physical and psychological effects of diabetes and help patients develop a sense of responsibility for their treatment to improve their overall health.

Based on this research, we recommend that clinical applications of our findings include integrating psychosocial care at the initial diagnosis of diabetes. Early psychological support can significantly alleviate the emotional impact and enhance patient management and adherence to treatment plans. This approach not only addresses the medical aspects of diabetes but also the psychological well-being of patients, ensuring a holistic treatment methodology.

For the next research, we suggest focusing on the interventions most needed by people with diabetes, especially to address psychosocial issues. This research could explore the effectiveness of various psychosocial interventions, such as cognitive-behavioral therapy, peer support programs, or stress management techniques, in improving the psychological well-being of individuals with diabetes. It would be valuable to identify which interventions are most effective in reducing stress, anxiety,

and depression among this population and how these improvements can contribute to better diabetes management. This approach could help develop tailored intervention programs that address the psychological and physiological needs of people with diabetes.

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