



What I felt as a diabetes fatigue survivor: a phenomenology study

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Abstract

Purpose Diabetes has resulted in an increase in diabetic fatigue syndrome, which has a negative influence on health, particularly the risk of worsening quality of life (QoL) due to physical and mental limitations. The purpose of this study was to evaluate the experiences of patients with unregulated type 2 diabetes mellitus (T2DM) and diabetes fatigue syndrome.

Methods This study used a qualitative phenomenological design and focused on patients from four primary health centers (PHCs) in Surabaya, Indonesia with higher incidents of unregulated T2DM. Thirty participants were recruited using purposive sampling with the following inclusion criteria: adult T2DM patients, willing to participate in the study, and able to recount experiences associated with their illness. Data collection took place between April and June 2020 across 36 interview sessions. Semi-structured interviews were carried out face-to-face with each participant with the principles of social distancing applied due to the COVID-19 pandemic.

Results Analysis identified five themes and thirteen subthemes. The first theme was participants' experiences during blood glucose imbalance. Other themes included experiences of boredom with diet, physical and psychological distress, financial problems during treatment, and sexual problems.

Conclusion Participants with T2DM who experienced diabetes fatigue reported negative effects on their life, especially on health, functional daily activity, and finances. The results of this study can provide information for nurses and other healthcare providers to promote interventions for patients with T2DM, such as modifying lifestyle, self-acceptance, and self-efficacy.

Keywords Blood glucose · Diabetes mellitus · Fatigue syndrome · Glycemic control · Phenomenology

Introduction

Indonesia ranks sixth in the world of countries with the highest rates of diabetes mellitus (DM) [1], and has one of the highest rates of new diabetes mellitus cases among South-east Asian countries [2, 3]. Type 2 diabetes mellitus (T2DM) is the most common type of diabetes, accounting for 90% of all cases [4]. This illness has resulted in an increase in diabetic fatigue syndrome, which has a negative influence on health, particularly worsening quality of life (QoL) due to physical and mental limitations. Symptoms can be debilitating and require patient adherence to complex management techniques that must be maintained on a regular basis [5].

Diabetes fatigue syndrome is a distressing problem among T2DM patients that causes physiological abnormalities such as hypoglycemia, hyperglycemia, or large swings between the two [6]. Fatigue may also be connected to psychological issues such as emotional anguish brought on by a diabetes diagnosis or the severity of diabetic self-management

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regimens [7]. Fatigue can also be connected to lifestyle variables like low levels of physical activity or obesity, which is common in patients with T2DM [8]. Fatigue can also be caused by the long-term effects of diabetes or other common comorbidities such as sleep issues, pain, depression, and obesity, which are frequent in patients with T2DM [9].

Along with the physical challenges of fatigue, T2DM patients face mental difficulties [10]. Burnout with diabetes treatment can lead patients to ignore it resulting in the condition getting worse and patients entering unregulated treatment. Unregulated treatment can prevent patients from getting a clear understanding of fatigue and how to overcome it. An improved understanding of diabetes fatigue is needed to help T2DM patients manage the negative effects of health changes and enable them to become more self-sufficient [11].

There are few published qualitative studies from Indonesia that address diabetes fatigue and its consequences. Previous studies mention that fatigue in diabetes patients comes from internal distress and the most common coping mechanisms are spirituality and acceptance along with healthcare assistance [12, 13]. Physical responses also result from changes in the activity of people with diabetes mellitus after diagnosis [14]. Both studies mention fatigue but do not examine the viewpoints and experiences among unregulated T2DM patients. Diabetes has emerged as a severe public health issue in middle and high-income countries, including Indonesia, and numerous cultural factors continue to influence diabetes management [3]. Therefore, cultural beliefs and environmental conditions should be explored because they can impact diabetes fatigue [15].

Exploring fatigue from the perspective of unregulated T2DM patients will not only provide actual information about fatigue in this population but also help identify barriers to prioritizing treatment goals. It would also help in the development of methods tailored to the culture and adjusting methods to the requirements of Indonesian T2DM patients. The purpose of this qualitative research is to learn more about the experiences of unregulated T2DM patients.

Methods

Design

This study was conducted using a qualitative approach to explore and understand the phenomenon of unregulated T2DM patients. Descriptive phenomenology is used to acquire an understanding of the true meaning of a phenomenon of interest through engaging in-depth with that reality [16–18]. This approach allows researchers to collect detailed data and deeper insights into phenomena of interest.

Participant and setting

The participants in this research were 30 T2DM patients who were recruited from primary health care providers using a purposive sampling method. The inclusion criteria were: adult patients (over 18 years) with T2DM, willingness to participate, and ability to recount experiences associated with their illness. The data collection took place between April and June 2020, with a total of 36 interview sessions. The time and place of the interview were established through an agreement with each participant. This was done because the participants came from four different primary health care centers (PHCs), in Surabaya, Indonesia, namely Asemrowo Health Center, Kedungdoro Health Center, Pucangsewu Health Center, and Tanah Kalikedinding Health Center. These PHCs were chosen because had a higher prevalence of unregulated T2DM. Interviews were carried out at the participant's house or at the PHCs, whichever made the participant feel most comfortable during the interview and where patient privacy could be maintained.

Ethical considerations

This study received ethics approval from the Health Commission Ethics Committee of the Faculty of Nursing, Universitas Airlangga, Indonesia (2092-KEPK). Participants were required to give their written informed consent to participate free of coercion and indicate their willingness to be recorded during the interview. They could withdraw from the study without giving reason, and with no impact on their health care, and could decline to answer any of the questions. Furthermore, the researchers maintained participant privacy throughout the interview process. The data was de-identified at the time of transcribing, with participants named according to a number such as P1, P2, and so forth. The study did not have the potential to harm the participants physically or mentally.

Data collection

Semi-structured interviews were conducted between April 2020 and June 2020 by three researchers. Each interview commenced with introductions and then consent was obtained including permission to audio-record the interview. The researchers followed the principles of social distancing due to the COVID-19 pandemic when the face-to-face interviews took place. They also used interview guidelines, field notes, and an audio recorder. The authors designed the content of the questions to capture the T2DM patient experience and develop a better understanding of diabetes fatigue. The content of the questions was reviewed by three experts

(one medical doctor who specializes in internal medicine, one lecturer of nursing with a medical and surgical specialty, and one nurse employed at a public health center). The interview questions focused around “How does the patient feel about diabetes fatigue?”, “How does diabetes fatigue affect daily activity”, and “How can patients adapt to the changes caused by fatigue?”

To ensure the validity and reliability of the content of the questions, we performed interviews with three patients with T2DM. After that, we identified which questions were challenging for participants to understand and revised them accordingly. Each interview began by building trust between the participant and interviewer. The interviews then proceeded with questions covering their experience as a patient with unregulated T2DM. Each participant was interviewed for approximately 40–60 minutes. In addition to recording the interview, the interviewers also took notes of their observations.

At the end of each interview, the interviewer summarized what the participant had said to confirm they had accurately understood; however, no participant made any changes at this point. Triangulation of the interview and fieldwork observation data was undertaken to enrich the data [19]. Recruiting additional participants ceased when the data reached saturation. Data saturation is obtained when the answers of new participants are matching those of earlier participants and no new themes are identified [20–22].

Data analysis

Data analysis followed the seven steps of Colaizzi and included reading the transcript, listening back to the transcript of interviews, selecting keywords, classifying categories, creating narratives, and seeking validation from the participants about their actual experiences compared with the researchers’ transcribed interview data.

The second step in the analysis was to code meaningful sentences using NVivo version 12 software, group the data into sub-categories, and develop the categories. The third step was to formulate the themes based on the categories. Findings were discussed by the researchers at a regular weekly meeting. The final step was to present the themes with quotes from the participants.

Trustworthiness

A qualitative investigation must be credible in order for the findings to be meaningful. Credibility, dependability, transferability, and conformability are used to increase the rigor of qualitative research [23]. To maintain credibility, participants in this study engaged in extended discussion and informal member-checking. The transferability section of the study contained a thorough discussion of the participants,

procedures, and study setting. To ensure dependability, we managed the data using NVivo 12 software, and all researchers took part in the study. Finally, for conformability, data was checked and rechecked and the interpretations were constantly shared and discussed with all researchers. To enhance the quality and transparency of the study results and the associated reporting, the researchers applied the Standards for Reporting Qualitative Research (SRQR) [24].

Results

A total of 30 participants participated in this study consisting of 18 women and 12 men. The average age of the participants was 45 years (range 33–65 years). Most of the participants ($n = 15$) had some level of high school education, nine participants had a high school education, four participants had a junior high school education, and only two participants had a primary school education. Most of the participants were married ($n = 21$), 10 participants were not married, and two participants were divorced. All the participants had been diagnosed with DM for a minimum of two years. Table 1 details the data for each participant.

Five themes emerged from the analysis related to the experiences of people with unregulated T2DM. The themes were (1) blood glucose imbalance, (2) boredom with diet, (3) physical and psychological distress, (4) financial problems, and (5) sexual problems (Table 2). The following is a description of each theme and the relevant signposted participant quotes.

The experience during blood glucose imbalances

Based on the results of the interview, it was found that participants have blood glucose imbalances due to non-adherence to diabetes treatment. During the theme analysis, four sub-themes were identified, including 1) irregularly taking medication, 2) irregularly attending public health centers, 3) dehydration, and 4) unstable blood glucose.

Irregularly taking medication

As time passes, participants can feel bored with their condition. They sometimes forget to take the medication or stop taking the medication completely (Quotes 1–2).

Irregularly attending public health center

Participants who feel bored with their condition tend to not obey the treatment. This includes unwillingness to go to the primary health care center as they feel it will not change anything and it is best not to go because the condition will be the same (Quote 3).

Table 1 Demography characteristics (n = 30)

Initials	Type Sex	Age (Year)	Status Marriage	Education	Work	Long Suffering from Diabetes
P1	Man	41	Married	senior high school	courier	2 years
P2	Woman	36	Married	university	housewife	2 years
P3	Man	39	Married	university	private	2 years
P4	Man	39	Not married yet	university	contractor	2 years
P5	Woman	57	divorced	junior high school	housewife	2 years
P6	Woman	35	Married	university	teacher	2 years
P7	Man	43	Not married yet	senior high school	entrepreneur	2 years
P8	Man	65	Married	senior high school	retired	3 years
P9	Man	53	Married	university	entrepreneur	2 years
P10	Woman	65	Married	primary school	housewife	3 years
P11	Woman	40	Married	junior high school	entrepreneur	2 years
P12	Woman	42	Not married yet	university	entrepreneur	2 years
P13	Woman	34	Not married yet	university	entrepreneur	2 years
P14	Woman	45	Married	senior high school	housewife	2 years
P15	Woman	33	Married	university	housewife	2 years
P16	Man	45	Married	senior high school	entrepreneur	2 years
P17	Woman	42	Not married yet	university	student	2 years
P18	Man	34	Married	university	private	2 years
P19	Man	39	Not married yet	university	entrepreneur	2 years
P20	Woman	57	divorced	junior high school	housewife	2 years
P21	Woman	41	Not married yet	university	private	2 years
P22	Man	43	Not married yet	senior high school	entrepreneur	2 years
P23	Man	65	Married	senior high school	retired	3 years
P24	Man	53	Married	university	entrepreneur	2 years
P25	Woman	65	Married	primary school	housewife	2 years
P26	Woman	40	Married	junior high school	housewife	2 years
P27	Woman	42	Not married yet	university	entrepreneur	3 years
P28	Woman	34	Not married yet	university	entrepreneur	2 years
P29	Woman	45	Married	senior high school	housewife	2 years
P30	Woman	38	Married	university	private	2 years

P: Participant

Dehydration

Participants may suffer from side effects if they do not follow the treatment. Unregulated blood glucose leads to dehydration. When blood sugar increases, the body then excretes more urine to balance the concentration of fluids. Therefore, an increase in blood sugar levels also triggers dehydration (Quotes 4–5).

Unstable blood glucose

Blood sugar levels can rise due to insulin resistance and non-adherence to diabetes medications. Participants may get confused because they are already taking medications regularly but their blood glucose is still unstable (Quotes 6–7).

Boredom diet experience

Dietary adherence of DM patients plays an important role in stabilizing blood glucose levels, while compliance itself is important to developing routines (habits) that can help patients follow a diet schedule. Unfortunately, participants can feel bored with the treatment, especially the diet. There are two themes relating to boredom with diet, including 1) unwillingness to follow the diet program, and 2) the habit of eating together.

Unwilling to follow the diet program

Dietary compliance is an important thing and developing routines (habits) can help patients follow their diet schedule. Participants who do not comply with diet therapy can experience uncontrolled sugar levels. However, most participants

Table 2 Distribution of themes and sub-themes (n=30)

Themes	Subthemes	Quotes	
The experience during blood glucose imbalance	- Irregular taking of medication	Q1: “I’ve never taken diabetes medication... I’m tired of having to take medication continuously” (P3). Q2: “Sometimes I forget to take the diabetes medication... maybe I’m bored sir... so I take medication if I remember...” (P2)	
	- Irregular taking control in public health center	Q3: “I’m lazy to go to the public health center... apart from being far away, the drugs and therapy given are just as usual... so I’m lazy. I just leave it to God. If it doesn’t cure, then just let it be...” (P13).	
	- Dehydration	Q4: “Every night, I used to drink more than 5 times... so I often urinated at night...” (P9) Q5: “I’m confused... why do you drink water every night. I’ve been drinking a lot of water... many times... but I still feel thirsty...” (P17)	
	- Unstable blood glucose	Q6: “My blood sugar is sometimes low, sometimes normal, and sometimes high... not sure...” (P3) Q7: “I’m tired... I’ve been taking medicine regularly, but my blood sugar is unstable... sometimes it goes up... sometimes it doesn’t... I’m confused about this disease” (P7)	
	Boredom with diet experience	- Unwilling to follow the diet program	Q8: “If I am hungry... I will eat... I don’t think about my illness (DM) anymore... the important thing is that I’m full and my mind is calm” (P29) Q9: “everything that my wife cooks, I must eat everything... I feel sorry if I don’t eat my wife’s food... so I’ll just eat it... blood sugar will go up or not... I’ll think about it later hehe (laugh)...” (P32) Q10: “when I’m sick, I often feel hungry sir... so I just eat when I’m hungry” (P19)
- The habit of eating together		Q11: “Here (where I lived) usually we ate together... thanksgiving and eating together... so yes I eat everything... eat with the other neighbors” (P20) Q12: “Usually every month, we ate together... so I ate together... about blood glucose, I’ll just take the medicine” (P2)	
Physical and psychological distress		- Emotions out of control	Q13: “Honestly sir... my emotions are unstable during this illness (DM)... I get angry more often... I’m disappointed... this pain doesn’t get better soon... so I asked God, what’s wrong with me? Why did God give this pain to me...” (P16) Q14: “I can’t control my emotions... I often get angry with my wife... but after that I regret it... I’m also confused as to why my emotions are getting more and more unstable... To be honest, sir, I’m tired and tired of being sick (DM) this” (P28) Q15: “I feel unstable emotions... such as irritability, sometimes also sad for no reason... is it possible that people with DM are always like this?” (P34)

Table 2 (continued)

Themes	Subthemes	Quotes
	- Desperate	Q16: “I’m often sad and think why this pain can’t get better soon... I’ve also thought about committing suicide... I feel hopeless. My life can’t be like it used to be...” (P39) Q17: “... already desperate... already taking medication regularly... but still this disease (DM) is not getting better. I’m tired of going through all of this, sir... now I just give up. I don’t know if I can recover or not” (P17).
	- Sleep disorder	Q18: “Recently I have nightmares more often... I also wake up often during sleep and my body feels very tired” (P37). Q19: “Every night I often wake up...because I am thirsty and urinate frequently. My sleeping hours seem to have changed... during the day... I’m often sleepy. While almost every night, my sleep is often disturbed” (P31)
	- Tiredness	Q20: “My activity pattern tends to decrease sir. I get tired more easily when I do something... My friend said, people with DM are like this... so I think it’s normal” (P27) Q21: “I feel tired easily it’s been quite a while. For the past 1 year or so, I have been more easily tired and sleepy. My productivity is also disturbed...” (P12)
Financial problems during treatment	- Low income	Q22: “During this diabetes illness, I was no longer working... because my legs were hard to stand for a long time... because I used to work in a factory and had to stand for a long time... but now I can’t work because of this illness” (P23) Q23: “I’m sad because I can’t work anymore... my wife also has to work... because the finances at home are also declining. I have also worked, but when I found out that I had diabetes, my working hours were reduced, and my salary was also deducted” (P38) “Q24: “Children need money for school, to pay for tutoring, to eat snacks at school too... while I am sick and can’t work... if everything has to be borne by my wife, I feel bad... but I am also confused about what to do, sir.” (P39).
Sexual problems	- Sexual desire	Q25: “From the beginning I was sick with diabetes, in the past year, I have felt a decrease in my desire to have sex. Hmmm... I feel like I don’t have any desire sir. I get tired easily too” (P29). Q26: “I’m also confused, why do I become less lustful with my wife... even though it wasn’t like this before hehe (laugh)” (P33).
	- Erectile problems	Q27: “Honestly sir... I also have erectile dysfunction. I am ashamed of my wife” (P32) Q28: “Erection quality has decreased sir... not like it used to be... not as strong as it used to be, besides that it also comes out quickly. I even took drugs so I could have sex with my wife” (P18)

Q: Participant’s quote

P: Participant

can become unwilling to follow the diet program and choose to eat what they want (Quotes 8–10).

The habit of eating together

Participants have a culture of eating together with friends or family. Participants will sometimes not follow the diet and eat any available food during Thanksgiving or other occasions. To keep blood glucose under control on those occasions, participants take diabetes medication after eating (Quotes 11–12).

Physical and psychological distress

Patients with diabetes are very susceptible to stress. If not handled properly, the stress experienced by DM sufferers can lead to health conditions in the long term. Stress can produce psychological and physiological changes. There are four sub-themes of physical and psychological stress, including 1) emotions out of control, 2) depression, 3) sleep disorder, and 4) tiredness.

Emotions out of control

Significantly elevated blood sugar levels in diabetic patients can cause mood swings. Treatment conditions that have many rules are tiring to carry out and can make the patient feel constantly worried, stressed, and emotional (Quotes 13–15).

Depression

Diabetes is a chronic disease that requires long-term treatment and there are many rules that must be obeyed. This can trigger a sense of hopelessness for people with DM about achieving their recovery (Q16-17).

Sleep disorder

High blood sugar levels can interfere with patients being able to sleep well due to the frequent urge to urinate at night. Sometimes they can also experience excessive thirst. Sleep disturbance is a common problem that occurs in DM patients, while DM itself can also cause sleep disturbances due to complaints of nocturia and pain (Quotes 18–19).

Tiredness

Even though patients with DM2 are not doing strenuous physical activity, patients often feel tired. This tiredness can be caused by sugar levels being too high or too low (Quotes 20–21).

Financial problems during treatment

In patients with DM, it is very important to protect assets to maintain financial conditions for personal, family, and disease treatment needs. One subtheme for financial problems is low income.

Low income

Financial management is very important for diabetic patients and must be managed properly because the burden of expenses increases, not only for family needs but also for medical needs. Difficulties in financial management can make patients with DM become stressed and unable to focus on their treatment (Quotes 22–24).

Sexual problems

Diabetes can damage blood vessels, which affects blood flow to the penis. This condition can trigger erectile dysfunction or loss of a man's ability to achieve and maintain an erection. Diabetes can also cause nerve damage, which makes it harder for men to maintain an erection. Two themes emerged in this study relating to sexual desire and erectile problems.

Sexual desire

Elevated blood sugar in diabetic patients can block blood flow to sensitive areas and intimate organs. As a result, DM patients can find it more difficult to become aroused and sexual desire can also disappear prematurely (Quotes 25–26).

Erectile problem

High levels of sugar in the blood can damage the natural function of blood vessels, so patients with diabetes cannot get an erection optimally. A participant may even need to take medication to get an erection (Quotes 27–28).

Discussion

In this study, we learned more about the experiences among unregulated T2DM patients with diabetes fatigue syndrome. We identified five themes that provide important information based on the experiences of unregulated T2DM patients, including the experience of blood glucose imbalance, boredom with diet, physical and psychological distress, financial problems, and sexual problems.

Blood glucose imbalance in patients with T2DM occurs because the patient does not follow the treatment properly. Patients who have been diagnosed with diabetes for a long time can become bored with following the regimen

obediently leading them to ignore the schedule for taking medication and skip visits to health services. These results are in accordance with a previous study that showed a tendency for patients to not believe in the recommended treatment and take treatments based on their own judgment [25]. One of the barriers to diabetic patients adhering to the regimen is their concerns about lifelong care. Patients think it is not necessary to remain obedient because diabetes cannot be cured [11, 22]. Although the two studies did not limit how long the patients had diabetes or the type of diabetes, both studies gave the same results that blood glucose imbalance is caused by patients' unwillingness to follow therapy.

Patients with T2DM also feel bored with the dietary requirements. Patients can know that dietary regulation is important to keep blood sugar stable, but will violate these rules at times because they are bored with the food choices. When participating in social activities patients cannot comply with the diet because the food menu is not appropriate. Following dietary rules can be difficult and preparing food according to a specific menu can lead patients to feel lazy and choose the available food [26]. In this regard, social gatherings are a barrier to patients adhering to their diet. A previous study found that T2DM patients sometimes get pressure from relatives or friends during social gatherings. Every now and then, not complying with the diet is acceptable and will not have a significant effect on health conditions [27].

There are many rules that must be obeyed by T2DM patients, and some patients find these rules inconvenient to implement. However, because they do not have a choice, patients feel forced to comply with these rules. In the end, patients feel stress, both physically and psychologically. Both of these forms of stress cause negative changes, such as the patient being more emotional, feeling hopeless, experiencing sleep disturbances, and feeling tired quickly [28]. The appearance of one symptom can affect other symptoms. Cumulative 10-year incidences of high levels of depressive symptoms in diabetic patients shows that stress and depressive symptoms are often triggered by the burden of managing diabetes [29] and environments that are unsupportive of treatment requirements [30].

Economic problems are one of the reasons patients become uncompliant with diabetes treatment. Patients have barriers to being able to get treatment and healthy food. A previous study of T2DM patients found that some struggle to meet basic needs. Such patients rarely check their blood sugar and eat foods that deviate from the diet plan [31]. Another study found that the main aspects of care that participants described as impacted by financial barriers were drugs, diabetes supplies, and healthy food [32]. This problem cannot be directly solved by health workers, but health workers have an important role in helping to identify barriers and minimize the impact of these obstacles.

Unregulated diabetes results in disruption of blood vessel flow. The perceived impact on the patient is a decrease in sexual arousal and erectile dysfunction. Diabetic patients are prone to various types of physical and mental disorders and treatment of sexual dysfunction is often neglected in these patients [33]. Psychological disorders, especially depression, cause sexual dysfunction in diabetic patients [34, 35]. Sexual dysfunction in female DM patients occurs due to a decrease in clitoral blood flow due to high and uncontrolled blood sugar [36]. Although both studies focused more on women, sexual disorders in diabetics had a real and significant impact, especially psychologically, with additional impacts on disharmony in domestic life.

Increasing self-efficacy in patients with diabetes fatigue is significant. With good self-efficacy, patients can improve their ability to manage diabetes well [37, 38]. In addition, self-efficacy can be the basis for patients to accept their illness so that the acceptance process can positively impact the healing process. Previous research has stated that with good self-efficacy and self-acceptance, diabetes self-management can be done well and affects controlled blood sugar [39–42].

Diabetes fatigue syndrome occurs in T2DM patients who continue to ignore their health conditions. However, patients may still face obstacles to complying with diabetes care. These barriers have a physical and psychological impact and are at risk of worsening the patient's quality of life. Adequate support is needed from the patient's family and health workers to provide reminders for the patient and provide motivation to continue to carry out diabetes care.

Conclusion

Diabetes fatigue syndrome occurs in T2DM patients who continue to ignore their health conditions. This study found that diabetes fatigue had a detrimental impact on participants with T2DM's quality of life, particularly on their health, ability to function in everyday life, and financial situation. On the other hand, patients still experience many obstacles to complying with diabetes care. These barriers have a physical and psychological impact that can worsen the patient's quality of life. Adequate support is needed both from the patient's family and health workers to continuously remind the patient and provide motivation to continue to carry out diabetes care, alter lifestyle, and encourage self-acceptance and self-efficacy among people with T2DM.

Declarations

Conflict of interest The authors declare that there are no competing interests in this study.

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