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Self-Care Behavior of Type 2 Diabetes Patients with Symptoms of Peripheral Neuropathy during the Covid-19 Pandemic: A Qualitative Study

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ABSTRACT
Purpose: This study aims to explore the experiences and perceptions of type 2 diabetes patients with symptoms of Diabetic Peripheral Neuropathy (DPN) in managing their self-care behavior during the COVID-19 pandemic.
Methods: Qualitative research with a descriptive phenomenological approach reveals diabetes self-care behavior during the COVID-19 pandemic. Individual interviews were conducted at the participants' homes with a semi-structured interview guide on twelve type 2 diabetes patients. All interviews were transcribed verbatim and analyzed using thematic content analysis.
Results: A total of five themes were identified from the interview analysis, namely: 1) Perception of diabetes self-management; 2) Efforts to control blood sugar; 3) Barriers to blood sugar control; 4) Perceived disturbance; 5) Social support. Since its emergence, the Covid-19 pandemic has become a new obstacle in controlling blood glucose in diabetic patients. In addition to the covid-19 pandemic, negative spiritual coping, low self-motivation, and perceived physical effects are inhibiting factors for blood glucose control in type 2 diabetes patients with symptoms of DPN.
Conclusions: Obstacles in efforts to control blood glucose in type 2 diabetes patients with symptoms of DPN include physical, psychological, social, and spiritual aspects. The suggestion in this study is that during the COVID-19 pandemic, it is necessary to adjust and modify diabetes self-management for patients with DPN symptoms. The interventions provided should not only focus on the physical aspect but also need holistic attention to the psychosocial and spiritual aspects simultaneously by involving family participation in the management of the patient's diabetes.

KEYWORDS: Diabetes Peripheral Neuropathy, Qualitative Method, Self-care behavior, Type 2 Diabetes.

BACKGROUND

The COVID-19 pandemic has become a new obstacle in the management of diabetes self-care behavior. It has had an impact in the form of worsening glycemic control in elderly patients with type 2 diabetes which is characterized by high blood glucose[1].Uncontrolled glycemic levels are caused by poor self-care behaviors that are exacerbated during the pandemic such as limited physical activity, poor dietary habits, and impaired medication adherence[2].

The practice of self-care behavior of type 2 diabetes patients in some countries is still low. A study at a rehabilitation center in Saudi Arabia found that diabetic patients rarely do sports and check blood sugar activities[3]. Likewise, a study in Kenya found a lack of self-management practices in diabetes patients in terms of carbohydrate diet regulation[4]. Several studies stated that the self-care behavior of type 2 diabetes patients in Indonesia was still low. A study at the Bandung City Public Health Center found that the majority of type 2 diabetes patients (52.2%) had inadequate diabetes self-care behavior[5]. The presence of peripheral neuropathy also reduced the interest of diabetic patients in self-care[6].

Diabetic peripheral neuropathy (DPN) is the most common complication in diabetic patients. Between 9.6 and 88.7% of people with diabetes around the world have DPN[7]. As many as 30-50% of diabetes patients are reported to have complications of DPN [8]. In Southeast Asian countries, the prevalence of NPD is also relatively high, such as Malaysia (54.3%), the Philippines (58.0%), and Indonesia (58.0%)[9]. DPN is a late complication of long-lasting high blood glucose levels [8].

Preventing complications from diabetes requires effectively identifying barriers and changing patients' and healthcare providers' perceptions of the risks associated with the disease. To choose the best care interventions, nurses must understand patients' opinions and experiences of their overall health situations [10]. However, holistic research covering the psychosocial and spiritual aspects of DPN patients is still limited. Several studies have identified psychological disorders in DPN patients, including

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depression, anxiety, fear, lack of sleep, and low quality of life[11–13]. Research to explore the spiritual aspect is still limited. In addition, identifying experiences and perceptions of diabetes self-care behavior during the Covid-19 pandemic is essential. Therefore, this study was conducted to explore the experiences and perceptions of type 2 diabetes patients in holistic diabetes self-care behavior on the physical, psychological, social, and spiritual aspects and the obstacles during the Covid-19 pandemic.

METHODS

Research design

The qualitative method explored how the experiences and perceptions of type 2 diabetes patients with symptoms of DPN when managing their diabetes. Data collection was conducted by a researcher as a critical instrument. Qualitative interviews describe, understand, and analyze structured data to determine the essence of experiences, perceptions, and barriers to self-management of diabetic patients. Interviews were conducted face-to-face in person using semi-structured questions.

Setting and participants

The interview sessions were conducted at the participants' homes (October-November 2020) in Kendari City. Covid-19 health protocols during the interview session (keeping a distance from participants and wearing masks) are still being observed. Participants were patients with type 2 diabetes who a doctor had diagnosed, with inclusion criteria: over 18 years of age; experience loss of protective sensation on monofilament 10g examination, at least one of three points on each sole[14,15]. Participants with comorbidities such as severe heart disease, severe hypertension, renal failure, and severe visual impairment were excluded. The number of participants was 12 people[16,17]. The selection of research participants used the purposive sampling technique.

Assessment tool

The study used a semi-structured interview guide (Table 1). More in-depth information from participants was explored using an open-ended approach. Interview questions were related to participants' perceptions of diabetes self-management, experiences during diabetes, diabetes self-care practices, obstacles faced, and perceived support.

Table 1. Interview guide

Specific purpose	Questions
Get a description of the perception of self-care management of diabetes.	What do you know that needs to be done in to manage diabetes or lowering blood sugar?
Identify experience in managing diabetes during the COVID-19 pandemic.	What have you done to manage diabetes or lower your blood sugar during the COVID-19 pandemic? What is the easiest way to manage your diabetes? What is the reason? What is the most challenging thing in managing your diabetes? What is the reason?
Identifying barriers and supports in self-care management of diabetes during the COVID-19 pandemic.	I. **DOES ANYONE HELP YOU REGULARLY WITH MANAGING DIABETES?** **II. WHAT IS THE ROLE OF THIS PERSON IN HELPING TO MANAGE YOUR DIABETES?** **III. WHAT ARE THE PERCEIVED OBSTACLES IN MANAGING YOUR DIABETES DURING THE COVID-19 PANDEMIC?** **IV. WHAT ARE THE COMPLAINTS YOU FEEL THE MOST NOW AND ARE THERE FEELINGS OF FEAR/STRESS/ANXIETY FROM WHAT YOU THINK HINDERS YOUR ACTIVITIES?** What can be done to overcome these feelings?

Tool development and validation

The interview guide was developed from some of the existing literature [18],[19] and discussed with two academics and one diabetes care practitioner. A pilot study was conducted to pre-test interview questions. An interview questions trial was conducted on two Government Health Center nurses and five diabetic patients, and all stated the questions were clear and easy to understand.

Interview process

The interview was conducted by the principal investigator. The average interview session lasts about thirty minutes. Before starting, participants explained the purpose of the study, then the foot sensation was examined using a monofilament test. If they

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meet the criteria, participants are given a structured questionnaire containing demographic data, information sheets, and a consent form. Random blood sugar (RBS) was also checked. Furthermore, interviews were conducted with participants. A voice recorder on a mobile phone was used to record conversations during interviews.

Ethical considerations

Research ethics approval was obtained from the Ethics Commission of the Indonesian Association of Public Health Experts (IAKMI) Southeast Sulawesi Indonesia (134/KEPK-IAKMI/X/2020) before the study began. All participants asked for informed consent before the start of the interview.

Data analysis

For verbatim transcription, all interviews were recorded. The principal investigator transcribed all interviews to avoid bias. Participants were allowed to validate the accuracy of the transcripts and proceed with data analysis after approval. The principal investigator recorded the raw data thematically and then develops these themes with other research teams to ensure reliability and trustworthiness[20]. Each transcript was read repeatedly by two experts to identify common themes. All researchers discussed emerging themes to complete the analysis. Then the principal investigator continued to interview other participants until they did not get any new information which meant that saturation had been reached[21].

RESULT

Characteristics of Respondents

A total of twelve type 2 diabetes patients with symptoms of DPN, aged between 35-62 years (P1-P12) were interviewed. Participants were dominated by women (n = 10), married (n = 11), and widowed (n = 1). As many as 75% (n = 9) of respondents said there was a family history of diabetes and seven respondents (58%) had diabetes duration > 5 years. The mean of random blood glucose (RBS) was 274 mg/dl with SD=74 mg/dl. The demographic and clinical characteristics of participants can be seen in table 2.

Table 2. Demographic and clinical characteristics of respondents

Characteristics	N	%
Sex		
Man	2	17
Women	10	83
Age (years), mean (SD)	55 (7,8)	
Marital status		
Married	11	92
Not married yet	0	0
Widow	1	8
Socioeconomic status		
Monthly income		
Low < 2,000,000 IDR (< 134 USD)	4	33
Moderate 2,000,000 – 3,000,000 IDR (134 USD-200 USD)	6	50
High >3,000,000 IDR (≥ 200 USD)	2	17
Family history		
Yes	9	75
Not	1	8
Do not know	2	17
Diabetes duration		
≥5 years	7	58
<5 years	5	42
Random Blood Sugar (mg/dl), mean (SD)	274 (74)	

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Research Themes

Five main themes were found, namely: 1) Perception of diabetes self-management; 2) Efforts to control blood sugar; 3) Barriers to blood sugar control; 4) Perceived disturbance; 5) Social support.

First Theme: Diabetes Self-Management Perception

When the participants were asked about their opinion on managing diabetes or lowering blood glucose, two participants who had diabetes >5 years, revealed the fewer benefits of exercise, maintaining a healthy diet, and taking medication. Participants revealed that there was no perceived change even though they had followed the advice of health workers.

"….I think there is no change; finally I stopped, I don't exercise, I don't take care of my diet, but I just eat….." (p1).

"...Now I don't abstain, I eat anything like meat, whatever I eat...my friend avoids all food, and he dies too….." (p6).

Lack of knowledge about the benefits of diet and medication, dominated by participants with a duration of diabetes ≤ 5 years and low socioeconomic level. A total of three participants expressed their ignorance about the importance of maintaining a healthy diet and taking regular medication.

"...I don't know-how,...I don't have any abstinence when I eat, I just eat what I have..." (p5).

"...if I eat anything I eat, just eat like a healthy person, I don't know why my body is getting thinner…"..."(p11).

"…as far as I know, if I drink these potions, my sugar will improve… I've never taken medication…"(p9).

Second Theme: Efforts To Control Blood Sugar

Participants revealed the efforts made in controlling blood sugar, such as: doing physical exercise, taking medication, regulating diet, checking blood glucose, controlling psychosocial responses, and taking a spiritual approach. The most frequent physical exercise by participants was walking and gymnastics. A total of 58% (n=7) of participants did regular physical exercises such as walking and gymnastics.

"I exercise every day, and I walk every morning…."(p3, p5, p9, p10).

"... I usually do gymnastics..."(p4, p5, p7, p8, p10).

The next effort to control blood sugar was medication. The types of treatment undertaken by the participants were medical and herbal treatments. A total of 33% (n=4) of participants took medication regularly, and 67% (n=8) were not compliant with treatment. The five participants who did not adhere to treatment were those who had diabetes for more than five years. Two participants prefer to drink herbal concoctions and three participants sometimes combine taking medicine and herbal concoctions.

"…....sometimes I take medicine, but sometimes I just take herbs." (p1, p6, p8).

"…....if I feel my sugar is high, I drink herbal concoctions..." (p2, p7).

The next effort in controlling blood glucose is to regulate the diet. Efforts made by participants were to reduce food portions and choose the types of foods they understood as low-calorie foods.

"I reduce the portion of food....usually one plate, now it's only half.." (p7, p8)

"I take good care of my food, eat brown rice, yams, meat with salt without drying, clear vegetables…"(p8, p9, p10, p12)

Psychosocial control is one of the experiences expressed by participants undergoing diabetes. Psychosocial control in the form of self-reinforcement and sharing stories with neighbors is an effort to avoid anxiety and fear due to perceived illness. The majority of participants who had diabetes for more than 5 years expressed self-strengthening abilities. The following are participant statements that support the theme:

"If I just enjoy it, I don't think about my illness…(p3, p4, p5)

"…so let's try to get rid of it, don't think about it too much, it's a disease" (p4)

"…sometimes, I tell my neighbors, when it's quiet at home, finally there is fear again (p2)

The next effort to control blood glucose is a spiritual approach. The forms of spiritual approach are surrender and religious practice. A total of five participants expressed statements as a form of surrender such as surrender, patience, gratitude, and sincerity to accept illness. The following is a participant's statement that shows the form of surrender:

"…so until now I have surrendered to Allah…"(p1, p3)

"... is it okay for me to just give up..."(p3, p10, p11)

"…just be patient with this disease…."(p3)

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"I'm just grateful for the current condition…"(p4)

Forms of religious practice that participants do to control blood sugar levels are praying and fasting. The majority of participants (58%) said that they always pray for healing, and there was one participant who said that his blood sugar fasting routine was controlled.

"...always pray, O Allah, give you health always…(p4, p6, p9, p11)

"…All this time I've been fasting continuously, if I don't fast, my blood sugar is always high". (p4)

Third Theme: Barriers To Blood Sugar Control

The barriers to controlling blood sugar expressed by participants such as the covid-19 pandemic are low self-motivation, perceived physical effects, and spiritual problems. The COVID-19 pandemic has disrupted self-management such as physical exercise, medication, and blood sugar checks. The COVID-19 pandemic has had an impact on stopping Chronic Disease Management Program (CDMP) activities managed by government health center nurses such as gymnastics for diabetes patients. As a result, participants no longer exercise regularly. In addition to exercise, participants' medication habits also became irregular. Participants became non-adherent to treatment. Participants stopped taking medicine because they ran out of stock of medicine at home, this was because they no longer went to the government health center to take medicine as was their habit before the COVID-19 pandemic. As a result of the discontinuation of Integrated Development Post-Non-Communicable Disease (IDP-NCD) activities, participants no longer carried out blood sugar checks that they usually did at IDP-NCD. The following statement shows the obstacles caused by the COVID-19 pandemic:

"…sometimes gymnastics…but because of the pandemic, there was no exercise before."(p4, p7, p8).

"During this corona, I stopped taking medicine... because I didn't go to the healthcare center..."(p4, p5).

"…since Corona, I have never checked my blood sugar…"(p5).

The next barrier to controlling blood sugar is low self-motivation in carrying out exercise and diet recommendations. Three participants with diabetes duration over five years expressed a sense of boredom doing exercise, so they rarely do exercise. In addition, they also said they could not control the desire to eat the food they liked.

"…exercise once in a while, because I feel bored."(p1, p10)

"I know that if we have this disease we have to maintain our diet, but sometimes I just ignore it". (p1)

"….my wife and children, forbid me to eat sweet food, but when I leave the house, I just eat."(p1)

The perception of physical effects felt by participants is one of the obstacles to diabetes self-management. Two participants revealed reduced energy, increased pain, weakness, and other diseases that appeared if they had to limit eating. One respondent said he felt tired when he did exercise.

"...if we avoid eating we will feel less energetic..., sicker, weaker, sluggish, 'and no enthusiasm..."(p6).

"I guess from the road, and I'm tired, I can't do activities at home, that's what makes me lazy"(p11).

The last blood sugar control barrier was a spiritual problem, in the form of effortless surrender to destiny, and low morale. Following are the statements of two participants with moderate socioeconomic levels who support the sub-theme of spiritual issues:

"...So I thought…rather than limiting what I eat, it's better to just eat because if the time comes, we will die too".(p6)

"… my spirit of Life sometimes decreases… sometimes laziness also appears…"(p1).

Fourth Theme: Perceived Disturbance

Physical disturbances that are felt include fatigue, pain, tooth decay, decreased foot sensation, easy foot injuries, sleep disturbances, and frequent urination. All participants stated that they felt numbness and pain when stepping on their feet. The following statements by some respondents support these categories:

"….which I think is shaky, weak….gets tired…"(p1, p4, p5).

"….I feel thick,…numb, cramping in my hands and feet…"(p1-p12).

"…..I am farsighted, on the left, I can't see…" (p11).

"…my teeth are easy to break and shake …"(p1, p2, p12).

"...both soles of the feet are numb, if you step on it, you don't feel it..."(p1, p4, p5).

"….if my sugar rises, this is my leg swelling, on the wounds…" (p4).

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"…I think if you want to sleep at night like someone is pricking you, that's why I can't sleep…" (p1, p3).

"…frequent urination at night …."(p1, p3, p6, p12).

Participants also felt stress and anxiety. Anxiety was felt by participants at the beginning of being diagnosed with diabetes. Anxiety in the form of haunting thoughts of death and the emergence of complications from the disease. One participant expressed stress because he felt he was a burden to others.

"….in the beginning, there was a feeling of anxiety…"(p1, p9, p11, p12).

"Many things stress me out…after I got sick, I couldn't get money anymore, I depended a lot on people, I felt helpless, I felt like I was a burden to others". (p1).

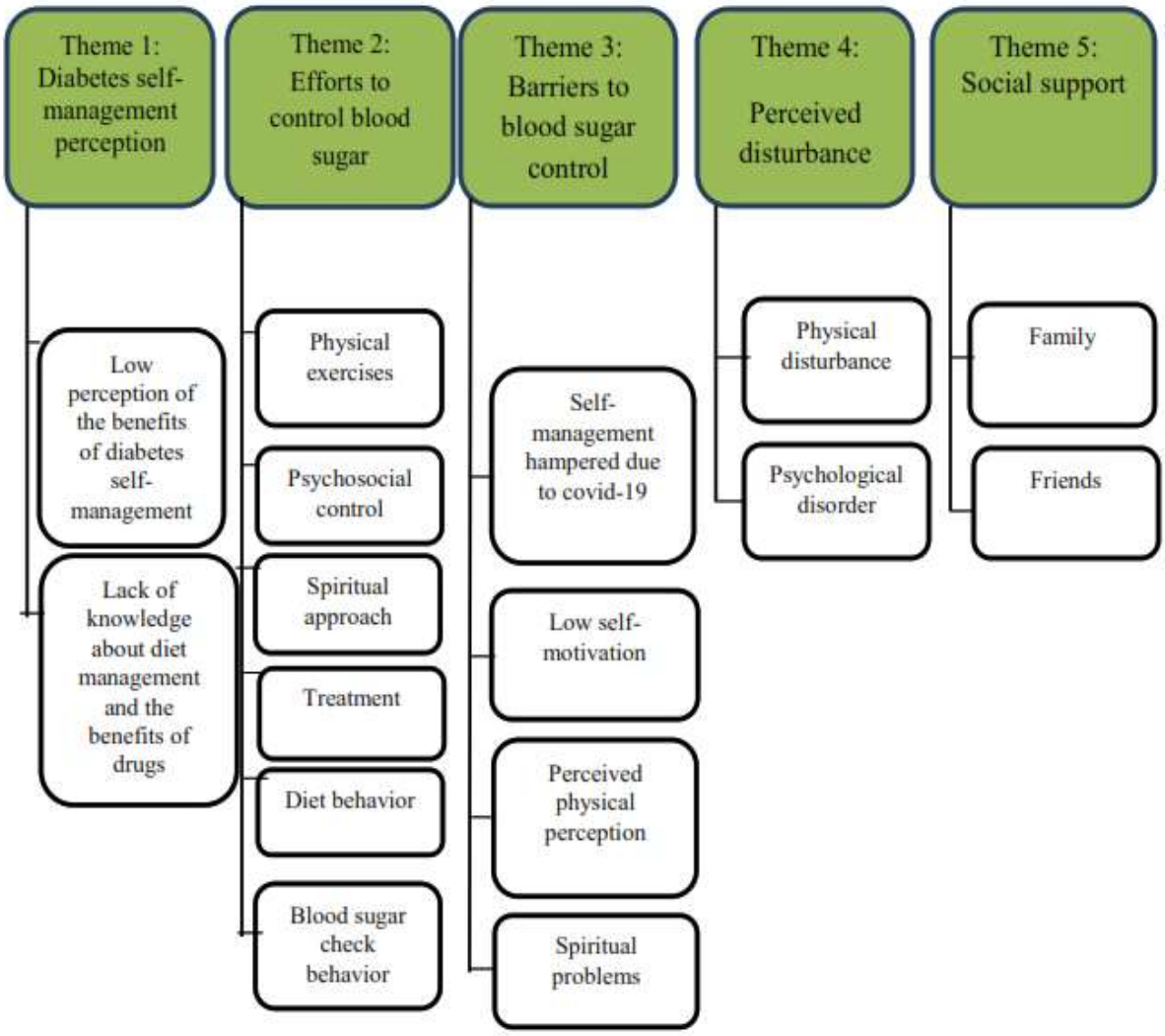
Fifth Theme: Social Support

Form of social support such as family support and friend support. Families remind the diabetes diet, while support from friends is an opportunity to share experiences. The following are the statements of respondents who support the existing subthemes:

"…my wife and children forbid eating sweet foods… his wife buys him brown rice. (p1, p5).

"...My children who always remind..."(p4)

"…yes neighbors, in-laws, share stories". (p2)



Scheme 1: Research themes and sub-themes

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DISCUSSION

The first theme in this study is the perception of diabetes self-management. These findings indicate that type 2 diabetes clients still have a low perception of the benefits of diabetes self-management. This finding aligns with[4] which shows common diabetes self-management practices and knowledge about diabetes. Low diabetes self-management practices are caused by economic factors such as poverty, education, and high costs of care [4]. Knowledge also influences diabetes self-management practices [22]. This condition requires appropriate interventions to improve diabetes self-management knowledge and practice.

The second topic identified in this study relates to blood sugar control initiatives. One of the ways the respondents try to control their blood sugar is through the sub-theme of physical activity. The recommended physical exercise for diabetes patients with peripheral neuropathy is light intensity, such as walking, stretching, chairing, and swimming [23]. Regular physical activity habits, among others, are influenced by knowledge and self-efficacy [24]. The respondents' exercise habits, such as walking and gymnastics, were more often done in groups. This situation shows that the support of friends, family, and groups also influences the sustainability of regular sports activities [19].

The next effort to control blood sugar is a psychosocial approach. The psychosocial process is carried out through self-reinforcement and story-telling. Sharing stories is a form of social relationship obtained through family, neighbors, and friends, providing reinforcement, sharing information, conveying problems experienced, and submitting complaints to doctors [25]. The sub-theme of the spiritual approach to controlling blood sugar is an interesting finding in this study. The spiritual approach taken by diabetes patients is in the form of praying to Allah, surrendering, patience, gratitude, and sincerity to accept the disease, as well as sunnah therapies such as fasting and reading the Qur'an. Spiritual practice through prayer improves diabetes self-management and stabilizes symptoms [26]. A spiritual approach is important to include in diabetes self-care behavior for diabetes patients.

In this study, the issue of obstacles to blood sugar regulation had four sub-themes: a lack of motivation, the Covid-19 epidemic, the perception of physical effects, and spiritual issues that interfere with self-management. Due to the Covid-19 pandemic, the integrated health service posts schedule was canceled, which prevented diabetes patients from obtaining treatments like blood sugar checks, oral anti-diabetic medications, and exercise. The rules for restricting social activities result in changes in healthy lifestyles, changes in the type and duration of exercise, irregular eating behavior, and excessive mental stress [27]. This situation is to research[1] in China, which showed that during the Covid-19 pandemic, elderly subjects with type 2 diabetes experienced worsening glycemic control. Providing medicine and checking blood sugar is difficult during a pandemic, resulting in an uncontrolled increase in blood sugar [2].

Controlling blood sugar is sometimes hampered by a spiritual issue. The customer does not adhere to the advised diet because the patient gives in to fate and accepts the circumstances as they are. This situation, which is characterized by a lack of support and inefficient coping mechanisms, reveals a barrier in the relationship with oneself. Adaptive spiritual coping enables clients to build motivation, set behavioral goals, and overcome obstacles [27]. The decreased enthusiasm for life in diabetes patients may be caused by boredom in diabetes self-management [28]. The client does not accept the condition he is experiencing, which may be indicated by feelings of hatred and displeasure for the illness that befell him [29]. Strategies in religion and spirituality to improve diabetes management are faith in God, reading the Bible or other religious books, praying, and seeking help from religious or spiritual people. Social support is obtained through spiritual and religious advice by someone who has good spirituality [26]. Religion and spirituality are essential in improving glycemic control.

The fourth theme is perceived disturbances in the form of physical and psychological disorders. Physical disturbances include pain, feeling weak, quickly tired, hurt, decreased vision, tooth decay, reduced foot sensation, easy foot injuries, sleep disturbances, and frequent urination. A study shows that diabetes patients with peripheral neuropathy have significant problems with physical and emotional functioning disturbances, such as instability, falls, and emotional stress[30]. Uncontrolled blood sugar levels in diabetes patients, among others, are caused by medication adherence and low diet [8]. In line with the results of interviews in this study, as many as eight respondents (67%) showed non-adherence to treatment, and nine respondents (75%) did not follow the recommended diet. Complications of diabetes are caused by various factors, including age > 50 years, obesity/overweight, duration of diabetes, lack of activity, and male gender [7]. The decrease in foot sensation in diabetes patients is affected by the lack of physical exercise, especially leg exercises.

Psychological disturbances that are felt include: anxiety about haunting death, pressure about complications of the disease, stress due to being a burden to others, decreased enthusiasm for life, and not accepting the situation. Anxiety and depression are closely

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related to the intensity of peripheral neuropathic pain [11]. The feeling of fear of death was expressed by one of the informants in this study. This fear is probably caused by the relatively young age of the respondent, where age, maturity at retirement, and religiosity increase confidence in overcoming death anxiety [31]. Diabetes clients experience fear of their disease condition[32], whereas diabetes clients experience anxiety. The assessment results of high sugar levels raise fears of complications and worsening the disease [32]. This condition reduces the client's desire to eat. Diabetes education is one of the factors related to the fear of Diabetes patients [33]. In addition to being anxious, Diabetes patients also feel stressed about their illness. Clients think they are a burden to others, which may be related to reduced income because they are no longer working [34]. Family support plays an essential role in reducing stress in Diabetes patients [35].

Social support is one of the elements that this study identified. Support from family is linked to better medication compliance and blood sugar management[36]. However, in other studies, the family can be an obstacle in the self-care behavior of diabetes clients. The family's unhealthy dietary behavior affects the diabetes client's diet [37]. In this study, the family supports providing an appropriate diet and reminding others about the proper diet.

Research limitations

This study has limitations in terms of the approach to data collection that is carried out directly individually. Data collection was not carried out in focus group discussions (FGD) due to the Covid-19 pandemic and social activity restrictions. Data interaction to obtain in-depth information through FGDs was not achieved. Further research is needed on how to model the right intervention to address the problems of diabetic patients holistically, which includes physical, psychological, social, and spiritual aspects by involving the family.

CONCLUSION

The perception and practice of self-care behavior of type 2 diabetes patients with symptoms of peripheral neuropathy is still low, which is exacerbated by the Covid-19 pandemic. Significant changes in self-care behavior in diabetic patients include cessation of exercise activities every week, not doing routine blood sugar checks, and not taking diabetes medication regularly. Barriers to self-care behavior other than the Covid-19 pandemic are low self-motivation, perceived physical effects, and spiritual problems.

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