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Self-care Behavior and Associated Factors among Type 2 Diabetes Mellitus Patients with Peripheral Neuropathy Symptoms: A Mixed-Methods Study

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SELF-CARE BEHAVIOR AND ASSOCIATED FACTORS AMONG TYPE 2 DIABETES MELLITUS PATIENTS WITH PERIPHERAL NEUROPATHY SYMPTOMS: A MIXED-METHODS STUDY

Abstract: This study aimed to explore perceptions, experiences, barriers, and support in performing self-care and to find out the factors associated with the self-care behavior of type 2 diabetes mellitus (T2DM) patients with symptoms of peripheral neuropathy. This exploration study used a two-phase sequential mixed-methods approach. A total of 12 participants were involved in Phase 1 (the qualitative study), with data analysis using the Colaizzi model steps. A total of 118 patients with T2DM were involved in Phase 2. Bivariate data analysis used Spearman correlation tests with a 95% confidence interval and significance set at $p<0.05$. Five themes were found in Phase 1 of the study: perceptions of diabetes self-management, blood sugar control efforts, blood sugar control barriers, perceived disturbances, and social support. A total of 59% of diabetes self-care behaviors were below the median. Significant correlations were found between diabetes self-care behavior and self-efficacy (p =0.000; r =0.662), quality of life (p =0.003; r =0.270), and family support (p =0.000; r =0.490). The self-care behavior of T2DM patients with symptoms of peripheral neuropathy was mostly poor. Self-efficacy, quality of life, and family support were related to self-care behavior. Appropriate, accessible, and sustainable program support is needed from policymakers to improve self-care behavior and related factors in T2DM patients with symptoms of peripheral neuropathy.

Keywords: type 2 diabetes mellitus, peripheral neuropathy, self-care behavior, mixed-methods study

Introduction

The practice of self-care behavior in T2DM patients in several countries around the world is still low. A study at a rehabilitation center in Saudi Arabia found that diabetic patients rarely exercise and check their blood sugar (Saad *et al.*, 2018). Likewise, a study by Abdulrehman *et al.* (2016) in Kenya found a lack of self-care practices in diabetic patients in terms of regulating carbohydrate diets. The practice of self-care behavior of patients with diabetes in several places in Indonesia is still inadequate. A study at the Bandung City Public Health Center found that 52.2% of the self-care behaviors of patients with type 2 diabetes mellitus (T2DM) were in the low category (Yamin and Sari, 2018). Meanwhile, in West Sulawesi, 62.86% of respondents were reported to be non-adherent to treatment and not following a healthy diet (Pamungkas *et al.*, 2017). These findings are in line with the results of this study, where as many as 59% of self-care behaviors of patients with T2DM in Kendari City, Southeast Sulawesi, were in the poor category. The presence of peripheral neuropathy also reduces the interest of patients with diabetes in performing self-care behaviors (Timar *et al.*, 2016).

Factors inhibiting diabetes self-care behavior include individual factors of the client, family, social community, environment, and health services. Individual factors such as weak self-control over diet, psychological conditions (stress), and knowledge of the causes and monitoring of blood glucose. Socioeconomic factors include finances, stigma or isolation, and support from family and friends (Blixen *et al.*, 2016; Byers, 2016; Gonzalez-Zacarias *et al.*, 2016). Weak support from family and friends in understanding and helping to ease the burden of the disease is another inhibiting factor in diabetes self-management (Blixen *et al.*, 2016). The Corona Virus Disease 2019 (COVID-19) pandemic has also exacerbated the obstacles to the self-care of patients with T2DM (Banerjee,

Chakraborty, and Pal, 2020). Identification of barriers to self-care, especially during the COVID-19 pandemic, needs to be done to assist health workers in preparing appropriate intervention plans.

Identification of barriers to achieving positive health behaviors is important because it has been proven to be one of the strategies to increase physical activity and glucose control (Avery *et al.*, 2015). Through the identification of barriers, it will be easier for health workers to formulate problem-solving strategies and appropriate interventions. In the primary care setting, identifying signs of DPN is a major aspect of appropriate interventions to reduce disability and limb loss and improve patients' quality of life through early detection and counseling (Khawaja *et al.*, 2018). This study focused on exploring the experiences and perceptions of patients with T2DM with peripheral neuropathy symptoms in self-care behavior, including barriers and supports in performing diabetes self-care behavior, as well as identifying factors associated with diabetes self-care behavior.

Methods

This exploratory study used a two-phase sequential mixed-methods approach to determine the factors associated with self-care behavior in T2DM patients with symptoms of peripheral neuropathy. The study began with qualitative interviews (Phase 1) with 12 participants to explore perceptions, experiences, barriers, and supports for performing diabetes self-care. In Phase 2, the study was conducted with a quantitative analysis approach involving 118 patients with T2DM to determine the factors associated with diabetes self-care behavior. All respondents provided informed consent. The study was conducted in the working area of the Kendari City Health Center from April 10 to August 31, 2022. A total of nine public health centers were selected in this study based on the representation of the geographical area (the points of the compass), namely north, south, west, east, southeast, southwest, northwest, northeast, and downtown.

Determination of Sample Size and Sampling Techniques

All patients with T2DM who had visited the health center during the last six months became the target population. Sample inclusion criteria were: patients with T2DM who have HbA1c values above 6.5% or current blood sugar values >200 mg/dl, have at least 1 of 3 points of decreased foot sensation using the 10 g monofilament test. The study sample size was calculated using the formula with a 95% confidence level (CI) and marginal error (d) of 0.05, and the number of samples obtained was 122. A total of 118 patients with T2DM were included in the study.

Ethics, approvals, and permissions

This study was approved by the research ethics committee of the Faculty of Nursing, University of Indonesia (FoN-UI). Materials sent to respondents, such as interview guides, research information, and participant consent, were also approved by the FoN-UI ethics committee. Participation in this study was initiated through an informed consent form. Verbal consent was obtained for the audio recording of the verbal interview.

Instruments

Questionnaire variables related to diabetes self-care behavior were identified, modified, and used in collecting quantitative data, including:

1. Measurement of self-efficacy. Researchers modified the Chinese version of the Diabetes Management Self-Efficacy Scale (C-DMSES) (Vivienne Wu *et al.*, 2008) and the Iranian version of the Diabetes Empowerment Scale (IR-DES-28) instrument (Mahjouri *et al.*, 2012) into 28 question items that have been tested for validity and reliability with a Cronbach alpha coefficient of 0.965.
2. Measurement of diabetes knowledge using the Diabetes Knowledge Questionnaire (DKQ) instrument (Menino, Dos Ad, and Cl, 2017), with Cronbach's alpha r value = 0.863.
3. Measurement of diabetes stress using the Diabetes Distress Screening (DDS) instrument (Fisher *et al.*, 2008), with an internal consistency coefficient of (0.93) and a Cronbach alpha coefficient of 0.69-0.71.
4. Measurement of family support, using a questionnaire (Hensarling, 2009) with an r value of Cronbach's alpha = 0.96, and a Content Validity Index (CVI) = 1.00.
5. Measurement of quality of life, using an instrument developed in the Indonesian version (Putri *et al.*, 2021), with the overall value of the Cronbach alpha coefficient = 0.883.

Quantitative data analysis

Univariate analysis was used to describe the characteristics of respondents, which were displayed in a table of relative frequencies and percentages, such as marital status, ethnicity, living with whom, age, gender, duration of diabetes, metabolic markers, goals to be achieved in self-care behavior, sources of information about preferred diabetes information, and preferred diabetes education materials. Since one of the variables was not normally distributed, bivariate analysis used Spearman correlation tests to see the relationship between independent variables and self-care behavior in T2DM patients with peripheral neuropathy.

Results

Qualitative interview findings

The five themes found using the analysis technique of the Colaizzi method in qualitative interviews are perceptions of diabetes self-management, blood sugar control efforts, blood sugar control barriers, perceived disturbances, and social support. When participants were asked about their experiences managing diabetes, various responses were given, including feeling the lack of benefits from exercise and taking medication. Some of the participants' subjective statements reflected their feelings that there was no change even though they had followed the recommendations, such as taking regular medication, eating as recommended, and exercising. Participants also expressed their ignorance of the benefits of maintaining a healthy diet for patients with diabetes.

When participants were asked about the efforts that had been made to control blood sugar, the answers that were given varied, including doing physical exercise in the form of walking every day and exercising regularly every week at the public health center. Other efforts include taking regular medication, maintaining a healthy diet, and checking blood sugar. Regarding treatment, there are three options: medical drugs, herbs, or both. Participants' diet efforts are to regulate the type and portion of the diet. The types of food that the participants chose were foods that were understood to be low in glycemic levels, such as brown rice, yams, grilled fish, and vegetable dishes. Efforts to control blood

sugar are also made through psychosocial control and spiritual approaches. Psychosocial control was done in the form of self-reinforcement and sharing stories with neighbors in an effort to avoid anxiety and fear due to the perceived illness. The spiritual approach involved healthy attitudes such as surrender, patience, gratitude, and sincerity accepting illness.

The barriers to controlling blood sugar expressed by participants included the COVID-19 pandemic, low self-motivation, perceived physical effects, and spiritual problems. The COVID-19 pandemic has resulted in the cessation of activities for the Chronic Disease Management Program (CDMP) in the form of exercise sessions previously held regularly every week. Participants also revealed that they no longer take medicine because they had run out at home. Patients with diabetes could no longer go to the Public Health Center to get their medicine, as was the custom before the COVID-19 pandemic. As a result of the discontinuation of Integrated Development Posts (IDP) for Non-Communicable Diseases (NCD) activities, participants no longer carried out blood sugar checks, which are usually done at IDP-NCD. Other obstacles to controlling blood sugar are patients' low self-motivation to do sports activities and failure to maintain a healthy diet. Another obstacle to controlling blood sugar is spiritual problems, in the form of surrendering to fate without making any effort, and low spirits.

Participants reported that they felt several complaints related to diabetes, such as aches and pains throughout the body that they felt throughout the day. Other physical complaints are pain, numbness in the hands and feet, body tingling, feeling tired quickly, visual disturbances, tooth decay, frequent awakening at night due to frequent urination, and constipation. Participants also reported comorbidities such as hypertension, hypercholesterolemia, and heart disease.

The last theme is social support. Forms of social support include both family and friends' support. Families remind patients about the importance of maintaining a healthy diabetes diet, while support from friends involves a willingness to share experiences.

Quantitative study findings

Characteristics of study samples

Respondents were mostly in the age rane of 45-54 years, with a total of 58 people (49.2%), while the majority were women, with as many as 91 people (77.1%). Based on the level of education, the majority of respondents were in the senior high school level group, with as many as 55 people (46.6%), and the type of work was mostly housewives, with as many as 62 people (52.5%). Characteristics of respondents according to marital status indicated most have been married, with as many as 93 people (78.8%), while the duration of being diagnosed with T2DM was in the group 1-5 years, with as many as 64 people (54.2%). For the characteristics of respondents based on ethnicity, the majority of respondents are in the Tolaki tribe, with as many as 43 people (36.4%). The majority of HbA1c values were above the median value (>9.7%), with as many as 57 respondents (56.4%). The characteristics of respondents and metabolic values can be seen in more detail in Table 1.

Diabetes self-care behavior

Most of the diabetes self-care behavior of respondents was below the median value (50th percentile), with as many as 70 people (59%). Further details can be seen in Table 2.

Table 1. Characteristics of research respondents and metabolic markers (n=118)

Characteristics of Respondents	n	Percentage (%)
Age		
a. 25 – 34	2	1.7
b. 35 – 44	4	3.4
c. 45 – 54	58	49.2
d. 55 – 64	46	39
e. 65 – 74	7	5.9
f. 75 – 84	1	0.8
Sex		
a. Man	27	22.9
b. Woman	91	77.1
Level of education		
a. Elementary school	10	8.5
b. Junior high school	24	20.3
c. Senior High School	55	46.6
d. Higher education	29	24.6
Job		
a. Civil Servant	27	22.9
b. Self-Employed	21	17.8
c. Employee	1	0.8
d. Housewife	62	52.5
e. Etc.	7	5.9
Marital status		
a. Married	93	78.8
b. Unmarried	2	1.7
c. Widow/widower	22	18.6
Duration of diabetes (years)		
a. 1 – 5	64	54.2
b. 6 – 10	42	35.6
c. 11 – 15	8	6.8
d. 16 – 20	4	3.4
Ethnicity		
a. Tolaki	43	36.4
b. Bugis	38	32.2
c. Muna	15	12.7
d. Buton	6	5.1
e. Toraja	3	2.5
f. Jawa	7	5.9
g. Etc.	6	5.1
The score of HbA1c		
a. < median; min-max (9,7; 6,5-15,3)	44	43.6
b. ≥ median; min-max (9,7; 6,5-15,3)	57	56.4
The score of random blood sugar (mg/dl)		
a. < median; min-max (296; 193-584)	60	51
b. ≥ median; min-max (296; 193-584)	58	49

Min-max, minimum-maximum.

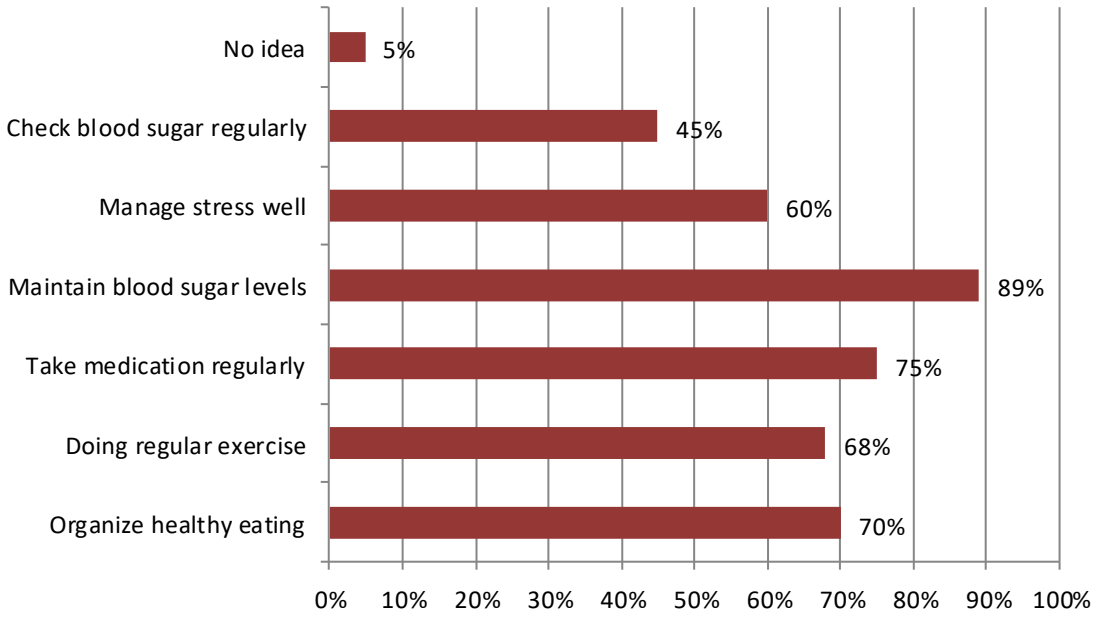
Table 2 Diabetes self-care behavior of respondents

	Median (Minimum-Maximum)	< Percentile 50		≥Percentile 50	
		n	%	n	%
Diabetes self-care behavior	57.50 (21-110)	70	59	48	41

Self-care behavioral goals, sources of information, and diabetes education materials

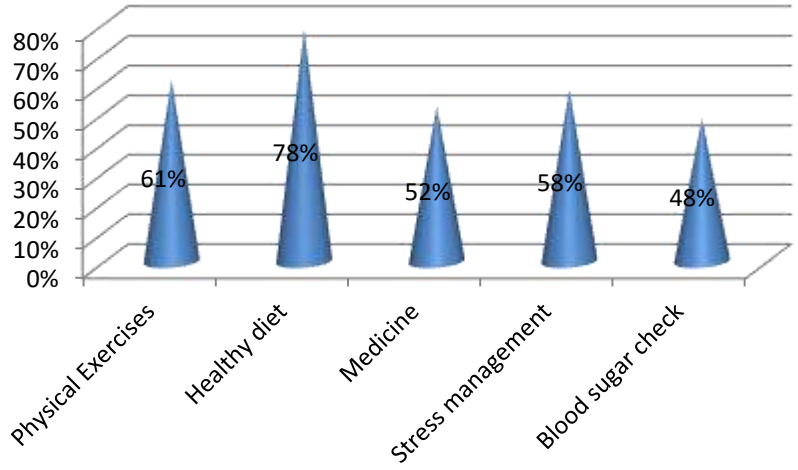
The most common choice of goals to be achieved in diabetes self-care management is to maintain blood sugar levels (n=105, 89%). Furthermore, there were managing a healthy diet (n=83, 70%), doing regular exercise (n=80, 68%), taking medication regularly (n=89, 75%), managing stress well (n=71, 60%), and checking their blood sugar regularly (n=53, 45%), while a few respondents said they did not know as much as 5% (n=6), as seen in Figure 1.

Figure 1 Distribution of respondents based on the goals to be achieved



The most preferred sources of information about diabetes by respondents was online information (n= 66, 56%), printed books (n=41, 35%), direct information from doctors/nurses/other health workers (n=97, 82%), and information from friends/neighbors (n=19, n=16%).

Figure 2 Most preferred and expected diabetes education materials



When asked about the desired diabetes education material, the most preferred choices were material about a healthy diet as much as 78% (n = 92), material about physical exercise as much as 61% (n = 72) and, diabetes treatment material as much as 52% (n = 61), while stress management was 58% (n = 68), and blood sugar examination was 48% (n = 57), as seen in Figure 2.

Bivariate analysis

Table 3 Relationship of variables with diabetes self-care behavior in T2DM patients with symptoms of peripheral neuropathy

Variable	Diabetes self-care behavior	
	Spearman Correlation	*p*- Value
Self-efficacy	0.662	0.000
Diabetes knowledge	-0.011	0.902
Diabetes Stress	-0.158	0.088
Quality of life	0.270	0.003
Family support	0.490	0.000

Spearman correlation tests

Spearman correlation analysis, as seen in Table 3, for diabetes self-care behavior and self-efficacy variables obtained an r value of 0.662 with a *p* value of 0.000, which shows that there is a significant relationship between self-care behavior and self-efficacy in T2DM patients with symptoms of peripheral neuropathy. The results of the Spearman correlation analysis between self-care behavior and quality of life, as shown in Table 3, obtained a value of r = 0.270 with $p = 0.003$, which indicates there is a significant relationship between self-care behavior and quality of life in T2DM patients with peripheral neuropathy symptoms. Likewise, the results of the Spearman correlation analysis between self-care behavior and family support obtained a value of r = 0.490 with $p = 0.000$. This result shows that there is a significant relationship between self-care behavior and family support in T2DM patients with peripheral neuropathy symptoms. Additionally, the Spearman correlation analysis of the diabetes knowledge variable with diabetes self-care behavior obtained a value of r = -0.011 with p = 0.902, showing that there was no significant relationship between diabetes self-care behavior and diabetes knowledge. Likewise, the correlation test between diabetes stress and self-care behavior showed that there was no significant relationship between diabetes stress and diabetes self-care behavior, which was indicated by the test results of r = -0.158 with $p = 0.088$.

Discussion

The findings of this study indicate the self-care behavior of T2DM patients with peripheral neuropathy is mostly poor. This finding is in line with the results of a study on patients with diabetes at a rehabilitation center in Saudi Arabia, where the patients rarely do sports and check blood sugar levels (Saad *et al.*, 2018). Likewise, the study at the Bandung City Public Health Center found that the majority of patients with T2DM (52.2%) had inadequate diabetes self-care behaviors (Yamin and Sari, 2018). However, a different study by Huang et al. (2014) found diabetes self-care behaviors among patients with T2DM, including drug management, diet management, blood sugar checks, foot care, exercise management, and prevention and treatment of hypo or hyperglycemia were mostly in the good category (Huang *et al.*, 2014). The low self-care behavior of patients with T2DM in this study was influenced by two main factors, namely internal and external factors. Internal factors include low self-motivation (such as laziness and low self-control), negative spiritual coping (such as surrendering to fate without any effort), and perceived physical disturbances (feeling weak all day, and complications of illness). This finding is strengthened by the results of the study, which found self-regulation, self-control, and self-discipline in patients with diabetes affect diet compliance, regular physical exercise, self-monitoring blood glucose, and medication adherence (Sridharan, Chittem, and Muppavaram, 2016).

External factors include environmental factors, one of which is the COVID-19 pandemic. The COVID-19 pandemic situation has limited patients' ability to carry out diabetes self-care management as a result of social restrictions and the cessation of service activities for patients with diabetes at IDP-NCD. Social restrictions have an impact on discontinuing joint exercise activities for patients with diabetes every week, and limiting food stocks changes the patients' habits. This finding is reinforced by the results of another study (Banerjee, Chakraborty, and Pal, 2020), which found the impact of poor glycemic control was a result of the decrease in diabetes management during the COVID-19 pandemic. The cessation of service activities at the IDP-NCD had an impact on the patient's stock of diabetes drugs at home, so the patient stopped taking their daily medication. This finding was reinforced by the results of the study by Banerjee *et al*. (2020), which found problems in drug stocks for patients with diabetes during the COVID-19 pandemic. Other external factors are the lack of

attention and family knowledge in managing diabetes self-care and the lack of intensity of health workers in providing education, assistance, and reinforcement for diabetes self-care. A lack of family understanding of diabetes makes individual patients pay less attention to and receive less support for diabetes self-care (Blixen *et al.*, 2016).

This study identified a significant relationship between self-efficacy and diabetes self-care behavior. Self-efficacy was significantly associated with diabetes self-care behavior and glycemic control. Self-efficacy is a predictor of diabetes self-care behavior (Kurnia, Amatayakul, and Karuncharernpanit, 2017). A study found that self-efficacy has an indirect effect on glycemic control through diabetes self-care (Lin *et al.*, 2017). This is in line with the results of a study that found poor glycemic control was associated with poor self-efficacy and self-care (D'Souza *et al.*, 2017). A study further found a positive relationship between self-efficacy and diabetes self-management activities, which indicated that the higher the self-efficacy of patients with diabetes, the better their self-care behavior will be (Kav *et al.*, 2017). Patients with diabetes who have strong self-efficacy will perform challenging self-care activities and consider themselves capable of overcoming the barriers to treatment adherence. Activities in diabetes self-management increased along with self-efficacy in patients with T2DM (Albikawi, Petro-Nustas, and Abuadas, 2015).

The results of this study found no correlation between the level of knowledge and diabetes self-care behavior. These findings are supported by the results of the study, which found that patients with T2DM who have low knowledge tend to practice good self-care (Kassahun *et al.*, 2016). However, these findings contradict another study (Moraes *et al.*, 2020), which concluded that diabetes education was shown to increase knowledge and improve diabetes self-care. The results of that study showed that there is an inverse phenomenon, where individuals with good knowledge tend to perform good self-care behaviors. This finding can happen since even if individuals have good knowledge of diabetes, it does not guarantee that they will perform good self-care behavior, and vice versa, someone who has low knowledge, will not necessarily perform bad self-care. The patients' knowledge is not a strong enough indication of their actual diabetes self-care. This assumption is supported by Coates and Boore (1996) who found that an adequate knowledge base alone is not sufficient for patients with diabetes to perform adequate self-care; but several other factors influence it.

This study found no significant relationship between diabetes self-care behavior and diabetes stress. These results are supported by the study, which found no clear relationship between diabetes stress and self-care behavior (Chew, Fernandez, and Shariff-Ghazali, 2018). However, this is in contrast to other studies that concluded that stress affects self-care behaviors such as an unhealthy diet for patients with diabetes (Dehghan *et al.*, 2016). It is known that psychological disorders affect diabetes self-care behavior. A study found that high depressive symptoms were closely related to low self-care behavior (not adhering to the diet, lack of exercise, and poor foot care) (Gonzalez *et al.*, 2008). An increase in depression scores over time can be predictive of poorer adherence to aspects of diet and exercise. Stress that is influenced by stigma causes clients to have a lower sense of self-esteem and social participation, which affects the level of medication adherence (Kato *et al.*, 2016). Diabetes stress in this study was not related to self-care behavior, because, in this study, the majority of stress levels were low, but the level of self-care behavior was mostly poor, so self-care behavior in this study was not related to diabetes stress but could be influenced by other factors.

The findings of this study show that the quality of life of T2DM patients with DPN was as much as 50% below the median. Quantitative analysis showed that there was a significant relationship between the quality of life and the self-care behavior of patients with diabetes. The majority of respondents

complained of leg pain, aches throughout the body, numbness, and tiredness throughout the day, which reduced their enthusiasm for physical exercise. These results are in line with previous research (Ghavami *et al.*, 2018), which showed that the majority of respondents with T2DM experienced severe peripheral neuropathy, with symptoms of pain, walking instability, and foot injuries that resulted in decreased quality of life. Quality of life generally decreases with age (Nasralla Saleh and Alwahedi, 2016). The results of this study showed that the majority of the duration of suffering from T2DM (54.2%) was in the range of 1-5 years. The acute attacks of peripheral neuropathy cause a stabbing pain that is felt to reoccur and has a rapid onset, with complaints of severe burning pain and pain with nocturnal exacerbations, while the severity of symptoms is usually moderate to severe and involves decreased ankle reflexes (Hershey, 2016). This cycle of pain greatly decreases the interest of patients with DPN in physical activity. Low quality of life is significantly associated with the duration of diabetes and prolonged complications (Nasralla Saleh and Alwahedi, 2016). The intensity and duration of pain are closely related to a decrease in the quality of life of patients with diabetes (Geelen *et al.*, 2017).

The results of this study indicate that there is a significant relationship between family support and diabetes self-care behavior. The closeness of the family and less conflict within the family promote deeper adherence to medication (Ahmed and Yeasmeen, 2016). Family roles are to provide economic and emotional support, a healthy diet while reminding patients to take medication, and psychological support to control stress and depression (Ahmed and Yeasmeen, 2016). Consumption of food managed by the family can lower serum lipid levels and help control blood sugar (Ahmed and Yeasmeen, 2016). The availability of family support increases adherence to treatment (Basu and Garg, 2017). The roles and responsibilities of each family member are not well described. Family support plays a role in preventing the impact of stress on glycemic control. The most frequently reported instrumental forms of support were support in diet management, exercise, medication adherence, managing doctor's appointments, and monitoring blood glucose (Ahmed and Yeasmeen, 2016).

Study limitations

Qualitative interviews do not use focus group discussions involving families and health providers, so some perspectives may not be explored regarding solutions to improve diabetes self-care behavior. Inadequate sample size and a lack of exploration related to diabetes self-care management support in the context of family and community are also some of the limitations of this study.

Research Implications

The findings of this study can become the basis for developing strategies to improve diabetes self-care behavior according to patient needs through increasing self-efficacy, family support, quality of life, knowledge, and controlling diabetes stress.

Conclusions

The practice of self-care behavior by T2DM patients with peripheral neuropathy is still low. Barriers to the practice of diabetes self-care behavior are caused by two main factors, namely external and internal. External barriers include social restrictions due to the COVID-19 pandemic, while internal barriers include low self-motivation, perceived physical effects, and spiritual problems. Diabetes self-care behavior was significantly related to self-efficacy, family support, and quality of life. Meanwhile,

diabetes stress and knowledge were not significantly related to diabetes self-care behavior in this study.

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