

16. Family Experience of Caring for a Diabetes Mellitus Patient A Qualitative Study

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Original Research

Family Experience of Caring for a Diabetes Mellitus Patient: A Qualitative StudyIndah Wulandari^{1,3}, Kusnanto Kusnanto¹, Sony Wibisono² and Titin Puspitasari³¹ Faculty of Nursing, Universitas Airlangga, Surabaya, Indonesia² Faculty of Medicine, Universitas Airlangga, Surabaya, Indonesia³ Nursing Program, Faculty of Health Science, Universitas Faletehan, Banten, Indonesia**ABSTRACT**

Introduction: Diabetes mellitus is a chronic disease that requires lifelong care. The treatment of diabetes mellitus patients at home requires a family role so then the patients can optimize their care. The diabetes complications can be reduced as a result. The aim of this study was to explore the family experience of treating diabetes mellitus patients at home.

Methods: A semi-structured phenomenological approach including inductive thematic analysis was used in this research. Thirteen family members of diabetes patients participated in the discussion. Participant recruitment was focused on families that have treated diabetes patients for more than 1 year with no complications. Data saturation occurred after 2-3 meetings per participant.

Results: The experiences of the family members while caring for diabetes mellitus patient can be used to determine the presence of 5 themes: family feelings that appear when caring for diabetes mellitus patients, patient adherence to taking medication, patient's disobedience of their diet, patient's disobedience of activity and the family expectations of the future

Conclusion: In every theme, family experience obstacles arise between the families' wants and the patients' needs. Diet and activity became a major obstacle to diabetic care at home. Some topics needed more attention, such as the information and support provided for the family.

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INTRODUCTION

A person's experience becomes one of the sources of learning when treating disease, one of which is diabetes mellitus. Experience teaches a person knowledge, prompts an attitude improvement, and results in behavior modification through the observation of the reaction to an action (Dziegielewski, Wodarski, Lawrence, Zittek-Palamara, & Dulmus, 2007; Royer, 1998). Diabetes mellitus is a chronic disease that must be suffered for a lifetime. Diabetes mellitus patients and their families must have good knowledge and skills because the treatment is done continually (Alpers, 2010; Ansari, Hosseinzadeh, Harris, & Zwar, 2018; Macedo, Cortez, Santos, Reis, & Torres, 2017).

Experience can be a true source of information but it can also provide incorrect information if it is not balanced with formal information. Patients and their families can assume that their experience is correct if the observations show there to be an improvement in their health status. They can assume that they are wrong if the observations show worsening symptoms (Royer, 1998). The results of these observations were discussed with the health workers to validate whether or not the actions needed are what they are actually doing. However, if the patients and their families do not have access to validate their observations, then they may infer incorrectly (Alpers, 2010; Royer, 1998).

The recent studies indicate that the family has a role in helping the diabetes patients to care for

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themselves at home (Kristianingrum, Wiarsih, & Nursasi, 2018; Shahab et al., 2019; Yue et al., 2019). The support received by the diabetes mellitus patients from their family comes in the form of helping the patients in their daily activities, assistance when preparing food, accompanying them to the health center, helping financially, helping them to solve problems and giving them attention (Kristianingrum et al., 2018). Family behavior has a positive impact but sometimes the patients feel that the family attention is nagging and disturbing (Mayberry, Harper, & Osborn, 2016). In addition, the differences in perception between the patients and their families are also obstacles in the treatment of the diabetes mellitus patients (Shahab et al., 2019; Yue et al., 2019).

The family is the closest environment that provides assistance to the patients with diabetes mellitus in terms of their care. The family experience of treating patients with diabetes mellitus at home is influenced by several things such as knowledge, attitude, motivation, socioeconomic level and access to information sources (Ansari et al., 2018; Coser, Sittner, Walls, & Handeland, 2018; Gomes et al., 2017; Mayberry et al., 2016). The family has an important role in supporting the patients with diabetes mellitus care at home (Coser et al., 2018; Gomes et al., 2017; King et al., 2010; Mayberry et al., 2016; Ramkisson, Pillay, & Sibanda, 2017; Shawon et al., 2016). Good support from their family member will help the patients with diabetes mellitus to undergo their treatment. The impact of good care for each patients is intended to enhance the patient's motivation to carry out regular care, to reduce the risk of complications, to reduce patient anxiety and to improve the quality of life of patients with diabetes mellitus (Ahola & Groop, 2013; Al-Khawaldeh, Al-Hassan, & Froelicher, 2012; Jannoo & Mamode Khan, 2019; Mogre, Abanga, Tzelepis, Johnson, & Paul, 2017; Pamungkas, Chamroonsawasdi, & Vatanasomboon, 2017).

The support provided by the family members also helps the diabetes mellitus patients to achieve compliance in terms of self care (Jannoo & Mamode Khan, 2019; Mogre et al., 2017; Simon-Tuval, Shmueli, & Harman-Boehm, 2016). A recent study showed that the patients had difficulty achieving adherence to their diet, recommended activities and medication when they did not get support from their family (Ahola & Groop, 2013; Al-Khawaldeh et al., 2012; Baek, Tanenbaum, & Gonzalez, 2014; Jannoo & Mamode Khan, 2019; Mogre et al., 2017). The impact showed that the patients did not achieve a stable regulation of their blood glucose and so their quality of life decreased. In addition, the patients also experienced anxiety and emotional disturbances (A.A., J.D., M., & A.-M., 2018; Pamungkas et al., 2017; Sina, Graffy, & Simmons, 2018). Therefore good family experience is needed in the care of diabetes mellitus patients at home. The aim of this study was to explore the family experiences when treating diabetes mellitus patients.

MATERIALS AND METHODS

Design

This study used a phenomenological approach. Inductive thematic analysis was used to get themes from the data collection. Phenomenology was used to describe the phenomena that exists as an integral part of the world in which we are living (Astalin, 2013; Berg, 2001). In this study, this refers to the family experience of caring for the diabetes mellitus patient. We conducted the data collection using in-depth interviews that were recorded and documented in the form of field notes. A semi-structured interview was selected as a guide. The determination of the theme used the 7 steps of inductive thematic analysis from Colaizzi: 1) transcribing all of the subjects' descriptions, 2) extracting significant statements, 3) creating the formulated meanings, 4) aggregating the formulated meanings into theme clusters, 5) developing an exhaustive description, 6) identifying the fundamental structure of the phenomenon and 7) returning to the participants for validation (Edward & Welch, 2011; Morrow, Rodriguez, & King, 2015).

Sample and setting

The families were recruited using purposive sampling in one of the Sub-District Level Health Centers. The selection criteria for the family members were that they were 18 years or older and that they had been living with and providing care for a diabetes patient for one year or more. A Sub-District Level Health Center officer was involved in the selection of the participants and they helped the researchers with their field notes. The families willing to become participants were given information on the research, on their involvement in the research, and if there were to be any rewards received. If the family was willing to become a participant, then they signed the prepared consent form. Thirteen family members participated in this study (see Table 1). The researcher explained to the participants that they could refuse to participate at any time.

Data collection

The interviews were held at the Sub-District Level Health Center. Thirteen semi-structured interviews were held based on the families' experiences. The interviews were conducted from November 2019 to December 2019, and they lasted between 30 and 60 minutes. We were started the interview with an open question: 'Could you tell me about the care that provide for diabetes mellitus at patient at home?' The semi-structured questions were based on the literature to ensure that the relevant topics were covered. Data saturation occurred after 2 - 3 meetings per participant.

Data analysis

The researcher used a type-recorder and transcribed verbatim. Inductive thematic analysis was used to enhance the understanding of the families'

Table1. Demographics of participant

No	Family Relationship	Age	Time of the patients cared for	Patients' health status
1	Wife	61	7 years	no complications
2	Wife	33	2 years	diabetic ulcer
3	Son	18	7 years	hypercholesterolemia
4	Daughter	18	5 years	hypertension
5	Daughter	20	2 years	no complications
6	Daughter	27	3 years	hypertension
7	Niece	42	2 years	no complications
8	Wife	56	5 years	hypertension
9	Wife	35	3 years	hypertension
10	Daughter	35	2,5 years	hypertension
11	Daughter	37	2 years	hypertension
12	Wife	44	4 years	no complications
13	Sister	30	8 years	no complications

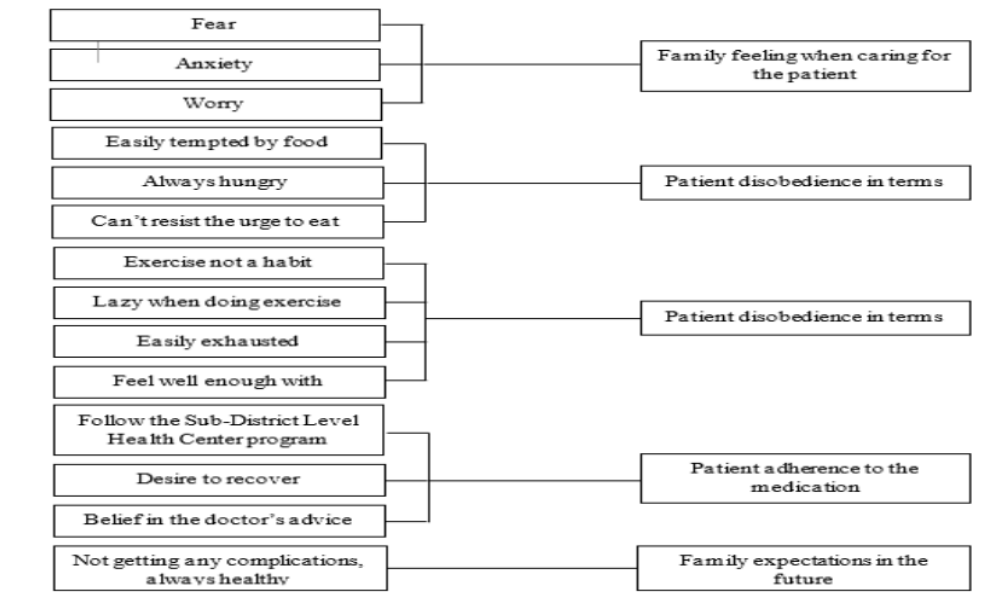


Figure 1. Scheme of the themes that the family experiences related to diabetes patient care

knowledge and their competencies regarding the caring of the diabetes mellitus patients. Some of the family members also talked about the disturbances or barriers when taking care of the diabetes mellitus patient. The inductive thematic analysis was conducted by the researcher and the transcripts were used to make up the content analysis. The transcripts were analyzed line by line and the codes were noted in the margin, creating a label for each sentence. The codes were grouped and labeled using broader categories and themes.

Ethical Approval

The data was collected after getting approval from the District Level Health Office of Serang in the form of a research permit. The researchers got a recommendation letter for the research permit from their institution and presented this to the District Level Health Office. The District Level Health Office examined the incoming letter, gave them permission and designated a place of research. The basis for the appointment of the research site is that it has the highest number of cases of diabetes mellitus in the

city of Serang, Indonesia. This research was conducted with respect to the subject's rights, justice, confidentiality and beneficence.

RESULTS

The study findings show that most family members had negative experiences when caring for the diet and activity of the diabetes mellitus patient. Most of the patients struggled to keep their diet and activity consistent with the health worker's suggestion. The experience of the family members when caring for the diabetes mellitus patient can be determined using 5 themes: 1) family feelings that appear when caring for diabetes mellitus patients, 2) patient adherence to taking medication, 3) patient disobedience of the diets, 4) patient disobedience of physical activity and 5) the family expectations in the future. In every theme, family experience obstacles arise between the families' wants and the patients' needs.

Family feelings that appear when caring for the diabetes mellitus patients

Most of the families expressed fear, helplessness and worry while caring for the patients with diabetes mellitus. The fear that arises among the family members due to the possibility of complications related to diabetes mellitus that can lead to early patient death.

'I was afraid that if my mother was sickI was afraid that her illness would cause death.' (Family member 4).

'I am worried and scared, I am afraid of the danger of my husband's illness...'. (Family member 2).

The family was also worried about the boredom felt by the patients undergoing treatment because the family realized that diabetes mellitus is experienced for a lifetime.

'I feel sad and scared... and afraid because my aunt was diagnosed [with] diabetes by a doctor. I was also desperate and worried that if there was a wound th[en it] would [not] heal for a long time.' (Family member 7).

Patient adherence to taking medicine

Most patients adhere when it comes to taking the recommended medication. According to the family, patient compliance arises because of the free program from the Sub-District Level Health Center that the patients can follow every month. In addition, the patients are more likely to trust the doctor's advice on medication, as well as there being the hope of recovery with routine treatment.

'My husband still routinely takes the medicine ... and [not] just injecting insulin by himself.' (Family member 12).

'My mom is still taking medication regularly...'. (Family member 5).

'My mother is taking routine medical treatment at the sub-district level health center every month...'. (Family member 11).

Patient disobedience - diet

Most of the patients do not adhere to their diet. The most common reasons were boredom, not holding to their diet plan and always feeling hungry. Families have difficulty helping the patients as they prepare menus separately or the patients do not want to follow the dietary advice. Patients who feel bored following a different diet have often been diagnosed with diabetes mellitus for more than 5 years. There were also patients who did not adhere to the diet because of the difficulty resisting their desire to eat or always feeling hungry. This was common in the patients diagnosed <5 years ago. Only 2 families stated that the patient adhered to the diet.

'My father is difficult when abstaining from eating. Drinking coffee is also still do[ne]... hard to stop...'. (Family member 8).

'My mother had difficulty being told to go on a diet. She just wanted [to eat] when looking at any food.' (Family member 10).

'In the past, she liked to stick to the diet, but now she likes to be disobedient. She likes to secretly eat without me knowing.' (Family member 13).

Patient disobedience - activity

The families said that one of the obstacles when caring for patients is regular exercise. Most patients do not want to exercise regularly because they are lazy. The other reason was that they had a complication that was a difficulty in the context of routine exercise. In addition, some of the patients were still actively working so it is reasonable for them not to have the opportunity to exercise.

'My mom just do[es] exercise sometimes ... It's usually just a morning walk...'. (Family member 6).

'My sister never do[es] any exercise. She know[s] that she ha[s] to exercise but if I t[ell] her to do it, the answer[is that she is] just lazy ...'. (Family member 13).

'My father still works every day. He is returning late [in the] afternoon or evening. He often feels [that it is] difficult to adjust the time [taken] to do an exercise. Sometimes he runs early on Sundays.' (Family member 5).

Family expectations of the future

Most families hope that the patients can live their lives normally without complications while always in a good condition. Most of the families said that if the patients were treated for complications or have unstable blood glucose, then they feel helpless and difficult during the recovery period. This is due to the fact that most patients fail to comply with the treatment because they feel hopeless, especially the patients who have the role of being the head of the family. They tend not to want to think about the disease and continue to work as though they were not sick.

'.....hopefully there are no complications that occur in my husband.' (Family member 1).

'I hope [that] my husband is always healthy. He is the head of the family. If he is sick, no one will support my family.' (Family member 9).

DISCUSSION

Feelings of fear, anxiety or a loss of hope that appear when treating chronically-ill patients are often experienced by the family. The causes include family knowledge, the patient's physical and psychological condition, and socioeconomic status (Abubakari et al., 2016; Baek et al., 2014; Mayberry et al., 2016; Salom? et al., 2017). The ignorance of the family when it comes to how to provide care and the impact of care is caused by anxiety or fear in the family (Jannoo & Mamode Khan, 2019; Joo & Lee, 2016; Mayberry et al., 2016). There is also the fear of facing pain or the death of the family member diagnosed with diabetes mellitus. The physical condition of the patient, referring to the complications due to diabetes or the psychological state of the patient, is also a source of stress for the family. The socioeconomic condition of the family, such as the existence of health insurance, is another factor that causes anxiety in the family. The knowledge that diabetes mellitus is a lifelong disease that requires a lot of treatment and the associated costs is a major obstacle for the families with a lower socioeconomic status with a family member who is a patient with diabetes mellitus (Abubakari et al., 2016; Jannoo & Mamode Khan, 2019; Joo & Lee, 2016; Mayberry et al., 2016; Sina et al., 2018).

The family members often cannot refute the patient's wishes when they are undergoing diabetes treatments, referring to their diet and exercise, due to their existing emotional attachment. Culture and race as well as the close relationship also allegedly causes the family difficulty when it comes to rejecting the desire of the patients to not adhere to the recommended diet (Ansari et al., 2018; Gomes et al., 2017; Mansyur, Rustveld, Nash, & Jibaja-Weiss, 2015). In this study, where the patient was the husband of the participant, there is the cultural factor where the husband's position is higher than that of their wife. The wife must obey her husband even though it is wrong. When a child is taking care of their parents, if they do not fulfill the parents' desire to eat what they want, there is a feeling of guilt. This feeling arises in the family so it is difficult to maintain consistency in terms of diet or exercise.

Apart from the cultural factors, the desire of the families to make the patients happy is one of the obstacles faced. In this study, if a patient with diabetes mellitus is given a diet menu that is recommended by their doctor, they often do not want to eat according to it. The patient does not eat and so the family will try to fulfill the patient's wishes. The study found that this is common where the patient is over the age of 50 years old. Another case is where the patient has a good level of desire and motivation when it comes to adhering to the diet and exercise rules. The results will be better than before.

The adherence of the patient showed better results, namely the achievement of blood glucose stability (Abubakari et al., 2016; Gamboa Moreno et al., 2018; Mansyur et al., 2015; Simon-Tuval et al., 2016; Sina et al., 2018). The study results showed that

the patients with diabetes who were supported by their family had better adherence than those without family support. The family support that is needed by the patients most is emotional support. This strengthens the patients when facing the disease, allowing them to carry out better care. The family experience of caring for patients provides additional family knowledge and skills in order to provide the best care for patients with diabetes mellitus.

CONCLUSION

The treatment of diabetes mellitus patients at home requires an equality of perception between the patients and their family members. The patients, as the main character and the focus of the care, must be fully supported by their family in order to have the passion and desire to undergo treatment.

CONFLICT OF INTEREST

This study does not have a conflict of interest. The research is independently funded and has no sponsor interests. Each participant was free to choose to be a participant or not, and they could have stopped their participation in the research whenever it was deemed to be necessary without any negative consequences.

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