



Family support in caring for older people with diabetes mellitus: a phenomenology study

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KEYWORDS

Diabetes mellitus;
Family support;
Older people

Abstract

Objective: This study was conducted to gain a deep understanding of the experience of older people with diabetes mellitus (DM) about their family support in Tasikmalaya, Indonesia.

Method: The qualitative design was used with a phenomenological approach. Data were collected through in-depth semi-structured interviews of eight older people with DM. Ethical clearance was obtained from The Ethics Committee of the Faculty of Nursing, University of Indonesia. All the participants were provided with information about the purpose and the type of the study. Participants' type of participation in this research was voluntary. The recorded interviews were reported anonymously. Data were analyzed using the seven steps of Colaizzi include reading the transcript, listening to the transcript, choosing keywords, categorizing grouping, creating narratives, validating, and translating findings into a complete narrative.

Results: Three themes were identified about family support toward older people with DM such as the changes in older people with DM, optimum family support and suboptimal family support.

Conclusions: The physical and psychological changes which older people with DM had experienced affect the family support they had received. Therefore, this study will give a valuable contribution to the improvement of health service for older people with DM in Indonesia.

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Introduction

One of the indicators of health development in a country is heightened life expectancy or in Indonesia known as Usia Harapan Hidup (UHH). Indonesia Center Agency of Statistic shows there is an ascension in life expectancy from 70.1 in 2010 to 70.9 in 2015¹. This condition has led to an increase in the proportion of older people from year to year. It also has an impact on the health especially risk of the emergence of a variety of health problems and one of them is diabetes mellitus (DM).

The percentage of DM cases in Indonesia in individuals aged 55 to 64 years was 4.8%, in individuals aged 65-74 years was 4.2%, and for those aged 75 years and above it amounted to 2.8%². Although these are low incidence rates, diabetes is a serious illness which can impair the functions of the heart, kidneys, nerves, eyes, and blood vessels. The percentage of complications of DM in the National Referral Hospital, Cipto Mangkunkusmo Hospital, can be broken down as follows: 33.40% diabetic retinopathy, 34% neuropathy, 1.3% amputation, 13.3% heart disease (angina: 5.3%, MCI: 5.3%, heart failure: 2.7%), 5.3% stroke, and 10.9% peripheral arterial disease³.

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Tasikmalaya is one of the cities in West Java, Indonesia that had an increase in cases of diabetes in the older people from 313 cases in 2013 to 570 cases in 2014, an increase of approximately 50% of outpatients from 321 to 656 patients, as well as an increase in inpatient cases of type 2 DM from 64 patients to 262 patients⁴. This phenomenon shows that when programs and efforts to control blood sugar have not been comprehensively and only focus on individual procedures. If these programs and efforts continue, it can cause the rise of cases of DM with various complications. Therefore, family members support in caring their older parents at home is so important.

Most of the people in Tasikmalaya are Moslems and Sundanese (an ethnic in Indonesia). They have high respect for their parents. Commonly, all older people are cared by their family. This fact implies that older people can achieve good health status if they get optimal support from their family who take care of them. However, in reality, the number of DM cases in older people in Tasikmalaya is still increasing. Therefore, it is necessary to investigate the support provided by the family, which can be known through the experiences of older people with DM. According to facts and urgency to enhance health status of older people with DM, researcher got a research question. The research question is "How is the experience of older people with DM toward their family support in Tasikmalaya?"

Method

This study was conducted using a qualitative approach in order to explore and understand the phenomenon of family supports for older people with DM. Thus, to analyze and explain the phenomenon in detail, deep, and broad.

The participants of this research were eight participants who recruited by purposive sampling from three primary health care centers with the highest number of older people with DM in Tasikmalaya. The inclusion criteria were as follows: age 60 years and over, willingness to become respondents, and be able to recount experiences associated with their illness. In addition, the number of 8 participants, as research's samples were determined when it meets saturation from twenty candidate participants. This number was in accordance with Duke's recommendation⁵. The number of samples in a qualitative research study should be as much as 3 to 10, or by saturation. In this study, the data collection took place between September and October 2016, with a total of 18 interview sessions.

The method of participant selection in this study involved key informants who were primary health care nurses and *Kader* (volunteers in health care centers). The researchers met the participants in their homes, where participants have experience the family support. Data were collected using individual in-depth semi-structured interviews, field notes, and voice recorded with tape recorders.

Ethical clearance was obtained from The Ethics Committee of the Faculty of Nursing, University of Indonesia (ethics approval number 058/UN2.F12.D/HKP.02.04/2016). All participants were provided with information about the purpose and the type of the study. They also had signed a consent signifying acceptance of the procedures involved in study,

the voluntary condition of their participation, and anonymous reporting of recorded interviews.

Data were analyzed using the seven steps of Colaizzi include reading the transcript, listening back transcript of interviews, selecting keywords, classifying categories, making narratives, and seeking validation from the participants about their actual experiences compared with the researchers' transcribed interview data.

A test of the trustworthiness of the data was conducted based on Lincoln and Guba's gold standards involve credibility, dependability, confirmability, and transferability⁶. The data's credibility in the transcript had through the recheck process if a statement was found to be confusing or poorly understood. It was clarified by consulting the statement with the participants. Dependability and confirmability in this study were tested by showing how the results were gotten from data collection and the analysis process by involving the promoter of this research as the external reviewer. The external reviewer checked the accuracy of the data and confirmed the analysis of the results. Transferability was ensured by describing the themes which identified by older people participants with DM from other place to check the participants' understanding about the delivered themes.

Results

Eight participants were interviewed, one of whom was male. The ages ranged from 63 to 74 years. The participants included individuals whose education varied from elementary school to university degrees. Three participants lived in a nuclear family and four in an extended family. Five were married, and three were widowed and had not remarried. The amount of time the participants had lived with DM varied from two to sixteen years, and all participants were Sundanese.

The results highlighted three main themes: changes in older people with DM, optimum family support, and suboptimal optimal family support. Psychological, physical, and spiritual changes were identified as subthemes of changes in older people with DM. The second theme, optimum family support contained several subthemes such as the provision of information, facilitation, and appreciation of the role played by older family members. Thus, the subtheme of suboptimal family support was limited facilities.

Changes in older people with diabetes mellitus

Psychological change was found to be one of the most prominent subthemes of the changes experienced by older people with DM. The psychological change was identified from several categories, including depression, anger, and acceptance, as indicated by the following statements of participants:

"I feel sad. I want to be alone and I always ask to my heart why the others do not have a disease like me ... even though I did not have any offspring diabetes, at the night before I go to bed I often cry, why when I so old became a sickly like this, I want to be healthy" (NS).

One 74-year-old participant mentioned that she often feels sad when her daughter speaks somewhat loudly, as described below:

“Now I often felt hurt especially if my child talks a little loud. I feel so sad, maybe they mean well, they care about me, worry about my blood sugar go up again” (KM).

Anger was expressed by half of the participants. A 72-year-old participant described often experiencing uncontrolled emotions:

“Since I have diabetes, I felt a change in my emotions, I get angry quite quickly ... I could still control for emotions before and I don’t know why” (TNG).

Three participants expressed feelings of resignation about their health issues, because what was happening was their destiny. One of these participants had suffered from diabetes for 16 years and made the following statement:

“Even though health control, medication, and diet are so important, but more important is surrender to God, accepting destiny happened and sincere” (YN).

Physical changes as the second subtheme are described by changes in the participants’ activities and the emergence of other disease such as heart disease, high blood pressure, and stroke. Some participants said that the changes in their daily activities were caused by numbness, blurred vision, weakness, and fatigue.

“Feet and hands were numbness, sometimes when I’m holding a bucket, I do not feel a sudden drop vision, my vision was blurred. After I had diabetes, for daily chores, I didn’t do it anymore since everything was done by my daughter” (NS).

“I felt my foot numbness and I felt fatigue, so I did not dare to leave the house unless accompanied my daughter. Once a day, I ever fall down because of my fatigue then my hand broken so until now, I am afraid to leave my house. I am not allowed to leave the house by my husband and my children so I just stay at home. While at home, I spend most of my time with sleep so I often feel sleepy” (YN).

In terms of other physical changes, three participants said they suffered other diseases after they diagnosed with DM such as heart disease, high blood pressure, and stroke. The following statements were disclosed by two of the three participants:

“I suffered from diabetes since 2014 and the last admitted to hospital in 2015 because heart disease and hypertension with high blood pressure, my blood pressure was 180/100 mmHg. I stay at hospital for one week and until now I often feel tired easily when I do some activities” (NS).

A male participant said:

“I attacked a mild stroke from 2010, maybe too much thinking, thinking about disease (diabetes mellitus). Thus I have diagnosed with diabetes mellitus since 7 years ago” (MR).

Spiritual changes were identified from the increase in religious activities. Six participants experienced an increase in religious activities after suffering from DM. Three of six participants said they had more prayers at night and always say the main prayers on time:

“I try to enhance religious activities for example, I seldom wake up at night before, but now I do *Salat Tahajud* every night. I do that because I think the most effective drug is prayer (YN).

“I often do *Salat Tahajjud* (Islam night prayer) every night, sometimes when I pray I cry. I cried because I remember my sins and death” (NS).

“I have never missed *Salat*. I pray on time. Even though I felt tingling and not strong enough to stand for long time, I do *Salat* while sitting” (TNG).

Optimum family support

Five participants described receiving optimum family support. Provisioning the information, facilitating, appreciating the role and expressions were subthemes identified. and these are further described in this section. The provision of information can be shown by the statements from participants that explain how family members always reminded them to live a healthy life, as disclosed below:

“My children always remind me to eat regularly, not too much, on a regular schedule, not having breakfast not too late, and not to eat sweet foods. I always do exercise at home with my daughter. She also has attended seminars about diabetes mellitus in hospital” (YN).

The oldest participant said that her family helped her meet daily dietary requirements. Additionally, her daughter was very attentive in general, as described below:

“My daughter was always cooking for me every day, it has been set aside, the rice yesterday, the meat is in the steam, and node vegetable, she always reminds me to do exercise or accompany me to jog when she has a free time” (YT).

Another participant said that his son was very attentive to his health care costs:

“Although I had my retired fee, my children always send me money especially my children in Papua. He is very attentive to me by giving some money for me every month to pay my health check-ups” (EM).

Families still pay attention to the existence and role of parents, as mentioned by the following participants:

“If my son was on duty out of town, he entrusts his children with us. We feel so very happy because we feel we’re needed besides caring for grandchildren is an interesting activity for us” (EM).

Suboptimal family support

Suboptimal support from family was identified by the sub-theme of the limitations of the facilities owned by the family. This condition was reflected by less fulfillment of older people's dietary needs, as well as the lack of availability when help was required. The following statements contain descriptions of these issues:

"If my daughter cook, she gives me side dishes, but if she is not cook, I will eat with salt which was familiar for me. I understand that my daughter's condition is still underprivileged" (NS).

"If I have any problem, I want to tell to my children, but they are so far away. If others have a cell phone, they can directly call their children, but not for me because I do not have a cell phone. Thus, I just do *Wudu* (Moslem ritual by washing to be performed in preparation for prayer and worship) to make me feel better" (TNG).

Discussion

The greatest strength of this study is the information obtained can be used as a reference to improve the quality of life of older people with DM through the optimization of family support to meet physical, psychological, and spiritual needs. Psychological changes are the most notable changes that occur as an impact of DM. Older people respond it as a loss in which older individuals identify that condition such a change in health status. This response is often manifested as expressions of anger, depression, and acceptance. Older individuals may become irritable because of their loss of freedom, especially in terms of food selection and what activities they are able to do. This is consistent with the statement of Susilawati that the angry response experienced by clients when they become aware of reality is an experience of loss. The client experiences increased feelings of anger, which are often projected to the existing environment.

Another emotional reaction that occurs as a response to this loss is depression, which is experienced as a deep sadness, lack of motivation, and despair. Life post-diagnosis becomes associated with rules and provisions regulating diet, activity, health control, and stress management, and this lost freedom creates a great deal of tension in older individuals. Some are unable to accept these conditions and fall into depression. A cohort study of older people aged 70-79 years in Japan showed that older people with DM have an increased incidence of depression compared to the incidence in older people without DM⁷. Other findings revealed psychosocial issues in older people with DM in east Taiwan expressed by a reduction in activities and feelings of despair and stress⁸.

Older individuals who diagnosed with diabetes are twice as likely to become depressed compared to the older individuals who do not have diabetes⁹. A study which has been done of 2,830 older people Americans from Texas, Colorado, New Mexico, Arizona, and California reported that 47% of older people diagnosed with DM have symptoms of minor depression¹⁰. In contrast, older people in Hong Kong do not

view DM as a disease which can be something that interferes their daily life activities. It happens because they have adapted DM as part of their lifestyle¹¹.

A successful adaptation process enables an older individual with DM to eventually accept his or her condition. Responses received regarding the disease in this study indicated older people show a patient manner in a way to get closer to God. Spiritual change in the older people participants of this study was reflected in an increase in the activity of worship. Older people with DM feel with good spiritual practice, they become closer to God¹². Based on the findings of this study, spirituality is one potential approach to manage stress and to act as a support for the older people in terms of minimizing irritability and depression.

Emotional stress is one trigger of blood sugar increase in older people with DM. Thus, a comprehensive approach to DM management is required. The family must become involved, because the older individual is particularly dependent on family due to his or her various limitations. Optimum family support can be one solution to maintain the health of older people with DM. The results of a social support study for 507 older people in China with chronic diseases and mental function disorders found that instrumental support and emotional support equally have a high correlation with symptoms of depression and anxiety, but emotional support has a greater influence on such symptoms. Emotional support is manifested in the form of affection and attention, whereas instrumental support refers to attention to physical needs such as food, drink, and rest¹³.

Other researches on family support involved the examination of efforts to control the risk factors for blood sugar-related metabolic control, diet, and exercise of 19 patients with DM. The results showed that family support is the most important factor in maintaining metabolic control of blood sugar that affects the quality of life of patients¹⁴. Meanwhile, the attitude and culture of solidarity among family members in Latin countries such as Mexico are reflected in mutual support among family members. The high level of responsibility taken on in the care of a family member with diabetes leads to a decrease in complications and a reduction in small stressors for that family member¹⁵. Based on the numerous studies above, it is evident that the level of family support has a significant effect on the older people with DM to maintain their health. In reality, however, not all families can provide optimal support, thus leading to health problems in older people with DM.

This study was limited by the difficulty in translating and interpreting some of the remarks expressed by the participants in the local language of the Sundanese. Thus, it was not uncommon for researchers to do reconfirmation with the participants about their statements which have recorded to get the same perception.

Conclusions

Psychological, physical, and spiritual changes often occur in older people with DM. These changes affect the way a family responds in terms of providing support to their elderly family members. Most older people feel their family support is optimum, though the way family members provide sup-

port is not always in line with expectations, thus causing stress. Additionally, suboptimal support toward older people with DM happen due to resource constraints is still perceived by some older people. Therefore, it is necessary to optimize support for families through a variety of approaches, both across programs and sectors. Therefore, family support can be a reference to create a family nursing intervention model in order to improve the health status of older people with DM.

Conflicts of interest

The authors declare that there are no conflicts of interest.

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