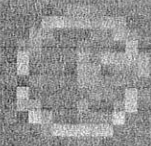


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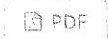


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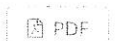


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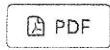
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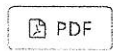
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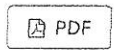
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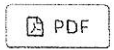
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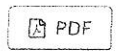
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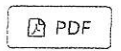
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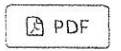
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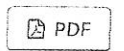
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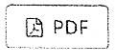
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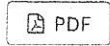
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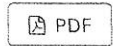
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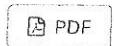
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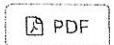
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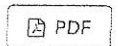
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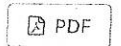


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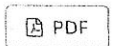
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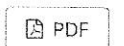


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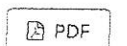
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Family Support in Caring for Diabetes Mellitus Patient: Patient's Perspective

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Abstract

BACKGROUND: Perspectives of diabetes mellitus patients on family support received during the treatment of their disease at home has high complexity. The family's intention to help patients to take care of themselves at home can lead to misperceptions or is not well accepted by diabetes mellitus patients.

AIM: The aim of the study was to explore the support provided by families in the care of diabetes mellitus patients at home based on the patient's perspective.

METHODS: A phenomenological study using semi-structured questions was chosen as a design in this study. A total of 19 participants were recruited using criteria including being diagnosed with diabetes mellitus for at least 1 year, outpatient, and willing to participate in the study. Data analysis used seven steps of descriptive phenomenological analysis from Colaizzi including data recognition, identification of significant statements, formulating meanings, grouping themes, developing complete descriptions, producing fundamental structures, and seeking verification of fundamental structures.

RESULTS: This research shows that the support needed by participants comes from the nuclear family. The first theme identified is the family function as participants' perceived support. The second theme identified is the family role as participants' perceived support. The fourth third theme identified is perceptions of family support received. Moreover, the final theme found in this study is perception of spiritual support by the family.

CONCLUSION: This research implies that diabetes mellitus patients need support from their families to accept the disease and eventually volunteer to carry out their disease care at home.

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Introduction

The number of diabetes mellitus patients in the world is projected to increase by 204 million (48%) from 425 million in 2017 to 629 million in 2045 [1]. Indonesia is ranked 6th out of ten countries with the highest number of patients diagnosed with diabetes mellitus in the world, which is ten million people. Most patients diagnosed with diabetes mellitus were aged 20–64 years, amounting to 327 million people compared to those aged 65–99 years with 123 million people [1]. The incidence of diabetes mellitus increases at the age of 55–64 years by around 4.8%, and diabetes mellitus is more experienced by women (1.7%) than men (1.4%). In addition, the occupation factor (2.0%) and higher education (2.5%) are one of the indicators of increasing the incidence of diabetes mellitus because it is above the prevalence value of diabetes mellitus (1.5%) [2].

Diabetes mellitus is also estimated to be the cause of death for 4 million patients between the ages of 20 and 79 years in 2017. The percentage of deaths of patients diagnosed with diabetes mellitus globally reaches 10.7%, higher than the death rate due to HIV/

AIDS infection (1.1 million people), and tuberculosis infection (1.8 million people). The total financing for the care of diabetes mellitus patients (aged 20–79 years) worldwide also increases every year, it is estimated that around 548 billion USD in 2013 to 673 billion USD in 2015 and 727 billion USD in 2017 [1].

Diabetes mellitus is a chronic disease that states with hyperglycemia [1], [3], [4]. The increasing number of diabetes mellitus patients each year also increases morbidity and mortality due to complications arising from diabetes mellitus. After a person is diagnosed with diabetes mellitus, he must do self-care because most of the care is done at home [5] including diet, blood sugar monitoring, exercise activity, medication, and foot care [6], [7].

Self-care that aims to allow patients to maintain glycemic control rises to complexity [8]. The achievement of glycemic control is the goal of treating diabetes mellitus patients at home and one of which is the achievement in carrying out self-care [9]. Self-care adherence to diabetes mellitus patients is currently not entirely good and optimal [10], [11], [12], [13]. This compliance can be obtained by internal and external factor of the patient.

External factors that indirectly influence glycemic control in diabetes mellitus patients are social support [14], family support [15], and support for health personnel and the health service system [5], [16]. Several previously described interventions were used to improve the care of diabetes mellitus patients, both individually and involving families in its implementation.

Implementing existing cultural care and adopting individuals diagnosed with diabetes mellitus are considered as daily values while implement self-care [10], [17]. The results showed that Korean-American immigrant diabetes mellitus patients had difficulty in adjusting the menu according to the type of food habits in their country [11], while traditions from certain ethnicities also increased the risk of diet failure in diabetes mellitus patients [17], [18], [19]. Barriers to implementing diet that improve patients such as diet changes before and after diabetes mellitus diagnosis, balance of food composition, frequency, and food control.

Compliance with self-care also takes advantage of the patient's spiritual values, which have enthusiasm, passion for gaining, belief, hope, and meaning in life [20], [21], [22]. Spirituality influences a person to show behaviors that support their health [23]. The spiritual meaning for a person diagnosed with diabetes mellitus is accepting the disease along with all treatment plans and self-care management, carrying out self-care with sincerity, patience, and "tawakal" or trusting in God's plan because what is lived is part of his daily life, as a part of more worship activities preferred in their belief or religion [20].

The phenomenon found in the field shows that the glycemic controversy of diabetes mellitus patients that is not achieved is not only due to internal factors of the patient but also from external factors, namely, family support. Obviously, the family support received by diabetes mellitus patients varies. The way patients perceive the support they receive will also vary. Positive support given by the family and also positively received by diabetes mellitus patients is also important. Often families feel that they have to provide support but are perceived differently by patients. As a result, there is no good mutual relationship and it has an impact on the treatment of diabetes mellitus patients in the future. This study aimed to explore the perceptions of diabetes mellitus patients on the support provided by their families after diabetes mellitus diagnosis has been enforced.

Methods

Design

A phenomenological study using semi-structured questions was chosen as the design in this

study. The purpose of this approach was to provide an interpretation of family support from the participant's point of view. Data collection using in-depth interviews begins with the question of "what kind of family support do you get after being diagnosed with diabetes mellitus?" The questions then develop based on the responses from the participants.

Setting and sample

A total of 19 participants were recruited using criteria including being diagnosed with diabetes mellitus for at least 1 year, outpatient, and willing to participate in the study. Data collection was carried out in three primary health centers representing rural and urban areas as well as the demographics of coastal, urban, and mountainous areas. The purpose of selecting sites is to represent the characteristics of the participants.

Data collection and analysis

Researchers received assistance from three nurses in charge of the non-communicable diseases program at each primary health center. The person in charge of the program played a role in selecting potential participants and providing a place for interviews. Interviews were conducted in three primary health centers before the COVID-19 pandemic. Some of the participants were interviewed using video calls during the COVID-19 pandemic.

The primary researcher conducted semi-structured interviews in a private room at the health center. The interview content included views of the family support felt by participants after being diagnosed with diabetes mellitus. Field notes were also collected. Interviews were audio recorded and transcribed verbatim. Interviews were conducted for 40–60 min each patient.

The study maintains the validity (trustworthiness) data obtained includes credibility (internal validity), transferability (external validity), dependability (reliability), and confirmability (objectivity) to the data obtained from participants.

Data analysis used seven steps of descriptive phenomenological analysis from Colaizzi's including data recognition, identification of significant statements, formulating meanings, grouping themes, developing complete descriptions, producing fundamental structures, and seeking verification of fundamental structures.

The analysis step was carried out to find the themes that emerged from the interviews conducted. In the initial stage of the analysis, the researcher read the existing verbatim transcripts carefully. Table 1 describes the significant statements identification and thematic clusters after we perform the verbatim analysis step. Table 2 describe thematic analysis and theme.

Table 1: The example of significant statements identification and thematic clusters

Significant statements identification	Thematic clusters
... my children's struggles, also my husbands, my son-in-laws, and my grandchildren struggles, right? They all really take care of me to be healthy huh... *P9	Family struggle
"When I See their efforts to take care of me, to cure me, its touch my heart. They have to work, but they always took care of me..." P14.	Family attention when I get sick
"...my children always care about me, especially when I got sick..." P1.	Family attention when I get sick
"When I was got sick, they always ask me to get some rest, not allow me to do anything..." P16.	The family care
"...my wife knows a lot about my disease, she always come with me to the primary health center if she can" P2	The family care
"...my family always help me with everything... my food, my blood-glucose, my medication... whatever they will do for me, they do their best for me..." P10	Family help me deal with illness
"they are really take care of me... if night fall and I get starving, they will allow to eat some snack, they understand what I want, what I need... And when I got sick, they always there."	Family presence
"... Sometimes I get annoyed when they not allow me to drink some coffee. I said I don't want to be banned anymore, how come I can arrange it myself. Now, my husband and my children understand me better..." P7.	Communication is important to each other
"When my wife reminds me about the medication, especially when she do it in front of the other people, I feel like angry. So uncomfortable, I don't want everyone know that I'm sick... I still can be a productive person, right? Now my wife knows what I want, and she not annoying me again" P17.	Communication is important to each other
"...my family make me strong, I cannot do anything without them..." P10.	Family is my strength
"When I see my children... they still need me, so I have to be healthy than now..." P9.	Family is my strength
"They always reminds me to present God in my life, especially when I get sick..." P14.	Reminds me to god presenting
"Thanks to God, when I got sick, I get a fully support from my wife, she always though me to pray for my own health..."	Reminds me to god presenting
"my partner reminds me to always worship when I sick" P7.	Spiritual faith from family
"only God gives us pain and then heal. As long as we are grateful for what happened, even though we are sick, it doesn't feel heavy anymore. Especially if there is a family who accompanies it	Spiritual faith from family
"They help me when I have to do a worship. I got obese for many years, so hard to worship and pray, someday my husband was made a special chair for me to do my worship" P9.	Family support to spiritual need
"I surrender to God's decision about my illness" P9.	Give up on God's decision
"Healing belongs to God, I leave it all to him..." P14.	Give up on God's decision

*P_number: Number of participant

Then, the researcher extracted significant statements that pertain to the phenomenon which were used for the next step in formulating meaning from significant statements. The researcher then aggregated the meaning that had been formulated into theme clusters and themes. Then researchers developed an exhaustive description of the phenomenon's essential structure or essence. The next step was making a

Table 2: Thematic cluster and theme

Thematic cluster	Theme
Family attention when I get sick	The perceptions on family function
The family care	
Family attention when I get sick	The perceptions on the role of the family
The family care	
Family help me deal with illness	The perceptions on family support received
Family presence	
Family help me anytime	The perception on spiritual support by the family
Communication is important to each other	
Family is my strength	The perception on spiritual support by the family
Reminds me to god presenting	
Spiritual faith from family	The perception on spiritual support by the family
Family support to spiritual need	
Give up on god's decision	

description of fundamental structure of the phenomenon which was subsequently generated. The last step was validating the findings of the study through participant feedback completing the analysis.

Ethical approval

We obtained ethics from the Health Research Ethics Commission of the Faculty of Nursing Universitas Airlangga number 1912-KEPK.

Results

Participant demographic

Table 3 shows the 19 participants, the majority of participants were over 45 years old, female, diagnosed <10 years old, and lived with their nuclear family. The results of the study also showed that out of 19 participants, nine participants did not work, four participants had a trading job, and six participants worked as employees both in state and private instantaneous. The youngest age of the participants was 19 years, and the oldest age was 70 years. The minimum time the patient was diagnosed with diabetes mellitus was 1 year (5 participants), and the longest was 20 years (1 participant). Eight participants live in rural areas and 11 participants live in urban areas.

Table 3: Participant's demographic

P	Age	Gender	WS*	ID ^b	FT ^c	LA ^d
1	59	Female	NE ¹	9	NF ¹	Rural
2	45	Male	NE ¹	1	NF ¹	Rural
3	50	Female	NE ¹	1	NF ¹	Rural
4	42	Female	NE ¹	1	NF ¹	Rural
5	48	Female	NE ¹	1	NF ¹	Rural
6	56	Female	NE ¹	8	NF ¹	Rural
7	60	Female	Tra ²	10	NF ¹	Urban
8	65	Male	CS ³	20	NF ¹	Urban
9	52	Female	NE ¹	2	EF ²	Rural
10	44	Female	CS ³	5	NF ¹	Urban
11	46	Male	GE ⁴	2	NF ¹	Urban
12	70	Female	NE ¹	15	EF ²	Urban
13	19	Female	St ⁵	2	NF ¹	Urban
14	70	Female	NE ¹	3	EF ²	Urban
15	50	Female	Tra ²	1	EF ²	Urban
16	52	Female	Tra ²	1	NF ¹	Rural
17	49	Male	Lect ⁶	3	NF ¹	Urban
18	54	Male	Tra ²	10	NF ¹	Urban
19	54	Female	Lect ⁶	18	NF ¹	Urban

*working state (1 not employee, 2 trader, 3 civil servant, 4 general employee, 5 student, 6 lecturers), ^billness duration in years, ^cfamily type (1 nuclear family, 2 extended family), ^dliving area

Source of family support

The question asked to find out the support received by participants is "who has a role to provide support after you are diagnosed with diabetes?." Almost all participants answered that that support was obtained from their family members/nuclear family, either those who live with the participants or those who live around the participants. The support provided was mostly obtained from nuclear families, namely, the children and the participants' spouse. However, support

from outside the nuclear family was also found, such as from siblings or grandchildren. It can be evidenced from the following answers from the participants:

All my children ma'am. Everyone reminds me. Even though they are far away, they are still calling. The children in Bandung are likely to remember (participant 14).

My wife is also very respectful, attentive, sometimes she reminds me (participant 17).

My younger brother who is in Tangerang, he said, 'Don't think about the costs, that's my responsibility (participant 2).

The support is come from my parents, of course, both ways (participant 13).

The perceptions on family function

The results showed that according to the family participants, they have carried out family functions as health-care providers. The participants received attention related to care since they were diagnosed with diabetes mellitus from their closest family, such as a partner or child. The results of the research are seen in the following statement:

The struggle of the children, the struggle of the husband, the in-laws, the grandchildren, right? They all really took care of me to be healthy, huh (participant 9).

The one who put concerned here, her name is Sri, she is not married. She works at gas station. She is who always take care of me, always come with to see a doctor (participant 16).

The perceptions on the role of the family

The role of the family that stands out in this study that is felt by the participants is the role of therapy. This role occurs when a member of the family experiences illness. The therapeutic role is felt not only by the participants physically but also psychologically and spiritually. The family becomes the closest person to provide care to the participants. The results of this research can be validated from the following statements:

My children have already paid attention to me. Especially when I am sick (participant 1).

It's too bad everyone (kids), just cry ... 'poor mother,' he said. InshaAllah (surrender to God's decision), just pray for recovery, just ask the children to pray, let me get together again, get well To get well (participant 15).

The role of family therapeutics received by participants supports participants in carrying out diabetes mellitus treatment at home. This can be seen from the following participant statements:

She knows (wife), if you have diabetes you have to reduce your rice, my wife also likes accompany me here (go to the health center) when she is on vacation (participant 2).

The wife is a little bit protective (chuckles), especially when eating, but now also changes this pattern ... the cooking pattern is like that ... Then my wife also reminds me when to take the medicine (participant 15).

The perceptions on family support received

The support given by the family to the patient has a big impact on the participants. The participants become stronger, more grateful, and accept their condition because of the support provided by their families. The participants' perceptions about the family support received are shown in the following statements:

They (family member) give me support 100 percent, no, maybe one thousand percent of times (laughs happily). Moreover, my children... especially all of them, the youngest, the first child, the husband. Sometimes my husband is silent, right, that's his own way ... yes ... cares for me in his own way. Help me Alhamdulillah (feel grateful). Even my grandchildren who are still small in their own way are always make me happy, even with words... even those who are sick become strong nanny. The one who was sick was finally ... oh my God ... I said, until that much (remembering the family sacrifice) (participant 9).

Previously, I refused, I didn't accept diabetes, I often complained, "oh why is this like this." Like screaming. Children who always remind me to pray, always pray, all kinds of things, are calmer now (participant 14).

The perception on spiritual support from the family

This study found one theme that was obtained several times from the participants, namely, the spiritual support provided by the family to the participants. This spiritual support is what makes the participants sincere in accepting their illness and living their lives more calmly. The following statements were made by participants regarding the spiritual support:

Grateful because that one child always accompanies me, prays for me, reminds me to worship (participant 15).

So the support capacity is extraordinary from the family, so it is very internal that can give a very strong giroh (the meaning of spirit in Islam). Alhamdulillah (feel grateful) it continues to strengthen sincerity (participant 19).

Discussion

Diabetes mellitus is a chronic disease and requires many years of treatment [3]. The standard

of care for diabetes mellitus patients includes management of diet, activity, medication, and glycemic control [24], [25]. The results of previous studies show that it is difficult for patients to undergo such treatment, so they need support from various parties, one of which is from their family [26], [27], [28], [29], [30].

One of the supports received by diabetes mellitus patients in their care at home comes from their families. Family support received by the patients will increase patient compliance in their care at home [10], [31]. The assistance needed by diabetes mellitus patients at home includes diet [30], [32] assistance for daily activities, health care, financial support, attention, and problem solving [32] as well as in activities, blood glucose monitoring, and medication [33]. Diabetes mellitus patients who get support from their families feel better due to emotional and behavioral support [34]. The results showed that most of the participants lived with the nuclear family and received care from their children or partners. The care that participants felt was starting from care when they were sick, attention, and support for running diet.

Every family has its own process in overcoming health problems in the family, both regarding the health of family members and the health of the family as a whole. The process in the family can have a big impact on the health status in the family [35]. The family has various roles among family members, such as provider roles (breadwinners), housekeeper and care roles (caring for the house and children), socialization roles (socialization and family interactions), sex roles (reproduction), and therapeutic roles (caregiver roles). The role that each family member plays in accordance with the developmental conditions in the family, aims to adapt and solve problems one of which is health problems in the family [35].

The support felt by diabetes mellitus the patients helps patients accept and adapt to their sick conditions [35], [36]. Although the patient may not show certain clinical symptoms, the chronic condition experienced by diabetes mellitus patients must occur and has impact on their physical and psychological health. Therefore, the support received, especially from the family, will help the patients accept and immediately adapt to their sick condition [27], [31], [37], [38].

The results of the study found four main themes about participants' perceptions regarding diabetes mellitus. The first and second themes are the participants' perceptions on the function and role of the family after the participants were diagnosed with diabetes mellitus. The analysis of the two themes was that the participants felt that after being diagnosed with diabetes, the participants needed a specific function and role from the accompanying family. These specific functions and roles are related to the function of providing healthcare by the family and the emergence of the sick role of the participants who need a therapeutic role from the family. These two things are related to each other in

the context of the relationship in the family. Every family who has a sick family member will demonstrate both functions and roles mentioned in efforts to deal with and resolve health problems [35], [39].

The third theme found was the participants' perceptions on the support they received from their families. Most of the participants needed psychological strengthening in the form of motivation and emotional support from their families to deal with their condition. This motivational and emotional support makes the participants strong in accepting and adapting to their conditions. In addition, most participants are in the productive age range and have children who are at school age or at the end of school. This condition becomes a separate reinforcement for the participants to accept and immediately adapt to the conditions. Mostly, the participants accept their condition because of their children or family, the participants still want to see their offspring succeed. Thus, they grow strong to make peace with diabetes mellitus. The acceptance of patients for their disease is certainly not easy and requires support from the family. The reciprocal relationship between family members in dealing with health problems in the family makes each family unique. The ability of the family to use the resources owned by the family to solve health problems in the family is an important point [39], [40], [41].

The fourth theme found was the participants' perceptions on spiritual support from the family. In this study, all participants involved are Muslims. The trust and values in the family influence family behavior in caring for family members who are sick, such as diabetes mellitus patients [35], [36]. The ease with which diabetes patients accept and make peace with their disease cannot be separated from their spiritual role [42], [43]. In this study, all participants expressed their surrender to God and took care seriously as one of the values of the worship. Finally, all participants gave everything to God, but almost all participants experienced rejection when they were diagnosed with diabetes mellitus. This condition is common, especially in participants who are in the productive age range. The confusion about the disease's impact on productivity is the main reason besides the fear of complications and death.

The previous studies have shown a link between spirituality and a person's acceptance of their illness [21], [44]. When someone is sick, it is only natural that he tries to treat himself to a doctor or other treatment. The effort made to seek this treatment is a form of acceptance of the disease being experienced. A person's acceptance of the pain he experiences is based on a sense of sincerity and submission to God's destiny, namely the illness he experiences. This is a form of complete submission of a creature to its creator [20], [22], [45]. The worship in the form of routine care, especially for patients with chronic diseases such as diabetes mellitus, can become a habit or culture in the family. As a result, in the end, self-care habits such as

maintaining diet, routine physical activity, and glycemic control and adhering to medication will be the main parts in treating diabetes patients will be accepted as a form of worship in a spiritual context.

Conclusion

This study concluded that family support is needed for diabetes mellitus patients to support their care at home. The greatest support comes from the nuclear family. In addition to physical support, spiritual support is also needed to strengthen patients for long-term treatment. Future studies can quantitatively examine the impact of family support on diabetes mellitus patient adherence and quality of life.

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