



Factors Affecting The Family Burden Of The Palliative Family

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ABSTRACT

The process of palliative patient care indirectly causes a burden on the family. This study aims to determine the description of the family burden in caring for palliative patients. This study is a qualitative research with a phenomenological study design. Participant criteria are families who care for patients for at least 6 months. The number of respondents in this study were 4 respondents as care givers of palliative patients. The research method using the analysis method used includes categorizing themes, compiling sub-categorization of themes and the last is the coding process. The results of the study showed that there was a description of the family burden of palliative patients and a description of the factors that influenced palliative patients including economic status, patient complaints, family support, family perception, availability of treatment support tools, and the ability of families to manage family burdens. The burden on the family can be reduced by training the family to manage the existing factors.

Keywords: factors; family burden; palliative

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INTRODUCTION

The family is a unit whose members influence each other. Friedman (2010), explains about the influence of families with sick family members, where serious illness or long-term disability of a family member greatly affects the family and its function. Bailon and Maglaya 1978 in (Friedman 2010), also explained that each individual in the family will influence each other, interact with each other in carrying out their roles. The explanation illustrates that if one family member is sick, it will affect other members, one of which is the burden of the family.

Palliative is a chronic and terminal disease. Families with palliative patients often experience limitations in social relationships and work activities, financial difficulties and negative impacts due to the process of caring for sick family members. Family burden is related to the psychological reactions of family members including feelings of loss, sadness, anxiety and shame in social situations, coping with stress on behavioral disorders and frustration caused by changes in relationships. Sugiyanto, (2020) explained that there is a family burden on the family of palliative patients, the burden of care is influenced by the ability to care for the family because of the considerable pressure associated with the care including physical, psychosocial and financial burdens.

In the preliminary study, a description of the burden of families with palliative patients was obtained. Description of the research environment Rt 06 Rw 09 Bintoro Demak is a village

area with middle to lower economic status. The results of the study found that there were 4 families who had palliative patients, from the results of the initial assessment, it was found that the burden of families caring for palliative patients was one of them feeling tired because all day caring for palliative patients. This study aims to determine the factors that influence the burden of palliative families using a qualitative research approach. The specific objectives of this training are being able to: Knowing the description of the family burden experienced by families in palliative patient care.

METHOD

This study uses a qualitative research method with a phenomenological approach. The number of participants in this study were 4 participants. Participant is a palliative patient's family in Centra Java who is a palliative patient with the criteria of having been sick for more than 6 Monts. The research method using the analysis method used includes categorizing themes, compiling sub-categorization of themes and the last is the coding process.

RESULTS

This study was followed by 4 respondents the family of a palliative patient in Rt 06/Rw 9 Bintoro Demak who is a palliative patient with the criteria of having been sick for more than 6 months.

Tebel 1.
List of Research Respondents (n=4)

No	Initials	Age	Education	Sex	Sick time	Disease
1	Mrs Yt	41	senior High School	Woman	9	stroke
2	Mrs Mr	60	Elementary School	Woman	5	Stroke,Hernia
3	Mrs Nm	64	Elementary School	Woman	5	Dm Can't See
4	Mrs Sp	52	senior High School	Woman	19	Chf, Oa, Dm,

Table 1, shows a description of the characteristics of the respondents, including the gender of the respondents mostly female, with the highest education being high school and the lowest being elementary school, for respondents the lowest age is 41 years and the oldest is 64 years, the longest duration of illness is 19 years, and according to There are comorbid diseases that have 1 diagnosis of disease and at most are 3 diagnoses of disease.

DISCUSSION

The results of the researchers have identified 2 research objectives including

1. Overview of the family burden of palliative patients

The burden of the family in caring for palliative patients can be described by four themes including:

a. Physical burden

Physical burden is a care giver's physical complaint that arises as a result of the impact of palliative client care. The results of the interview obtained a description of the physical problems of the three respondents.

" Truly, I'm tired, but that's normal. Otherwise, his conditions are getting better than those days at the early stage when I start to care of him. Everything had to be on my assist. Walking, taking meal, going to the toilet (because he's not willing to wear diapers), etc. He's heavy and that quite exhausting." (P4)

"..... I don't know what I have to say anymore. My husband wasn't the only one who I had to care off, there's still many things that I had to care. I've spent my whole time for

him and sometimes I can't get enough time to sleep. These conditions annoy me and make me angry." (P2)

b. Psychological burden

Psychological burden is described as negative feelings that arise as a result of palliative patient care activities. The four respondents conveyed negative feelings or psychological burdens.

"I feel very annoying when my mother wants many things for her meal, whereas those meals are prohibited for her. Then all of us get annoyed. As a daughter, I wish to care of her as good as I can, but on the contrary, she feels like we restricted her in many ways. All I worry and afraid of, is the time that might will come, when she's getting relapse or even getting fall by any case. Because I can't be by her side all the time." (P1)

"It is true that I'm getting very annoy and sometimes angry. Suddenly all come together. Taking care of him, house need, children, etc. All of that become worse when my thought is getting busy with many things while he is on demand for other many things. So irritating, so annoying, makes me angry (P3)

"Sometimes when he wants any prohibited meals or drinks, we debate each other. Then suddenly it makes him angry. My aim - also my children's aim - it's just to keep him well and healthy. But on the other side, he feels like we restrain him." (P4)

c. Financial burden

Financial burden is described as a limitation in meeting the needs of palliative patients, including efforts to meet the needs of care and treatment.

"We don't have any insurance. It's all from our personal saves. We've spent approximately IDR 15 million for the surgery and medicine. I've got nothing to rely on. I still depend on my children's help and selling chips" (P2)

d. Social burden.

Social burden is described as an obstacle in meeting the needs of socialization and interaction of the care giver with the surrounding environment.

"So, because he can't move or lack of mobility, I have to accompany and assist him in many things. It spent a lot of my time because I can't go anywhere else."(P2)

2. Factors that affect the family burden of palliative patients

Factors that affect the family burden include:

a. Patient complaint factors

Patient complaints are described as a response to the patient's symptoms that arise because of changes in the physical condition experienced, complaints can be in the form of physical symptoms, as well as psychological symptoms.

1) Physical symptoms

Physical symptoms are physical complaints of patients caused by the patient's disease process. The following is a description of the physical symptoms that arise

"So, because he can't move, I have to assist him in everything. Having meal and drink, going to the bathroom, taking a bath, and so on. Everything."(P2)

"His condition is getting better nowadays. Much better than in early days when he gets this illness. I have to assist him in any activities, such walking (mobility), having meals and drinks, going to the bathroom (because he's not willing to wear diapers), taking a

bath, etc. All of it was getting hard because he has a fat body. So heavy and need an extra effort to assist him." (P4)

2) Psychological Symptoms

Psychological symptoms are response psychology resulting from the response to the disease process. The following is a description of the physical symptoms that arise.

"It's normal to say that I'm upset. Especially when he asks something un patiently. Everything looks wrong in his eyes. I know it when he's yelling and shouting to me just because the meal doesn't match to his taste or when something seems not proper to him." (P2)

b. Family economic factors

Economic factors include the ability of the family to meet the needs of patient care and treatment. The description of economic factors is shown by:

"We don't have any insurance. It's all from our personal saves. We've spent approximately IDR 15 million for the surgery and medicine. I've got nothing to rely on. I still depend on my children's help and selling chips" (P2)

c. Family support factor

"Alhamdulillah. My children still care on their father's condition so far. They help me a lot. I don't know what will happen if they didn't do a favor to me, even though their own child was having an illness." (P2)

d. Family perception factor

"I believe it's normal. It's my responsibility as a child" (P1)

"It is true. It is my responsibility, so I have to be patient" (P2)

e. Factors of Willingness for Treatment Support

"Because we can't be right next to her all time. So, the important thing is that all her needs has been prepared beside the bed. Sometimes when there's nobody near her, she turns on the TV loudly, and that become a sign that she's calling for help" (P1)

"I remember when he starts to lose his ability to walk. I have to carry him to the toilet because I can't buy the diapers for him. He's unfamiliar to it either. I have no regret or upset to care him. Otherwise, we really have to be patient" (P2)

f. The factor of the ability to manage stress or coping mechanisms used to reduce the burden on the family.

"I just take a deep breath and read *Istighfar* a lot. In such this condition, all I have to do is to be more patient. I don't know what will happen if I didn't have enough patient. (P4)

"Sometimes I just take a distance from her when she was angry or take turns with other brothers or sisters so that mommy calms down first." (P1)

The female gender is often found as the main care giver in a family, it is influenced by one of them is gender roles where the role of family caregivers is usually women. Tripodoro, (2016). Tripodoro further explained that women are the main and most dominant caregivers compared to men. Age is the next characteristic of the respondent which is described as being vulnerable to the age of the respondent in the middle age group, where at that age has the duty as a child to take care of parents who are getting old. Maryam et al., (2012) explained that the average age of the respondents as care givers was between the ages of 21-44. Other characteristics of

the respondents that can affect the family burden include the length of illness and the number of comorbid illnesses of the patient. Puspitasari et al., (2020) explaining the length of stay and the limitations of the patient's function can also affect the level of family burden explaining the longer duration of care per day can affect the level of family burden.

The description of the family burden shown includes: physical burden, psychological burden, financial burden, & social burden. Supporting research results include the research of Widyastuti, (2011) which explains that there are 4 family burdens in caring for the elderly in Depok, namely physical burdens, psychological burdens, economic burdens, and social burdens. Physical burden, where several care givers have complained about physical disorders such as tired, tired, hard to sleep. Widyastuti, (2011) explains that care givers who take care of the elderly complain of feeling tired because they have to take care of clients for 24 hours. Ike Wuri, (2018) in his research results illustrates that the family's physical burden is shown by the emergence of health problems.

Psychological burden is indicated by negative feelings such as feeling irritated, angry, sad, and worried. Nuraini, (2019) explained that the psychological burden of the family includes feelings of worry and stress. Kelli I. Stajduhar, (2013) explains the description of the psychological burden experienced by care givers including showing an overview of the level of anxiety and depression. Juana Perpiñá-Galvañ, et al (2019) explained that in his research, it was found that the level of depression and anxiety in the care giver of palliative patients who were treated at home was obtained.

The financial burden or economic burden is also experienced by the care giver. Adha, (2020) explained that the family burden that care givers often experience in caring for patients with cancer is a financial problem. (Ngadiran, 2010). The last burden is the social burden, some care givers report limited interaction with the surrounding environment, this is because palliative patients require continuous care. Ike Wuri, (2018) explains that social burdens often occur where the longer the duration of care per day, the burden of care, especially the social burden, will increase, this is because care givers feel that their time is running out to treat patients, making it difficult to do other activities outside the home environment.

The description of the severity of the family burden is influenced by several factors including the client factor. Palliative patients are often found in conditions of limitations and low levels of independence. In addition to the limited independence of palliative patients, there are also conditions with psychosocial problems such as helplessness and hopelessness so that some show aggressive and more emotional behavior. As stated by P2, P4 who experience obstacles in the treatment process where the patient tends to be uncooperative during treatment, causing a separate burden for the care giver. Heike Gudat, (2017) explains that some palliative patients report feelings of guilt, feeling burdened by their family members, psychosocial problems arise due to the disease process, and this affects the care giver.

The next factor is the economic factor of Setiawan's family, (2018) explaining that families who do not have health insurance are an obstacle in caring for clients, especially in meeting care and treatment needs. Families who do not have health insurance will affect the family burden, especially the financial burden. The factor of family support, Ngadiran, (2010), explains that the support of the surrounding family has an important role in overcoming the burden of the family. This support can be in the form of social support, for example by sharing other support roles, including financial support that can be given to reduce the financial burden of care.

Family perception factor or care giver Christine, (2007) explains that there is a relationship between family perception and physical symptoms and the burden of palliative family care. Perceptions of the conditions faced by the family will indirectly affect the burden on the family, families who perceive or show acceptance tend to have a lower burden than families who have not received. The availability of supporting equipment is also a factor that can affect the burden on the family. The availability of supporting tools is an important factor in providing care and quality of nursing, Samar M. Aoun, (2016) explains in his research about the needs desired by families in the care of sick family members including equipment to help care.

The last factor is the family's ability to manage the burden. Some families report that there are several things that can be done to cope with family burdens, one of which is spiritual action or seeking help. Maryam, (2017) explains that coping strategies aim to overcome situations and demands that are felt to be pressing, challenging, burdensome. The ability to manage stress or better known as family coping skills influences the level of family care burden. (PIPIT et al, 2017) in his research, he found several coping abilities that are often used by palliative families to manage their stress, and explained the benefits of coping strategies, namely: viewing problems as easy to overcome; maintain an emotional connection with the patient; understand the patient's condition; understand the feelings of the patient-family caregiver; changes in health behavior; assist in the caregiving role; managing temporary feelings; reduce depression, anxiety, burden, responsibility, uncertainty, and hopelessness; improve quality of life, well-being, bonding, psychological mental health.

CONCLUSIONS

The impact of treatment is a burden on the family. There are 4 kinds of family burdens, including physical burdens, psychological burdens, financial burdens, and social burdens. Family burden is influenced by several factors including patient factors, economic factors, family support factors, family perception factors, availability of supporting equipment factors, and the ability to manage family burdens.

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