



Spouse's Coping In Caring For The Elderly With Dementia

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Abstract

Dementia is a condition that is still considered normal in the elderly by the general public. Dementia clients often experience hopeless situations that include feelings of helplessness, frustration with their surroundings, economic dependence on family members, and inability to socialize with other people. Most dementia clients are cared for at home by family members due to financial limitations and supportive health services. This research is qualitative research with a descriptive phenomenology approach. This research was conducted in the period November 2018 - May 2019 in the Bekasi City area and the number of participants obtained by the researchers was 10 people. The theme obtained by the researchers was how the coping mechanism carried out by the carer while caring for the elderly with dementia which was described in 3 themes, including care efforts made to heal a partner, activities taken to avoid boredom and resources owned by caregivers. In addition, there is a need for socialization for the community about dementia and an increase in understanding for health workers who work within the scope of the health office as well as the development of dementia conditions that occur.

Keywords: Coping; COVID-19; Pandemic; Vulnerable Populations

INTRODUCTION

Dementia is a condition that is still considered normal in the elderly by the general public. Dementia is a collection of symptoms that causes irreversible brain damage that occurs over a relatively long period of time (not immediately) and makes the elderly to become unproductive and fully dependent on their family in their daily lives (Wallace, 2008). Dementia is a negative consequence of aging changes in the central nervous system and accompanying risk factors that have implications including the inability to carry out daily activities and the need for full supervision by the caregiver.

Dementia clients often experience hopeless situations that include feelings of helplessness, frustration with their surroundings, economic dependence on family members, and inability to socialize with other people (Mazaheri et al., 2013). The increase in the incidence of dementia that occurs due to the negative consequences that arise can cause the elderly to increase their dependence on other people.

Dementia clients have complex needs that may be a burden to those who care for them. Most dementia clients are cared for at home by family members due to financial limitations and supportive health services. Dementia clients need

emotional ties and full support in bio - psycho - socio - cultural - spiritual - material from all family members.

Research conducted by Ivey, Price, Tseng, & Logsdon (2012) states that families have developed a positive coping mechanism from within them when they treat dementia clients. Another study conducted by Clissett, Porock, Harwood, & Gladman (2013) found the fact that caregivers often experience changes in their daily routine patterns and try to use positive coping with these changes.

Indonesian society has a culture of mutual cooperation and high social solidarity when compared to Western societies which have an individualistic culture, this has implications for higher positive coping patterns that are owned by families caring for elderly people with dementia. Research related to partners' experiences in dealing with dementia shows that couples have a desire to maintain a closer relationship and the emergence of feelings of empathy experienced by partners who experience dementia (Wadham et al., 2015).

A preliminary study conducted by researchers in the August - September period in Bekasi City was faced with the challenge of not having definite data on the number of dementia clients and the number of partners who were caregiver in Bekasi City. Researchers collaborated with the Bekasi City branch of the Alzheimer Indonesia organization to collect data on caregivers in the city, the results obtained were that most of the caregivers for dementia clients in Bekasi City were couples, a small proportion of families used professional services. The main reasons for families to do independent care are due to limited costs, family understanding that the client's dementia condition is not a serious problem, the lack of understanding of partners and families about the role of professional services, and the

family culture that caring for the elderly is evidence of partner loyalty and family members's devotion.

In connection with what has been explained above, the researchers are interested in getting a clear picture and meaning of a partner's experience in living with the elderly with dementia in Bekasi City. The results of the research carried out are expected to provide new insights and knowledge to community members so that they can become social support for couples who are dementia survivors and are able to jointly support dementia-friendly regulations or environmental conditions. For health workers who are in health services, knowledge of partner responses while caring for elderly people with dementia, coping mechanisms used, expectations during care, and burdens that must be faced while being caregivers can help health workers in providing appropriate interventions.

METHOD

This research was qualitative research with a descriptive phenomenology approach. In this study, researchers wanted to explore coping patterns in husband/wife in providing care to elderly couples who experience dementia in Bekasi City. Sampling from this population was carried out by using the purposive sampling technique. The sample criteria in this study include: the main caregiver is a spouse (husband/wife), able to communicate well using Indonesian, and has cared for dementia clients >6 months. This research was conducted in the period November 2018 - May 2019 in the Bekasi City area and the number of participants obtained by the researchers was 10 people (attached).

Ethical review is carried out by submitting a research proposal to the ethics board of the Faculty of Nursing, University of Indonesia. After getting a letter of passing the ethical test, the next step the

researcher took was to send a research permit to the Bekasi City Government, a research permit from the Bekasi City government was obtained in March 2019.

Data collection was carried out through interviews and direct observation of the participants. Interviews were conducted to get a clear meaning of the husband or wife's experience in caring for a partner who has dementia. The interview process lasts for 45 - 60 minutes, while the verbatim results of the interview have been consulted with peer-reviewed. Data analysis was carried out by systematically compiling data obtained from interviews and field notes then organizing them into categories, describing them into units or themes, conducting a synthesis, and selecting the important meanings contained in them.

Table 1. Characteristics Of Participants And Demensia Patients

No	Name of participants (age)	Period of marriage	Employment status
1.	Mrs. T (64 years old)	42 years	Housewife (IRT)
2.	Mrs. J (65 years old)	40 years	Housewife (IRT)
3.	Mrs. E (67 years old)	40 years	Housewife (IRT)
4.	Mrs. S (78 years old)	60 years	Housewife (IRT)
5.	Mrs. R (67 years old)	47 years	Entrepreneur
6.	Mr. R (65 years old)	45 years	Entrepreneur
7.	Mrs. C (60 years old)	28 years	Housewife (IRT)
8.	Mr. E (68 years old)	43 years	Private employees
9.	Mrs. I (60 years old)	35 years	Laundry Worker

10.	Mrs. N (65 years old)	49 years	Housewife (IRT)
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RESULT

The theme obtained by the researchers was how the coping mechanism carried out by the carer while caring for the elderly with dementia which was described in 3 themes, including:

Theme 1: Care efforts made to heal a partner

The theme of the care efforts carried out for the healing of the partner by the participants while being caregiver is divided into 3 sub-themes, namely daily services provided by the carer to the partner, efforts to get health services: hospital & traditional, and lack of confidence in professional services.

The daily services performed by the participants are revealed in the category of daily activities carried out. supporting statements, including:

"...Can still handle it by myself, so i prepare it (the tool)..." (P1)

Efforts to get health services: Hospitals & traditional are divided into 2 categories, namely traditional medicine and medical treatment provided. For traditional medicine, several statements that support these activities include:

"...Yes, try our best to seek (alternative) medication everywhere for mom to get well..." (P6, P10)

As for medical treatment, it can be seen in several statements:

"...then I took he/she to the neurologist..." (P1, P7, P10)

The lack of confidence in professional services experienced by caregiver is reflected in 2 categories, namely the perception of unsatisfactory elderly care services and less than optimal caregiver services.

Perceptions of unsatisfactory elderly care services were shown by participants through:

"...if you put him in nursing home, sometimes he is rarely taken care by the caregiver" (P2, P5, P9)

In addition to the unsatisfactory perception of elderly care services, participants also mentioned that caregiver or caregiver services were not optimal. This view can be seen from several statements, including:

"...in my opinion, taking care of him must be maximized, whether cleanliness, the food, and the menu..."(P5, P7, P8)

Theme 2: Activities taken to avoid boredom

Caretakers have carried out various activities to prevent burnout conditions, in this theme, there are 3 sub-themes consisting of diverting attention with fun activities, self-coping activities, and spiritual activities. As for the explanation of the activities carried out by the carer, among others:

Diverting attention with fun activities is carried out by caregiver through 3 things, including telling stories to children, doing fun activities with family, and doing activities outside the home. The category telling stories to children is obtained from the following statements:

"...my daughter who in Central Java is better at listening to my burden and complaints, I'm please with that way..." (P2, P8)

While activities carried out with family include:

"...The longest time will be taken care of my grandchildren..." (P3, P9, P10)

The last category is doing activities outside the home, this can be seen in the following statements:

"...one of them is I take part in activities for women near the neighborhood..." (P1, P9)

The sub-theme of coping activities that are carried out alone can be interpreted as activities carried out in the house without involving other people. The activities carried out by the participants consisted of 3 categories, namely eating or drinking, resting or sleeping, and managing the house.

The meals done by the participants can be seen in the following statements:

"...yes sometimes I got my snack and a cup of tea when I'm alone" (P3, P9)

Meanwhile, the activity of sleeping or resting was carried out by the participants, "...Yes, just take it to sleep..." (P9) and "Yes, it was brought to sleep. After had a good sleep, it's gone..."(P10).

Other activities carried out were taking care of the house, this was reinforced by the participant's statement "...So now, Saturday, Sunday, I clean up" (P8) and "...Cleaning, for example sweeping, mopping ..." (P10)

The sub-theme of spiritual activities carried out by participants can be seen in several pronounced statements, including:

"...I pray the most so that it would strengthen me..." (P1, P2, P4, P5, P7)

Theme 3: Resources owned by caregivers

The theme of resources owned by caregiver is divided into 2 sub-themes, namely the supporting factors obtained from the environment and the ability to independently finance the partner care process. An explanation of the identified sub-themes is as follows.

Sub-theme Supporting factors obtained from the environment are divided into 3 categories,

namely child support, family support, and social support. The child support can be seen in the statement:

"...Alhamdulillah, my dear children love and care us as their parents..." (P1, P2, P3, P7)

As long as they are caregiver for their partner who has dementia, caregiver say they also get help and support from their families, this can be seen in several statements:

"...not alone, sometimes our grandchildren helping with the tasks..." (P4, P5, P9)

In addition to support from children and families, participants also mentioned that they received support from the social environment, this can be seen from several supporting statements, including:

"...they understand, they are actually supporting us..." (P1, P5, P8)

The second sub-theme on theme 6 is the ability to be independent in financing the partner care process. This sub-theme consists of 3 categories, namely owning assets, economic independence, and having income. The explanation is as follows.

Ownership of assets when caring for a partner who has dementia is one of the factors for the independence of the caregiver to finance the treatment process, this can be seen in several statements:

"...because we have some assets..." (P1, P3)

The second category is economic independence which can be interpreted as the ability of the caregiver financially without assistance from other parties, which can be seen in the following statements:

"...at the moment, at least all kinds of routines like seeing the doctors can still be handled..." (P1, P5, P9)

The third category is having income, which can be seen from the statements below:

"We still have our monthly income as usual..." (P2, P3)

DISCUSSIONS

Identification of partner coping mechanisms while caring for elderly with dementia is aimed at understanding how caregivers are able to withstand various stressful conditions that arise from caring for a partner and to find out what actions are taken by caregiver. The coping mechanism of the carer consists of care efforts carried out to heal the partner, activities carried out to avoid burnout, and the resources owned by the carer.

Theme 1: Efforts to care for a partner

The family is considered to have a successful or good coping pattern if the family is able to present a health care pattern to family members who experience chronic disease without experiencing changes in the integrity and burden of the caregiver (Allen & Hilgeman, 2016). Treatment efforts undertaken for the recovery of a partner are various activities and actions undertaken by the caregiver in order to prevent the process of further deterioration as well as various assistance provided by the carer to a partner with dementia. Treatment efforts undertaken for the recovery of the partner by the participants while being caregiver were divided into daily services performed, external efforts made, and lack of confidence in professional services.

The treatment that is carried out is all the actions of the caregiver taken to help a couple with dementia in carrying out their daily activities which include bathing, eating, drinking and so on.

Pozzebon, Douglas, & Ames (2016) show that couples who are caregiver show acceptance of their partner's condition and try to meet their partner's daily needs. Meanwhile, Conway, Watson, Tatangelo, & McCabe (2018) stated that the dementia condition experienced by a partner can increase the state of adaptive response and the relationship between married couples. Caregiver have a tendency to serve partners in daily activities carried out together. As for the role of the couple in becoming caretakers for the elderly with dementia, among others, as a provider of daily needs including bathing, eating, decorating, defecating, and daily activities; decision makers for the elderly with dementia; friends communicate; friends in social activities (Brown & Bond, 2014).

The similarities that arise between field cases and the theory found can illustrate that couples become more reactive and proactive in meeting their partner's daily needs, the researcher found that there is a feeling of indebtedness for the daily services provided by the partner before suffering from dementia to the carer. is one of the reasons for caregiver to repay their partner's kindness. One male participant even learned to cook so he could cook for his wife who currently has dementia.

Treatment efforts undertaken for the recovery of a partner include seeking traditional medicine and medical treatment for the couple in the hope of obtaining a cure. There are differences between the treatment efforts undertaken between couples in Indonesia and couples with dementia in developed countries, partly due to differences in understanding of existing dementia conditions. In couples in developing countries, especially in Indonesia, dementia is considered not a disease and is still considered to be cured as before. The caregiver's lack of understanding and confusion regarding the condition of dementia experienced by

their partner can have implications for reduced health care functions performed, this is indicated by Miller (2012) who states that a lack of information and knowledge about the condition of the disease being experienced can increase the risk. the emergence of negative consequences in the elderly.

The caregiver's lack of understanding and confusion regarding the condition of dementia experienced by their partner can have implications for reduced health care functions performed, this is indicated by Miller (2012) who states that a lack of information and knowledge about the condition of the disease being experienced can increase the risk. the emergence of negative consequences in the elderly. A further effect is distrust of professional services in caring for or providing health services for partners who have dementia.

The distrust conditions that arise in the study can be influenced by several things, including the low level of public understanding of the condition of dementia so that they think this condition is not a sick condition, the inability of the community to access quality health services, and the low quality of health services and health workers. existing in Indonesia, especially in primary care.

Theme 2: Activities undertaken to avoid Burnout

Activities carried out to avoid burnout can be interpreted as various activities or activities carried out by caregiver in order to prevent burnout in caring for a partner. This activity is divided into activities that are carried out alone, divert attention with fun activities, as well as worship activities and get closer to the creator.

Activities carried out on their own include recreation, praying, resting and sleeping, as well as taking care of the house or cleaning the house. Activities such as eating and snacks and cleaning

the house have the effect of increasing endorphins which can cause feelings of happiness and pleasure to arise. Lee & Tang (2017) stated that the elderly, especially women who do homework, can increase the level of physical fitness and the level of happiness experienced. However, this is inversely proportional to research conducted by Harryson, Aléx, & Hammarström (2016) which states that cleaning the house can often be a stressor factor for individuals who do this, this is due to other activities that have become a burden to the individual such as work and child care. The differences that arise between Lee and Harryson's research can be explained through a hormonal mechanism where when individuals who are tired of carrying out activities such as working or taking care of children as mentioned in Harryson's study will experience increased levels of cortisol in their bodies, cortisol or what is often referred to as stress hormones has an effect which is more or less the same as the endorphins secreted by the brain which can increase heart rate and blood pressure.

Sleep and rest activities carried out by caregiver as a coping mechanism to avoid burnout are supported by research by Liu et al., (2017) which found that sleeping and resting by the elderly can significantly reduce the risk of stress and depression. Sleep and rest can reduce heart rate, blood flow, relax the brain and give the body time to rest from various stressors that arise.

Activities to divert attention with fun activities include telling stories or confiding in children, doing family activities, and doing activities outside the home. This is in accordance with research conducted by Higgs & Gilleard (2017) and Bielsten, Lasrado, Keady, Kullberg, & Hellström (2018) which show that the social environment has a large impact on the development of clients with dementia in both positive and negative directions as well as with the effect felt by

the caregiver. Øksnebjerg et al., (2018) further showed that the elderly should be included in activities that can improve their welfare status, self-confidence, health and social participation.

Doing activities with other people can periodically increase the status of self-confidence and mental health of the caregiver, this is because by socializing with other people, caregivers can exchange stories and get social support which is useful in carrying out activities to care for couples with dementia. Activities of worshiping and getting closer to the creator carried out by the carer include prayer, dzikir, and praying and listening to strings of spiritual verses and songs. This is also in accordance with research C.-Y. Chiao, Wu, & Hsiao (2015) who say that a partner who cares for a partner who carries out regular worship activities can reduce the risk of stress due to caring for a dementia partner.

The similarity found in the field case with the theory in spiritual activities carried out by caregiver is because humans have a spiritual side to themselves which, when connected with conditions in Indonesia, has a large level of influence. Indonesian society is a religious society which in their daily lives cannot leave worship activities according to their beliefs. Indonesian people have a tendency to go to worship when they experience joy, sorrow, and challenges and obstacles in their daily lives.

Theme 3: Resources owned by caregivers

The caretaker said that the resources he had while caring included supporting factors obtained from the environment and the ability to independently finance the partner's care process. Research conducted by Adelman, Tmanova, Delgado, & Dion (2015) states that isolation by the surrounding environment for caregivers can increase the risk of stress experienced, and vice

versa. The financial stress factor is also a source of depression experienced by the partner who is caring for it.

Supporting factors obtained from the environment are divided into support from children, support from family. The family is considered to have a successful or good coping pattern if the family is able to present a health care pattern to family members who experience chronic disease without experiencing changes in the integrity and burden of the caregiver (Allen & Hilgeman, 2016). Papastavrou, Andreou, Middleton, Tsangari, & Papacostas (2015) stated that the low level of participation in the social environment in supporting couples to care for dementia clients can lead to a high incidence of the burden of caregivers being felt. Likewise, the opposite shows that the support of the social environment in the care of clients with dementia can help couples reduce the risk of experiencing the burden of the caregiver.

Caregivers say social support can have a big impact on the continuity of care for couples with dementia, this is due to the support from the surrounding environment, caregivers do not experience feelings of isolation and alone in their partner care. Bielsten et al. (2018) said that informing neighbors regarding the dementia condition experienced by a partner can be an reinforcing factor for caregiver. In addition, by informing neighbors, neighbors will be more supportive of the behavior of support given.

Tatangelo, Mccabe, Macleod, & You (2018) stated that emotional support and social relationships are one of the needs needed by caregiver for couples with dementia. Meanwhile, research conducted by Higgs & Gilleard (2017) shows that the social environment has a large impact on the development of clients with dementia in both positive and negative directions as well as

the effects felt by caregivers. Feelings of isolation caused by low social support can increase the risk of depression experienced by caregiver, while high support from the social environment can increase self-confidence and acceptance of the conditions experienced by caregiver in caring for their partners.

Based on the results of participant interviews and the suitability of supporting theories, it can be concluded that support from children, family, and the social environment has an important role in increasing the ability of caregivers to care for their partners with dementia. The support provided can improve the psychological condition of the caregiver, reduce depression, isolation, and feelings of being disrespected by family members.

CONCLUSSIONS

Couples coping mechanisms while caring for a spouse with dementia can be seen through the care efforts made to heal the partner obtained from daily services performed and external efforts made, activities carried out to avoid burnout obtained from domestic activities, activities that involve other people, and worship activities, as well as the resources owned by the caregiver obtained from the supporting factors obtained from the environment and the ability to independently finance the partner care process. The government has an important role in facilitating long term assistance for couples who are caregiver for elderly dementia, term assistance can be interpreted as home visits and mentoring and advocacy for caregivers at home regarding the care of dementia spouses within a certain period of time (6 months) for thereafter can be considered independent in treating dementia couples. In addition, there is a need for socialization for the community about dementia and an increase in understanding for health workers who work within

the scope of the health office as well as the development of dementia conditions that occur.

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