

Caregivers' Experiences in Providing Self-Care Needs of Elderly with Rheumatoid Arthritis: A Phenomenology Study in Aceh, Indonesia

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Abstract: Providing a self-care need of the elderly with Rheumatoid Arthritis is a primarily complex activity conducted by the caregivers. Varied responses from elderly with rheumatoid arthritis also required different responses in providing self-care needs. This study aims to explore experiences of caregivers in providing self-care needs of elderly with Rheumatoid Arthritis at Social Welfare Institution in Aceh, Indonesia. This qualitative study employed transcendental phenomenology design, and involved eight caregivers of elderly with Rheumatoid Arthritis. The data collected in the form of interviews and field notes and analyzed by using Miles and Huberman techniques. This study identified four themes: 1) respond to elderly changes; 2) universal self-care fulfillment; 3) self-care development fulfillment; and 4) self-care fulfillment in unhealthy condition. These findings show the conditions that must be considered by the caregivers in providing self-care needs of elderly with rheumatoid arthritis. This study suggested on preventing the risk of mistreatment of elderly by improving the caregivers' knowledge and skill in providing caring to elderly with chronic diseases, especially Rheumatoid Arthritis.

1 INTRODUCTION

Caregivers are individuals who give attention and care directly to other individuals both children and adults. The role of caregivers is assistance in self-care, mobility, performing nursing tasks and carrying out household tasks (Friedman, 2010; Arksey, et al, 2005).

A self-care nursing theorist, Dorothea Orem (2001) mentioned that there are some self-care needs or self-care requisite that can be linked to the needs of the elderly that must be cared for by the caregivers, namely (1) universal self-care needs, (2) self-care development needs, and (3) self-care needs in conditions of health irregularities. Moreover, Maryam, et al., (2012), explained that the most contributed factor to the burden of caring in health is the health status. Novak and Guest (1989) in Gallo et al (2006) explained that caregiver's burden is a multidimensional measure that measures five domains, including time, development, physical,

social and emotional domains. Allowing the burden to occur will tend to be risky and susceptible to the emergence of stress on caregivers and will have an impact on the elderly.

The World Health Organization (WHO) estimates that by 2020 the number of elderly people will reach 28.800.000 (11.34%) of the total population. The estimated number of elderly people over 65 years of age in Indonesia is 12.740.265 (5.4%) of the total population of Indonesia (Indonesian Ministry of Health, 2014). Moreover, in the province of Aceh in 2015 there were 25.553 (0.57%) of the total population of Aceh, and the elderly under the care of Aceh Provincial Social Welfare Department are 1062 people (Aceh Provincial Social Service, 2016). Indonesian Ministry of Health (2016) started that medical aspects become one of the problems with the increasing number of elderly people. According to the 2013 Indonesian Basic Health Research (RISKESDAS) data, the prevalence of joint disease

in elderly is 11.9% and the tendency of joint disease/rheumatoid arthritis/gout (24.7%). Whilst in Aceh the prevalence of rheumatoid arthritis (18.3%), where in Banda Aceh alone has reached 8.484 cases.

Several studies explained the experience of caregivers who provide care for the patients with rheumatoid arthritis (RA). A study from Brouwer, et al (2004) explained that caregivers who provide care for the RA patients considered the elderly as relatively unhealthy. This become the illustration that caregivers having the experience of burdened on the treatments and risk creating *caregiver role strain* that will affect the elderly such as the elderly mistreatment, harmful as well as abusive actions, neglect, exploitation and crime that can harm the elderly. Therefore, this study aims to examine the experience of caregivers in providing self-care needs of the elderly with RA in Aceh, Indonesia.

2 METHODS

This study used qualitative research methods with a transcendental phenomenology design. It is directivity to a specific object about experience, knowledge and the design reflects the meaningful of life experience in a person's life with a concept or phenomenon (Creswell, 1998).

The study involved 8 caregivers who provide care to the elderly with RA health problems at *Rumoh Seujahtra Geunaseh Sayang* social welfare (nursing home) in Banda Aceh, Indonesia. This research was conducted using in-depth interview method equipped with field notes. The interview results were made in the form of transcripts and analyzed using the Miles and Huberman techniques.

This technique emphasizes on the interactive steps consisting of data collection, data reduction, data presentation stage, and conclusion. The results of the transcripts were grouped and then produced a theme related to the fulfillment of elderly self-care needs with RA.

3 FINDINGS

There are 4 themes emerged in this study, 1) responding to changes in the elderly, 2) fulfillment of universal self-care, 3) fulfillment of the development of self-care, and 4) fulfillment of self-care in conditions of health deviations.

3.1 Responding to Changes in the Elderly

In this theme, the participants referred changes in the elderly as the physical changes and complaints that often occur within the elderly. The study resulted complaints in the joints and musculoskeletal disorders:

3.1.1 Complaints in the Joints

Participants revealed that the elderly had complaints in their joints and having musculoskeletal disorders during the recent years.

I also often see he (the grandfather) massage his knees, he said they were feeling sick and numb. (P1)

In the morning, sometimes in the afternoon they (the elderly) complained of feeling numb, the sense like something creeping into the bones, and also feeling sick within their joint. (P2)

3.1.2 Musculoskeletal Disorders

Beside complaints in the joints, the participants said that musculoskeletal disorders also appear along with the elderly physical activity.

Because I can see that he (the grandfather) has trouble when he walked... (P1)

Complaining about the movement also exists but sometimes they (elderly) also complain about experiencing the slow movement (because of the musculoskeletal disorder). (P4)

3.2 The Fulfillment of Universal Self-care

This theme focuses on the needs of the elderly related to their physical care. These needs consist of 1) The needs of water resources and utilization, 2) the needs of food and drink, 3) the needs of elimination/bathing, 4) the needs of rest / sleep, and 5) the needs of exercise.

3.2.1 Water Resources and Utilization

Participants revealed that one of the important things in providing self-care in the elderly is the source of

water. The participants expressed that the water resource in the nursing home was from the well and local water company (PDAM).

The water resource is available in here, for taking shower also doing the laundry, so there is no problem with water (P1)

We use the well and PDAM (for elderly) in this nursing home. (P2)

3.2.2 The Fulfillment of Eating and Drinking

Most elderly at nursing home obtained their food and drinking water directly from the kitchen:

In order to eat... I take the food three times a day from the kitchen, and then the elderly ate by themselves, if the grandmothers are sick, I will feed them. (P2)

I deliver the (drinking) water from the kitchen, the elderly just wait at their room. I deliver it (drinking water) three times a day to their rooms.... (P2)

3.2.3 The Need for Elimination/Bathing

The participants revealed that elimination/bathing needs were not an obstacle for the elderly in the nursing home because everything would be taken care by the caregivers, both healthy and sick elderly.

The grandfather is independent, he is still capable of himself. If he is feeling sick again, I help him to the bathroom. (P3)

For bathing, the elderly is independent so, mostly they don't need any support. However, I keep them monitored. (P4)

3.2.4 The Need for Rest/Sleep

The participants revealed that the elderly had no complaints about the need of rest or sleep:

There are no complains of sleeping needs, after the Isha prayer (at the evening) he (the elderly) went to sleep, sometimes after recitation of (the qur'an) at mushalla he went straight to the room to sleep. (P1)

If the grandfather sleep (early) at the night, he will wake up early in the morning, I usually help him to bed at 10 o'clock... (P5)

3.2.5 The Fulfillment of Exercises

Besides the biological needs for physical care, the participants revealed the need of exercises activities. The physical exercise is part of the weekly activity in the nursing home, in the form of elderly light gymnastics which is led by the gymnastics instructors:

There is gymnastic (activity) every Thursday morning in the hall of nursing home which is led by the instructors. (P3)

The gymnastics for the elderly is every Thursday morning in the (nursing home) hall...Most elderly attend but not all of them join the activity. (P7)

3.3 The Fulfillment of the Development of Self-care

The elderly focused on the development of self-care to the things that they thought could support their self-care and the needs that they categorized as self-care. The data resulted 3 sub-themes, namely the availability of facilities and infrastructure, the need to interact and anticipating threats:

3.3.1 The Availability of Facilities and Infrastructure

The participants revealed that the nursing home provides the walking path training for the RA patients. This path mostly considered for the elderly whom having the difficulty in mobilizing their physical activity:

There is walking path training at the front of the nursing home... Sometimes, I help the elderly to use it. (P3)

3.3.2 The Need to Interact

The participants expressed that some elderly like to be alone or rarely want to interact with others. It was based on the following participant's statement:

But she (the grandmother) rarely interact with another, she doesn't like noisy (having chat) environment especially close to her

bedroom. Also she has a habit to be alone in the room. She doesn't have any problem with another (elderly), she just like to be alone...she will have a chat when she need to chat (with everybody in this nursing home). (P4)

3.3.3 The Need to Anticipate the Threats

The participants revealed that the elderly had no fear or worry during their stay in the nursing home. It was in accordance with the following statement:

As long as I am here there is no complaining (about fear) from the elderly, why they are not afraid, because there is a security guard and (the place) is crowded... (P1)

There is a security guard; they also go around (checking) in the night. (P1)

3.4 The Fulfillment of Self-care in Conditions of Health Deviations

In this theme, it explains the needs of elderly people related to their care when they are in unhealthy condition. The results of the study obtained 4 sub-themes namely the existence of health assistance, receiving care, getting therapy and lifestyle needs:

3.4.1 The Existence of Health Assistance

The participants said that in the nursing home the elderly receive health assistance from the clinic, health center, and hospitals.

There was also the Otolaryngology (specialist doctor) from the RSZA (hospital), also an ophthalmologist and the staff from Ulee Kareng Health Center comes regularly every month to the nursing home. (P1)

3.4.2 Receiving Care

The participants revealed that the elderly received the care and treatment while in the nursing home. This was in accordance with the following participant's statement:

Some of the elderly were very obedient while they were sick, but sometimes, some of them went back to their hometown to get the treatment in their hometown. (P7)

3.4.3 Getting Therapy

The participants revealed that the elderly obtained the therapy, such as light therapy, massage and therapeutic modalities in the nursing home.

The therapist (the nursing home clinic physiotherapy) usually provide the treatment to relieve the pain and also to improve blood circulation of the grandmother – grandfather (elderly). (P4)

3.4.4 The Lifestyle Needs

The participants said that some of the elderly have a habit of accepting what they obtained from the nursing home, but some of them were also have lots of requests.

Some of the elderly will accept (the care) but some of them are not... (P2)

The grandfather is very clean and neat in terms of the habit of placing his goods.”(P3).

4 DISCUSSION

The results of the study found that the participants responded to the changes within the elderly with RA health problems. The elderly responded having complaints in the joints and musculoskeletal disorders.

Furthermore, McCulley, et. al (2018) described some of the symptoms that can be marked as RA including the joints pain in the morning for about an hour together with the stiffness and limited physical movement, inflammation of more than three joints followed by swelling, gradually feeling weak. If this response improperly handled, the independence of the elderly in providing their daily needs will be reduced. In accordance with Ru, et. al (2018), found a significant relationship between RA pain and the level of independence in carrying out the daily activities within the elderly.

Participants revealed that the changes were perceived such as feeling pain of the knees as if the feeling of, numbness, felt like something was crawling on both feet especially in the morning and when the weather was cold. Moreover, the elderly also feeling, the difficulty in walking and it affected their physical movements. These changes have caused weaknesses, limited activities, and have a higher tendency to dependent on their caregivers.

It can be assumed that caregivers need to have good knowledge and skills in dealing with and treating the elderly with all the limitations. This situation allows limited problems that will aggravate the condition of the elderly with RA health problems. Therefore, the caregivers will have the ability in providing the care in the form of physical problems and the elderly will be less at risk.

Within the theme of the fulfillment of the universal self-care refer to the ability of the elderly to fulfill their basic needs. The self-care theory from Orem (2004) mentioned that universal self-care requisites are divided into eight self-care needs, including: maintenance of air, water/fluid, food, the process of normal elimination, balance between activity and rest, balance between loneliness and social interaction, prevention of danger for human life, function and welfare, as well as the efforts to improve the function and development of individuals in social groups according to their potential, limitations, and desires for normality (Brouwer, et. al, 2004). Ndosu, et. al (2016) explained the self-care needs of patients with chronic disease problems, which consist of the fulfillment of self-care needs: eating, air, bathing, hair shaving, dressing, elimination of defecation, rest and sleep, drink and interaction. In accordance with this study, the fulfillment of daily self-care needs were conducted by participants in the form of water resources and utilization, fulfillment of food and drink needs, elimination/bathing needs, rest/sleep needs, and exercise needs.

The study emphasized the caregivers to have good communication skills when they oriented the elderly in providing their daily needs. The tendency of mood changes cannot be avoided, since the age increasing within the elderly coincides with the occurrence of social changes such as the tendency of having low interest in continuing to interact with those around them, which can be caused by the health problems especially with RA. The caregivers in dealing with the older adults must embed the patience and sincere intentions; thus, the daily needs of the elderly can be continue to be fulfilled optimally.

The theme of self-care development refers to the Orem's self-care theory, which emphasized on the development of self-care requisite as a stage of self-development according to the stages that can occur in humans. It is the provision of conditions that support the development process in the form of facilitating individuals in the development stage, involvement in self-development and activities and prevention against threatening disturbances. Chung

et. al (2016) describes the family's experience providing the care and fulfillment of self-care in patients with chronic disease problems found the fulfillment of developmental tasks relate to the age of elderly. This need is connected to the development process, which can be influenced, by certain conditions and events. Therefore the form of different stages experienced by each individual is affected by the changes in body condition and social status. Experts explained to achieve re-empowerment of the elderly can be sought by creating a climate or atmosphere that allows its potential to develop, strengthen the potential that has been owned, protect and prevent the weaknesses of becoming weaker and through direct practice of the learning process. In this study, providing the needs of daily personal care carried out by the caregivers supported by the availability of facilities and infrastructure also the need to interact and anticipate threats.

The study revealed that the assistance system which is provided by the caregivers to the elderly with RA in terms of improving the development of self-care, involvement in self-development and the development of prevention of life-threatening effects has been carried out but still inadequate. The study suggested that participants need to gain the knowledge and provide the optimal support related to the utilization of training facilities for self-development, education and therapeutic modalities to overcome rheumatic health problems in the elderly.

Another theme that emerged from the study is the fulfillment of self-care in health deviation. The *Health Deviation Self-care Requisites* in Orem's self-care theory is associating the needs with the deviations aspects of human structure and function. Someone who is sick, injured with certain pathological conditions, disability or inability, or someone who is undergoing treatment still require adequate self-care. The conditions of health irregularities or health changes including the health assistance and awareness of the risk of problems, therapy, and lifestyle, also need self-care support.

Guoxia & YuDing (2016) described the *Health Deviation Self Care Requisites* related to the existence of health status deviations such as: illness or injury conditions, which reducing an individual's ability to fulfill his self-caring needs in a permanent or contemporary manner. The self-care needs on the occupational therapy, which in accordance with the statement from the Department of Health (2006), were the physical therapy and occupational therapy can reduce pain in a non-pharmacological way since

the physical therapy and physical exercise will assist in maintaining and restoring the range of joint movements and reduce the pain, stiffness and muscle spasms of the elderly with RA.

The fulfillment of self-care needs in the condition of health deviations carried out by the caregivers should emphasize on accompanying the elderly during the physiotherapy. Furthermore the caregivers should also teach the elderly in order to perform their simple physiotherapy and activity, in order to support the elderly being independent in fulfilling their self-care needs.

5 CONCLUSION

The study identified the caregivers' fulfillment of the elderly self-care needs. It was revealed that the caregivers have the spirit and belief in the value of worship in order to provide care of elderly with health problems, especially RA. To sum up the caregivers emphasized on considering providing the care to the elderly in the social welfare institutions as caring for their own parents.

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