

Being a Caregiver for a Husband with Alzheimer's: A Phenomenological Study

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ABSTRACT

This study aimed to investigate the experience and the meaning given by a wife of being a caregiver for Alzheimer's husband. The study was conducted using qualitative method with a phenomenological approach. Participant was a woman (63 year old) who has a husband with Alzheimer's. Data were collected through in-depth interview and analysed using Interpretative Phenomenological Analysis. The results showed several themes: confused and suspicious, shocked and disbelieved, sad and lost, regret, looking for more information, feeling annoyed, fatigue, stressful, coping, acceptance, redemption, obligation, devotion, and the way to get rewards from God. The experience and meaning evolved from negative feelings to acceptance, influenced by religious beliefs that caregiving would be rewarded by God. Therefore, the caregiver survived the difficulties in the process of caregiving despite the minimum support from the family.

Keywords: Alzheimer's, caregiver, experience, meaning

1. INTRODUCTION

Nowadays, Alzheimer's is one of serious illness among elderly. In 2012, According to World Health Organization (WHO) and Alzheimer's Disease International (ADI) there were an estimated 35.6 million people with dementia[1]. This number is predicted to double by 2030 and triple or about 115 million people by 2050. On the other hand, in Indonesia, there were one million cases of Alzheimer's in 2011, which could be increased over time and along with the rising of life expectancy. ADI also reports that Indonesia is included in the ten countries with the highest dementia patients in the world[2]. Given the high costs for the care of patients with dementia, WHO and ADI urge all countries to raise awareness that dementia is now a public health priority[1]. According to WHO, Alzheimer's is the most common type of dementia[3]. At the moderate level of severity of Alzheimer's, people with dementia find it difficult to do activities without the help of others[4].

According to Kring et al.[5], Alzheimer's is caused by a deterioration in brain tissue function. Alzheimer's begins with a loss of attention to what is being done and difficulty in concentrating and remembering new things. As the symptoms of the disease get worse, the impairment in language skills and word discovery also get worse. On the other hand, people with Alzheimer's will experience a decrease in visuospatial ability, which presents with symptoms of disorientation and difficulty in copying numbers. They are usually unaware of their cognitive problems at first and may blame others for missing objects even until delusional behavior appears. Their memory is

getting worse and disorientation is increasing as well as their worsen agitation. When the disorder gets worse, they do not recognize their friends or family. Psychological conditions are also seen in individuals with dementia even before cognitive symptoms are evident, namely rigidity, apathy, egocentrism, and impaired control over emotions[6].

Similar to the elderly in general, most individuals with Alzheimer's stay at home and receive care from a spouse or adult child [7]. This is a result of the limited services available for the elderly with dementia and factors of socio-cultural responsibility. In the initial phase, family members can maximize the function of the patient but as time goes by their cognitive function decreases. The burden of caring for a person with Alzheimer's at home becomes too great, both physically and mentally.

Caregiver is a person who carries out the caregiving process, such as the process of helping others who are unable to carry out their activities physically, mentally, emotionally, and socially[8]. In general, Trisnasari[9] said there are two kinds of caregivers, namely formal caregivers and informal caregivers. A formal caregiver is an individual who is part of a health center service or other paid professional. Meanwhile, an informal caregiver is a caregiver who is not professional, who provides care without being paid. An informal caregiver is usually a member of the family. In this paper, the caregiver refers to the informal caregiver.

Research conducted by Kim & Schulz [10] found out that female caregivers were more at risk of feeling the burden of caring for elderly dementia than male caregivers. This was due to the demands placed on female caregivers to be fully involved in caring for the elderly, for example in terms of maintaining patient hygiene and nutrition.

What becomes more difficult for a female caregiver is if she has more than one role at home, for example as the wife of a husband with Alzheimer's and also as the child of an elderly person. The Ministry of Health conveys data that currently 25% of the elderly in Indonesia is included in the frail category or is in a sick condition and cannot carry out activities as usual. Meanwhile, as many as 61.6% of the elderly are in a pre-frail condition, i.e. they have a disease but can still carry out activities. Vulnerability to diseases and disabilities experienced by the elderly will continue to increase with age[11] By this condition, the elderly also need caregiver assistance to be able to live their daily lives.

The load of the burden that must be borne by the caregiver is affected by the condition of the caregiver. Caregivers who afford the cost of treating people with Alzheimer's often experience role conflicts because they have to care for and work [12]. If the caregiver chooses to focus on caring for and stops working, then she must consider how to finance the care of people with Alzheimer's. Another thing that also affects the caregiver's burden is the relationship between caregivers and the individuals with Alzheimer's. Research conducted by George and Gwyther[13] found that caregivers whose spouse suffering dementia tend to be more prone to have low psychological well-being, financial problems, and minimal involvement in the community, compared to other caregivers.

The stress experienced by caregivers tends to affect their health. A number of studies have found that caregivers tend to be more susceptible to illness and have higher mortality rates than non-caregivers[13],[14]. Caring for a person could be unhealthy especially when the person is often exposed to the suffering of loved ones with Alzheimer's[15]. In addition, the burden for caregivers is also related to the role that is too heavy in dealing with changes in the behavior of their partner with dementia and the feeling of being trapped in a routine circle of roles as caregivers[16]. Slow decline, dementia-related behaviors that are already severe, and the knowledge that it will only end when they die generally make Alzheimer's disease is more difficult for families to accept than other chronic illnesses.

During the process of caregiving for people with Alzheimer's, caregivers must make adjustments to survive in this role[12]. In the context of research in Indonesia, religious themes emerged in treating them, such as caring for them was considered a test of patience or redemption for past mistakes[17]. As an effort to survive, caregivers tried to find information, manage emotions, solve problems and seek social support[12]. In reality, each caregiver chooses a different way to fit in. This occurs because the problems that arise from each person with Alzheimer's can be different. In addition, each caregiver has different stages of the caregiving experience, which causes what is ultimately felt after the caregiving process ends differently[18]. This determines the caregiver's capability to adapt to life after the caregiving process ends.

Based on the explanation above, researchers are interested in conducting a qualitative study of the

experience of the individual to be a caregiver whose husband has Alzheimer's. The experience of each individual in caring for individuals with Alzheimer's is specific and unique. Therefore, this must be explored through qualitative research methods. What makes this topic important to study is that the population of people suffering Alzheimer's in Indonesia and the world is predicted to continue to increase so that the population of Alzheimer's caregivers will also continue to increase. The role of caregivers from the family is important to be concerned because of the limited services for people with dementia in Indonesia and the existence of socio-cultural responsibilities to care for them.

Research in other countries about caregivers for people with Alzheimer's revealed problems with patience related to care, regret not helping immediately, problems related to facilities, finances, and support from those closest to them, and also declining health conditions[19],[18]. Alzheimer's is the most common type of dementia[3]. A research in Indonesia found that religious themes such as caring for elderly patients with dementia as a redemption for past actions as well as the way to get rewards from God [17]. The relationship between different caregivers and adult patients with dementia (e.g., spouse, children, and relatives) can lead to different experiences in which the spouse is caring for his or her health condition, well-being, and income decreased, as well as reduced community interaction[13].

These differences probably can affect the meaning given by the caregivers towards their experience. Hopefully, the results of this study can provide an overview for caregivers for husbands with Alzheimer's to be able to understand the process of caring for and its obstacles as well as gain insight to understand how the process bringing benefits. This is in line with the importance of raising awareness to prevent and detect Alzheimer's, one of which was initiated by ALZI.

2. METHODOLOGY

2.1. Design

This qualitative research used a phenomenological approach which is a study that investigates the meaning of individuals' life experience[20]. The type of this study is Interpretative Phenomenological Analysis (IPA). The focus of IPA is to view a particular experience means to the person[21]. The purpose of IPA research is to explore in detail the participant's point of view on the topic being studied. The IPA studies tend to have small sample sizes due to the time-consuming analytical process involved. IPA's participants also tend to have specific characteristics. As IPA concerns with enabling the experience to be expressed from the view of participant's, the study needs the detailed examination[22]. Hence, the data collection was conducted using in-depth interviews to allow participants in conveying as many details as possible from their experiences.

2.2. Participant

Participant was obtained through purposive sampling method. Using this method, participant who was selected based on certain criteria related to the objective of the study[23]. The participant was Tuti (alias), a 63-year-old woman who has a 71-year-old husband Polan (alias) who suffers from Alzheimer's. Tuti was a retired education staff in a state university who has three grown up children. Tuti lived with her husband, Polan, her 83 years old mother, Yati (alias), and her third child Budi (alias), who worked in Jakarta. As a housewife, Tuti was responsible for daily household chores, being a caregiver for her husband since 2016, participated in the community of Alzheimer Indonesia (ALZI) and a religious group.

2.3. Procedure

This research has been approved by the Research Ethics Committee of the Faculty of Psychology, University of Indonesia (SK. No. 824/FPsi.Komite Etik/PDP.04.00/2020). Interviews were conducted at the participant's homes at the time agreed upon between the researcher and the participant. The participant was interviewed twice with each session lasting approximately one hour. The first interview was conducted face to face, but the second interview was conducted by phone due to the pandemic. Before the interview, participants filled out an informed consent form and interviews were recorded with a voice recorder with the participant's permission. To ensure the accuracy of the data, the researcher provided a copy of the interview transcript to the participant and asked her to verify the accuracy of the data or to clarify any inaccurate data.

2.4. Data Analysis

The data obtained were analyzed using thematic analysis techniques carried out through the following steps. Firstly, the data that has been obtained through in-depth interviews were transcribed or presented as it is. During the process of preparing the transcript, the researcher used *epoche*, that is the researcher ruled out personal experience and knowledge to gain new perspectives from participant regarding the phenomenon being studied. Secondly, the data were coded. The researcher looked for all participant's statements. These statements were categorized into different themes to describe the participant's experience. Thirdly, the researcher analyses the themes and concluded the results. Data interpretation was carried out using textural description techniques (descriptions of what participants experience), structural descriptions (descriptions of how participant's experience phenomena in terms of conditions, situations, and contexts), and a combination of the two to convey the essence of the overall experience[20].

3. RESULTS

From the results of the interviews, several themes were found as follows:

3.1. The Experience

3.1.1. Theme 1: Confused and Suspicious

At the age of about 66 years old, after work, Polan began to come home late. Tuti suspected her husband's habit as infidelity.

"Because he often came home late. I thought he had an affair"

Later, she realized that, it happened because he was disoriented, so he was confused about finding his way home. Then, she laughed at her husband when he got lost. She thought that it was just a symptom of senile dementia in the elderly.

"Earlier, I was joking and laughed. I thought it was just normal... people have changed. So I took senile dementia easily."

In addition, the forgetfulness symptoms experienced by her husband previously became more severe in the past years, even forgetting the child's name, reading prayers, and where to put things.

"He began to forget about putting his belongings, our children's name, and other things"

Tuti began to realize that her husband was having trouble when other symptoms started to appear, such as wearing sandals on the wrong foot and clothes inside out.

"Then his behaviour became weirder and funnier, such as wearing sandals on the wrong sides"

However, at that time, he often dodged by saying that he intentionally wore things wrongly to keep him warm. But after that, her friends advised her to take him to a neurologist.

"My friend said that I should take it more seriously and take my husband to be examined by doctors."

3.1.2. Theme 2: Shocked and Disbelieved

Tuti said that at the age of 67 years old, her husband was examined and diagnosed by a doctor as having various deficits, such as in the function of attention, orientation, and memory. The results of the examination surprised her because she felt that people of her husband's age should still have good cognitive abilities. She did not believe that he had health problems. This happens because he had a character who liked to joke.

"He was as same age as me. So I thought if there was something wrong, he was just joking. So I did not take it seriously."

"The doctor said that his cognitive function was only 20 percent. I was surprised that it was so severe that it should be around 70-80 percent. He had lost most of his cognitive function already. I was shocked."

3.1.3. Theme 3: Sad and Lost

According to Tuti, this is the saddest thing in her experience watching her husband having Alzheimer's disease. It is like she lost her husband.

"The saddest thing was when I saw that he had changed a lot because of Alzheimer's. He was not like before."

3.1.4. Theme 4: Regret

Tuti just realized that the symptoms of senile dementia should not be underestimated. She regretted that she was lack of knowledge about Alzheimer's. Finally, she knew that the results of a cognitive function test indicated the presence of Alzheimer's condition. She was surprised and regretful because she had never thought that her husband had Alzheimer's.

"I regretted it when I just found out that his condition was dropped. It was a sudden and significant drop for him. It turned out that if it was already there (in a severe Alzheimer condition) it was hard to get back again."

She also added that her regret was not only because she only found out that her husband's condition was quite serious, but also because she had not paid attention to her husband's condition for a long time.

"When I first received information that the results of his cognitive function were like that, I recalled the memories back then. It turned out that because we both worked, we did not pay attention to each other, what we have done at work, and so on. Daily, I did not pay attention to what changes were happening to him."

3.1.5. Theme 5: Looking for More Information

When Tuti first accompanied her husband to be examined at the hospital, she did not know the actual illness experienced by her husband. The difficulties in treating him prompted her to follow the advice of doctors and friends to finally join ALZI. She expressed her desire to educate people about Alzheimer's because in the past she found it difficult when she did not have complete information. After

joining ALZI, she finally got the motto "Don't Underestimate Senility".

"Because I was confused, what should I do with this (certain symptom in Alzheimer's) and finally a friend at the hospital said: All right, just join ALZI, many caregivers were sharing their personal experiences in caregiving people with Alzheimer's. Having people with dementia was not easy and it was not easy to get information either thus the group was very informative."

She felt the information from other caregivers was very helpful and related to her condition. For instance, when another caregiver told her that one of the symptoms in the early stages was spitting everywhere. She did not think she will get information like that from a doctor.

3.1.6. Theme 6: Feeling Annoyed

Tuti began to feel annoyed with her husband since he had Alzheimer's. Her husband often did not listen to what she had said. Her husband repeated the same mistake despite being warned. She was annoyed because often her expectations of her husband's behavior were not met. What she said to him seemed to be taken for granted. Eventually, she realized that her husband was unable to do what she hoped for because of the disability due to Alzheimer's.

"It feels like we both did not know what was happening. So at that time, everything did not seem right. I did not click with him. For example, when I asked whether he could do several things. He said he could but turned out he could not. It was annoying. What I saw in him was that he underestimated me. Even though it was because of his actual incompetence."

3.1.7. Theme 7: Fatigue

Tuti said since experiencing spatial disorientation, her husband often urinated in any place. Consequently, she had to clean it up. To avoid this, she chose to wait for the time when her husband usually urinated. She felt fatigued because every day she had to wait for her husband to urinate at 11 pm until she eventually got sick.

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3.1.8. Theme 8: Stressful

The doctor advised Tuti to find a caregiver for her husband, since he seemed need a friend to talk to. After

getting a caregiver, her burden was reduced. Until one day, the caregiver tricked her and causing a huge financial loss. Only six months after the caregiver worked for her husband, she then decided to take care of her husband by herself. The frustration and stress of caring of her husband came back.

"He somehow made me sad. I was angry. How should I adjust again? I did not understand what it was. It was pressure."

3.1.9. Theme 9: Coping

Tuti felt that being "ignorance" in dealing with her problems sometimes was quite helpful for her to survive as a caregiver for her husband. She never minded the burdens and the feeling of tired. She perceived it was bearable as long as she could sleep.

"I was an ignorant person. If I was tired, I would just sleep."

Her 'ignorance' led her to express her feelings freely, to relieve her stress.

"So if I was angry... I just expressed my anger.... I said whenever I disagreed or had any objection ... I never talked behind anyone's back. If I wanted to talk, I just said it out loud."

3.1.10. Theme 10: Acceptance

After a year of caring for her husband, Tuti began to feel that her husband's condition was difficult to change. She started to learn to accept all her husband's shortcomings as she accepted him when he was still healthy.

"I personally realized why he always rebelled against what I told. But it was okay. What else I could do? He had reached his maximum potential. If I continued to scold him, it was just adding my sins."

"I clearly remembered that I often listened to wise people, such as *ustadzah* or *ustad* (religious teacher). They preached to me and gave me the insight that he was, after all, my husband. In the past, I experienced the good times, so I had to take care of him also in the bad times."

I used to enjoy the moment when he was in a good condition, why can I accept him now, so I would be fine."

3.2. The Meaning

3.2.1. Theme 1: Redemption

In the past, she did not consider obeying her husband's request as an obligation. She used to think that she should not be too obedient to him because she also

played a role in earning a living. When her husband suffered Alzheimer's disease, and her religious teacher reminded her, she realized that her refusal to her husband's request was a major sin. Tuti thought that her husband behavior as a karma to her attitudes in the past. For instance, when he defecated randomly, she thought that in the past she had disobeyed her husband so that it would be her redemption

"By the time the Alzheimer's symptoms emerged in my husband, I remembered what I used to behave to my husband, like my disobedience to my husband. Well, that's what awakened me. I started to stop the fight with him. Since that day, I tried to give my best to make him happy under any circumstances."

3.2.2. Theme 2: Obligation

Tuti remembered that her teacher in her religious group taught her that caring her husband and accompanying him in joy and sorrow were an obligation as a wife. So, she began to feel that caring for her husband was not a burden because it was an obligation.

"I did not take it as a burden. Because it was an obligation."

3.2.3. Theme 3: Devotion

Tuti also thought that caring for her husband an expression of devotion.

"Yes, it was a devotion to my husband."

3.2.4. Theme 4: The Way to Get Rewards from God

After a while Tuti considered that her duty to care for her husband was the way to get rewards from God.

"He became a way for me to get the reward from Allah. I thought he was the way to the reward, even though it was hard, no matter how I did it, I had to fix it so I could get to the reward. That was my principle now."

"So, I considered that these all were reward from Allah. Yes, I could easily get the reward. No need to go anywhere, it was all in front of my eyes. That's all."

The meaning that she gave to her experience helped her to survive in caring for her husband, although as time goes by he needed more assistance, for example, when his Alzheimer's symptoms got worse, such as hallucinations. She would tell herself that she would be fine.

4. DISCUSSION

This study aimed to explore a caregiver's experience and meaning in caring her Alzheimer's husband. In general, most caregivers of people with Alzheimer's are women[24]. In the context of Indonesian society, the caregivers are mostly family members due to the limited health facilities available for dementia patients[16].

When the early symptoms of Alzheimer's emerge, most people around the patient do not realize them, so Alzheimer's sometimes was diagnosed at the later stage [25]. In the beginning, most caregivers ignore the symptoms or even deny it in the early phase of knowing the diagnosis [26].

From the participant's experience, it was found several themes. These themes are confused and suspicious, shocked and disbelieved, sad and lost, regret, looking for more information, feeling annoyed, fatigue, stressful, coping, and acceptance. Then, the meaning given by the participant towards her experience were redemption, obligation, devotion, and the way to get rewards from God.

The first theme was "confused and suspicious". According to Khikmatin and Desiningrum[12], confusion arises because there is a great decline in the patient but the patient does not want to be helped. In this study, the patient often refused the help saying that he could still do what she requested but in fact he could not. The patient's early symptoms of being disobeyed along with a lack of information made the caregiver even more confused. Confusion and lack of information make caregivers do not understand the reason for the patient's actions so that suspicion arose on the patients.

The second theme was "shocked and disbelieved". Lim[27] explained that this stage sometimes begins with a feeling of shock until running off words to describe the feelings itself. Most family members of patients who experience terminal illness do not believe the patient's condition when they first know. In this case, Alzheimer's is not terminally illness, but untreatable illness.

The third theme was "sad dan lost". The participant had lost the image of her husband in past, as a smart, neat, healthy, and funny man, who was able to carry out daily activities independently. Now, she watched that her husband with Alzheimer's had changed his characteristics to become unrecognizable and very dependent on her assistance. This sadness is a common thing for caregivers of people with Alzheimer's, as revealed by research done by Manalu[28]. Sadness generally arises after seeing a drastic change in the people they care about. Sometimes, remembering their past abilities can also make caregivers even sadder. The ability to interact closely with caregivers in the past also is included as the thing that could make them sadder[29]. What might also increasing the sadness is that the hope that their loved ones can enjoy their old age happily is now unattainable.

The forth theme was "regret." After being shocked, regret often emerges in Alzheimer's caregivers. Although in several studies regret appears in institutional caregivers and long-distance caregivers, this can also occur in family caregivers, for instance feeling regret for not

helping and doing the best for the patient[18]. Regret arose as a result of the lack of caregiver's comprehension of the patient's condition and not realizing the changes experienced by their loved ones as characteristics of Alzheimer's.

The fifth theme was "looking for more information". Regret was a factor that encouraged participant to join ALZI with the aim of getting information about treating her husband. According to Khikmatin and Desiningrum[18], seeking information is part of the adjustment process that is generally carried out by Alzheimer's caregivers. In this study case, the participant also wants to share her experiences so that other caregivers were able to overcome the hardship she ever had.

The sixth theme was "feeling annoyed" because the caregiver's expectations for the patients did not match reality. Following the research conducted by Yuniati[30], feeling annoyed usually appears at the beginning of the caregiving process. Annoyance appears as a response to behavioral changes in people with Alzheimer's due to memory loss. However, with the frequent occurrence of 'weird' behavior, caregivers can finally realize it is part of Alzheimer's. Slowly, the caregiver learns to adjust.

The seventh theme was "fatigue". Being a caregiver for Alzheimer's patients puts the individual under a greater burden than caregivers for other patients[31],[32]. This can be seen from stress and susceptibility to psychological disorders prevalence which is higher than other caregivers due to the long duration of caring and assistance. Caregivers are also reported to have low immunity and short sleep duration. In addition, what distinguishes caregivers for Alzheimer's from other caregivers for other patients is the lack of reciprocity[18]. In other diseases, the patient is able to show reciprocal behavior from the caregiver's attention through words and acts which are full of gratitude, willingness to help, cooperation, and support.

The eighth theme was "stressful". According to Widiastuti[33], sources of stress in Alzheimer's caregivers consist of objective stressors and subjective stressors. In general, objective stressors come from people with Alzheimer's. In this study, the objective stressor emerged from the changes experienced by the patients, such as a decrease in cognitive condition and dependence in carrying out daily life. On the other hand, subjective stressor emerged from the caregiver's feelings because of the changes in her lifestyle being a caregiver. As a family caregiver, the participant got an additional role in her life which add up to her current demands.

The ninth theme was "coping". In general, Folkman[34] describes two types of coping, namely emotion-focused coping and problem focused-coping. Emotion-focused coping works to regulate emotional responses to stress experienced. Meanwhile, problem-focused coping is done to reduce demands and stressful situations by developing individual resources. The caregiver's ignorance could be seen as a form of emotion-focused coping or denial. Taking a break from stress and expressing the feelings could be seen as avoidance of the

problems but it helped her get through the caregiving process with better emotions.

The last theme was “acceptance.” After going through hardships experienced during the caregiving, she was eventually able to accept her husband's condition. This acceptance is a form of gratitude and indicates a good coping mechanism[35]. Gratitude is part of greater life orientation in terms of paying attention to and appreciating the positive things in life[36]. She learned to accept that her husband's condition was irreversible. Therefore, there was no reason to be constantly angry with the situation. She even considered this condition as an opportunity to get the maximum reward. Later in life, she found this very helpful for her to survive and bounce back when she was tired of caring for her husband.

The meaning of the caregiving experience given by the participant was shown in four themes. The first theme was “redemption”. The experience of taking care of the patient was seen as the redemption of her sin toward the patient (her husband) in the past. In her study, Widyastuti[17] interpreted caring as a test of patience which may be an act of redemption for what we did in the past.

The second and third themes were “obligation and devotion”. Caregiving for patients was seen as the obligation of healthy family members in helping other members who were sick[37]. In the context of Indonesian society, families choose to take care of elderly members rather than sending them to the nursing home because it is a part of their responsibility[17]. In the context of a marriage, caring for our spouse is an obligation, which is stated in the Indonesian Marriage Law No. 1 of 1974, namely the obligation to love, respect, be faithful, and provide physical and spiritual assistance. The concept of obligation which was interpreted by the caregiver made her perceived the process of caring for her husband as an act devotion she had to do under any circumstances. This could lead her to the stage of acceptance of her role as a caregiver for her husband who had Alzheimer's.

The fourth was “The Way to Get Rewards from God”. The caregiver considered the caregiving process was the way for her to get the rewards from God. The religious theme that emerged was in line with other researches in Indonesia. In her study, Widyastuti[17] interpreted caregiving as the process that can bring rewards. The participants' religiosity increased as their husbands had Alzheimer's and they get older[16]. Based on Glock[38], believing in the existence of sin and reward is part of the ideological dimension in religiosity. The presence of religiosity in difficult times helps individuals improving psychological well-being, preventing the negative impact of events experienced, and enabling survival spirit to emerge in difficult conditions as well as rising from the problem and arranging the future[39].

5. Conclusion

In this study, undergoing a role as a caregiver for people with Alzheimer's is an experience that proceeds from feeling confused and suspicious to acceptance of the

condition. The meaning given by the caregiver to her experience as redemption, obligation and devotion and the way to get rewards from God, made her accepted her role as a caregiver for her Alzheimer's husband.

6. Limitation and Suggestions

The limitation of this study is that it is only conducted based on the experience of one participant. It was very difficult to get participants who meet the criteria. The researcher has asked for support from ALZI. However, due to certain procedural steps, the researcher could not get more participants to get more understand of the Alzheimer's caregiver experience.

Other limitation of this research is the limited access to conduct research due to the pandemic. Interview conducted by telephone made the researcher unable to observe many things on the participant during the interview. If it is possible to obtain data through observation, the researcher will get a deeper and broader data to understand the phenomena.

Although there has been a lot of literature depicting individual experiences of caring for Alzheimer's patients, experience and meaning could be different for each individual. In this study, the participant's meaning of her experience was affected by her understanding about religious matters, that caring for a partner is an obligation and can bring reward. Thus, the negative emotions and fatigue experienced in the early days of caring for Alzheimer's patients can turn into more positive emotions and behaviors in the end.

This study contributes to understanding more about the experience and meaning given by a caregiver of an Alzheimer's patient. This study only had one participant, it had shown that religious beliefs had an important influence on the meaning given by a caregiver towards her caregiving experience. The future study with more participants could give more understanding of factors that could contribute to caregivers' meaning to their experience. In addition, if possible, the next research should be done through face-to-face interaction and in a longer time so the researcher could obtain more detailed information about caregiving process, for Alzheimer's patients

One of the benefits of this research for clinical practitioners is the acquisition of knowledge about the experience of caregivers for husbands suffering from Alzheimer's. Given that the role of a caregiver is quite difficult, early information from clinical practitioners will help individuals identify symptoms of decline that occur so that they can provide early treatment.

Clinical practitioners could provide groups of people who share the same difficulties and are mutually reinforcing that help the caregivers to get more information and support. Support groups are also expected to be a means of sharing stories so that each individual can obtain therapeutic benefits from the interactions that occur. The group could also provide information related to health services that can be accessed both by the patients and

caregivers who experience a decline in health as the result of their role.

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