

Original Article



Experiences of Family Caregivers Caring for Patient with Alzheimer's Disease: A Hermeneutic Phenomenological Study

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Email: evelyntambunan@unai.edu**Abstract**

Introduction: Alzheimer's disease (AD) becomes one of the diseases that greatly increased in the older adult population. Family caregivers play an important role in caring for family members who suffer from AD. The aim of this study was to illuminate the meaning of family caregivers' lived experiences caring for a family member with AD from the perspective of an Indonesian.

Methods: Narrative interviews were conducted with 13 family caregivers. These interviews were audio-taped and transcribed verbatim and analyzed using a phenomenological hermeneutic approach.

Results: The findings are presented under two main themes: Descent and ascent in caring for which emerged from category from being denial to acceptance, from lack of patience to compassion, from using to not using medication, and desperate yet responsibility. Another theme, caregivers' life learning emerged from the category of ongoing caring for and getting through in caring for.

Conclusion: Expressed concerns have shown that family caregivers not only face challenges in caring for family members suffering from AD, but also gain a lesson for life. It is necessary for family caregivers to manage caring processes for family members who suffer from AD.

Introduction

The number of older adults has greatly increased in recent years due to increasing life expectancy and decreasing mortality and fertility rates.¹ According to data from the World Health Organization (WHO), there were 703 million individuals 65 and over in the world as of 2019. By 2030, that number is projected to increase to 1.5 billion. However, developing countries like Indonesia will experience a quicker growth in the number of older adults than developed countries, resulting in 79% of older adults living in developing countries.² Along with these events, Alzheimer's disease (AD) becomes one of the diseases in the older adult population. The prevalence of these cases almost doubles every 5 years after age 65.³ Cognitive loss and diminished behavioral skills are brought on by brain atrophy and aberrant protein buildup, such as beta-amyloid and tau. With time, AD sufferers lose their ability to function independently. The typical AD post-diagnosis survival rate ranges from 5-8 years.⁴ However, it often varies amongst patients due to other aspects like age, gender, ethnicity, socioeconomic position, and other health issues, most recently COVID-19.⁵

Family caregivers play an important role in caring for family members who suffers from AD. This disease

is a degenerative chronic illness which is the leading cause of dementia.⁶ This condition greatly affects the patient's quality of life as they require the assistance of others to fulfill their needs.⁷ Caregivers have numerous stressful occurrences as the disease progresses because of its natural progression. Uncertain or unpredictable circumstances, reduced life and health expectations, a lack of both personal and social resources, a lack of comprehension, stigma and heredity, family problems, and interpersonal conflict are just a few examples of these kinds of events.⁸ Caregivers might experience low quality of life, social isolation, psychological anguish, and bad caring experiences.⁹ Due to the long-term and progressive nature of AD, family caregivers embrace long-term care obligations.¹⁰ Undoubtedly, caring for Alzheimer's is challenging and demanding that may lead to the occurrence of difficulties including physical, emotional, and mental exhaustion among caregivers.¹¹

It is estimated that two-thirds of people with AD live and are cared for by their families worldwide.¹² Specifically in Indonesia, where there are strong traditions of filial piety that demand the Indonesians to respect their family members and take responsibility to care for them when they get old. However, Indonesia is currently undergoing

a range of sociocultural and demographic changes which have had a significant influence on the capacity and availability of the traditional family support care system. There are several nursing homes to care for elderly, yet they only accept elderly who do not have AD. Hence, family members, especially parents who suffer from AD are cared at home.^{13,14}

Caring for people with AD has been widely studied in other countries, especially in the western culture, but little knowledge of this topic exists in Indonesia. Studying this topic can help families better cope with their roles. Because cultural differences exist between countries, the international literature may have only limited application to AD caring in Indonesia. Describing and identifying the lived experiences of the Indonesian family caregivers caring for patients with AD can lead to obtaining a comprehensive understanding of the related meaning and concepts. Therefore, investigating Indonesian family caregivers' experiences of looking after a family member with AD is important. Such a concept has been studied widely in western literature, however, rarely in Indonesia. In addition, studies using qualitative phenomenology appear to be more suitable for determining the breadth of lived experiences and the significance of a complex phenomenon because quantitative research approaches are insufficient to understand human lived experience.¹⁵ Thus this study has aimed to illuminate the meaning of family caregivers' lived experiences caring for a family member with AD from the perspective of an Indonesian.

Materials and Methods

This present study is a qualitative study with an interpretive phenomenological approach. It was conducted in Bandung, Indonesia from January 2023 to June 2023. Interpretive phenomenology is the process of extracting and revealing hidden experience.¹⁵ In proportion to the qualitative research, purposive sampling was used with maximum variation in terms of age, sex, work experience, and academic degree. In purposeful sampling, the researcher seeks those who have a rich experience of the phenomena under study and have the ability and desire to express it.¹⁶ Indonesia Christian Religious Community in Bandung, West Java, Indonesia, was selected as one of Christian Communities where caregivers had relatives suffer from AD. Thirteen caregivers, 3 men and 10 women aged 38 to 65 years were selected from this community. The inclusion criteria were caregivers whose relatives were diagnosed with AD and had been involved in caring them for at least three years and a desire to share experiences. Also, caregivers have lived with an Alzheimer's patient.

Data was collected through individual narrative interviews with open-ended questions to capture lived experiences of family caregivers caring for AD.¹⁷ Written consent was obtained from all family caregivers to participate in the interview and audio recording. Participants were assured of the optional withdrawal

from the study, it was also assured that their names and identities would be kept confidential and that the information would be used for research purposes only. Interviews with family caregivers were performed during non-spiritual activity hours to ensure that spiritual activity was not affected. Interviews were conducted after the religious activities and in different groups religious activity. In this way, the second author first referred to the participants and stated the purpose of the study, and if they wished to participate in the research, an interview time was scheduled. None of the caregivers refused the interview and continued to do so eagerly. Interviews with caregivers were conducted in a private room at the spiritual activity building by the first author. Open-ended questions were designed as interview guides that had open-ended and interpretive answers, and follow-up questions were asked after interviewees' responses. With the participants' written consent, interviews were audio recorded. The general question in all interviews was: "Please describe or express how you feel about caring for your family suffering from Alzheimer' disease" and "What is it like to care for her/him?" They were then questioned further to elicit their thoughts, feelings, and worries. More specific inquiries regarding the causes motivating them, obstacles to care, and issues they faced were made as the conversation went on. The interviews lasted 40 to 60 minutes on average. In total, 13 interviews with 13 caregivers were conducted in this study. No new data or concept was obtained after analyzing the last (13th) interview.

Data analysis was carried out in accordance with the phenomenology-hermeneutic methodology developed by Lindseth and Norberg.¹⁷ This method means moving between the whole text and parts of that using three steps: naive reading, structural analysis and comprehensive understanding. In the first step of naive reading, every transcribed interview has been converted into time repeatedly by open-minded researchers. The naive interpretation was the initial interpretation of the full and the main random interpretation of the impact of the researcher's pre-understandings. The naive reading provided initial raw data of the text and enabled researchers to have insight for the next step. The narrative has been synthesized by the naive reading of the text. In the second step structural thematic analysis, several structural analysis approaches were applied. The applied thematic structural analysis with the aid or a reflective distance to condense the meaning units within the text, create themes, and sub-themes. The whole text was examined and divided into meaningful units. These units were compared to results of naive reading and each unit was expressed in concise, ordinary words. These words were used to create sub-themes and subsequently themes. As the final step in comprehensive understanding, in the formula of systematic know-how, the definitions within the textual content have been developed into a vital

dialect between the pre-know-how and components of the researchers and the whole textual content. And this interpretation has changed into re-contextualized in some of the related literature to deepen and extend what has been known by researchers from the textual content. In this last phase, the in-depth interpretation was built primarily on the basis of naive understanding, thematic structural analysis, prior research knowledge, and the theoretical context.¹⁷

Lincoln and Guba’s criteria were used to ensure rigor of the study. These criteria include credibility, dependability, confirmability and transferability.¹⁸ The credibility was established in this regard through ongoing interaction with the participants and interviews, member checking, peer debriefing, and organizing collaborative sessions. Dependability was also attained through the use of an external audit in which a professional was asked to review the analyses and procedure that had been used. Through reflexivity and an audit trail, confirmability was attained. In order to avoid bias, the authors wrote about their personal experiences and viewpoints before examining the data. Finally, in order to increase the transferability of the results, a homogeneous sample was chosen with the greatest diversity of demographic traits and family caregivers caring for patients with AD.

Results

Participants in the study were 13 caregivers who were in the 38-65 age range (mean 47.5). Ten caregivers were female and three were male. Three of the participants were sons, seven were Females, and three were the wife of the family member who suffers AD. Two of them had a master’s degree, eight had a bachelor degree, one had a three year diploma degree, one had a senior high school degree, and one had a junior high school degree. All caregivers had provided care for 5-7 years (mean 5.9 years). In addition, all caregivers had a domestic assistant who can help them

Table 1. Demographic characteristics of the participants

| N | Age (y) | Educational level | Length for caring (y) | Relationship with Client AD |
|-----|---------|--------------------|-----------------------|-----------------------------|
| P1 | 65 | Junior high school | 6 | Spouse |
| P2 | 52 | Bachelor’s degree | 7 | Man |
| P3 | 45 | Master’s degree | 7 | Female |
| P4 | 39 | Bachelor’s degree | 7 | Female |
| P5 | 42 | Master’s degree | 7 | Man |
| P6 | 45 | Three year diploma | 5 | Female |
| P7 | 43 | Bachelor’s degree | 5 | Female |
| P8 | 38 | Bachelor’s degree | 6 | Female |
| P9 | 60 | Bachelor’s degree | 6 | Spouse |
| P10 | 45 | Bachelor’s degree | 6 | Man |
| P11 | 42 | Bachelor’s degree | 5 | Female |
| P12 | 63 | Senior high school | 5 | Spouse |
| P13 | 38 | Bachelor’s degree | 5 | Female |

caring for their family with AD (Table 1).

The results of the study are presented under the topics of synthesis of naive reading, structural analysis, and main themes: Descent and ascent in caring for and Caregivers’ life learning (Table 2).

Descent and Ascent in Caring for

This theme contained experiences of family caregivers’ caring for patients with AD. In the interviews, family caregivers in caring for their family members with AD laid from denial to acceptance. Participants reflected that they struggled to accept their family members’ suffering from AD. However, after several years, after experiencing various challenges in taking care of a family who suffers from Alzheimer’s, some participants admit that they are trying to accept these conditions. Although it is difficult to accept the condition that has progressed to a more severe stage, the family caregivers are increasingly trying to accept the circumstances of their family member suffering from Alzheimer’s. In the subcategory lack of acceptance, it was inferred that in the early stages of the condition of family members experiencing Alzheimer’s, caregivers felt as if the behavior demonstrated by Alzheimer’s patients was pretending, acting out or joking with dementia, mad, irate, etc. It seems that the behaviors are consciously repeated. Participants reflected as follows:

“I initially thought my spouse was making a joke when he kept asking the same question. I don’t accept his condition and assume he’s pretending to forget what he asked previously.” (Participant No.1)

Another participant said:

“I don’t accept my father’s condition because of his advanced age and recent retirement. I hope it’s just a fad that he doesn’t take care of much anymore, like his job. It happened at the very beginning when the symptoms of dementia appeared, about seven years ago.” (Participant No. 8)

On the other hand, the participants’ lived experiences revealed that they accepted the Alzheimer’s condition of their family members at an advanced stage. Having experienced various challenges in caring for Alzheimer’s

Table 2. Extracted themes, category and sub-category

| Theme | Category | Subcategory |
|----------------------------------|--------------------------------|------------------------------------|
| Descent and ascent in caring for | Being denial to acceptance | Lack of acceptance in early stages |
| | | Acceptance in late stages |
| | Lack of patience to compassion | Emotional tendencies |
| | | Compassion stress |
| Using to not using medication | Using medication | |
| | Not using medication | |
| Caregivers’ life learning | Desperate yet responsibility | Hopelessness |
| | | Family responsibility |
| Ongoing caring for | Get through in caring for | Still in the learning process |
| | | Memories as life lessons |

patients, family caregivers find it very difficult to accept the fact that family members have Alzheimer's. One participant reflected:

"As his wife, it is very difficult for me to accept my husband's condition, which is getting more and more stupid, to the advanced stage, his behavior is increasingly dishonorable. But how else? I tried to understand his behavior even though it was difficult."

(Participant No. 12)

While one participant expressed:

"When I was feeling very weary and there was no one to help take care of my father at the time, I did not accept his behavior, but when I was thinking clearly, I could tolerate his behavior, such as being furious or suspicious."

In the category of from lack of patience to compassion, the family caregivers experiencing impatience in dealing with the AD patient behavior. Anger, crying, fear and anxiety are experienced when caring for family members who are increasingly showing poor behavior. In conditions where AD sufferers are behaving badly, family caregivers mostly show lack of patience. However, when the condition of AD sufferers is calm, caregivers often feel sad and feel sorry for seeing the condition of family members suffering from AD. In the subcategory of emotional tendencies, it was expressed that caregivers were resentful, offended, embarrassed and anxious. Some of family caregivers stated as follows:

"In my rage, he continually performed things I had instructed him not to do, such repeatedly moving the sofa and even turning it over when we hadn't segregated him in a different room."

"My biggest anger was when my father beat my mother, because she was forbidden to leave the house."

"I felt embarrassed in front of my neighbors because of my father's actions, which included shouting to anyone who walked by from the front of the home. I think that other people don't understand what Alzheimer's is, and I think they think my father is weird."

"I was disturbed that my mother no longer recognized me, and I took offense at this."

"At the early condition of my parent, there was a sign of dementia, I was disturbed sleep and even experienced anxiety about facing in the future, how a more difficult condition might occur."

In the subcategory of family caregivers who remarked compassion stress, some participants experienced pressure by having to forebear from negative behaviors in caring for a family member with AD. In fact, the natural reaction of family caregivers is stress, but sometimes they feel sorry for the behavior of patients who increasingly don't understand anything. Participants expressed as follows:

"I feel bewildered, stressed out by his outbursts, distrustful and slamming things. I wanted to lock him

up at that moment. But I often also feel sorry that he was not like that before."

"My burden caring for him at home might have risen if it weren't for the way we as children helped and supported one another. We share responsibility because we feel sorry for our parents whose behavior is getting out of control. For example, just arrived at my sister's house, immediately asked to be delivered again to my house..huuhhh."

"My mother often expresses her feelings of stress but then feels sorry..."

In the category of using medication not to use medication, family caregivers are experiencing the dilemma. In the subcategory the use of medications, family caregivers pointed out that they have side effects aside the therapeutic effects. Moreover, family members have different perceptions about the use of medications that are considered not to have a healing effect. On the other hand, family caregivers are constrained by various factors in bringing patients to see a doctor. Obstacles such as, patients no longer patient wait for the doctor and difficulties for patients to take the medicines that have been given by the doctor. Participants statements as follows:

"When our parents were diagnosed with Alzheimer's, we tried to reduce the symptoms our parents experienced. Using some of the medicines prescribed by the doctor. But we were also frustrated, because our father became even more stupid after taking the medicine."

"I gave my mother some medicine, but it depends on whether or not she wants it. If she does not want to, sometimes my hands are beaten."

"For the treatment of our parents, my husband and I still administer medication. Even though my sister's family pointed out that these medications do not cure, they only lessen the worsening of condition."

In the subcategory not to use medications, family caregivers experienced a number of constraints in using medications to family members who suffer from AD. They revealed the obstacles in such:

"We don't currently administer medication to our father. We are still trying to find out how much impact the medications had on our father's recovery."

"It is difficult to take him to the doctor, in fact the doctor does not want to prescribe medicine if the patient does not come and be examined by the doctor. So we don't give medicine to our father anymore."

"My mother doesn't want to take the medicine prescribed by the doctor. It is difficult to give medicine to drink, sometimes it is spouted when it is in her mouth. Sometimes my hands are beaten and the medicine is wasted. Then we decided not to give medicine anymore."

In the category desperate yet responsibility illustrates

participants' experiences with hopelessness in caring for family members with AD. As a family caregiver, it is a responsibility to care for AD family members. Over time, people with AD experience more severe signs and symptoms. Thus, family caregivers face the hard reality of caring for AD family members. In subcategory hopelessness, most participants believed that there was no hope for their loved ones' future as well as themselves. The participants expressed as follows:

"Given that my spouse must take medication constantly, as I already stated, I believe there is no reason to treat him. It's getting harder and harder to deal with his rude behavior every day." (Participant No. 1)

"The severity of Alzheimer's disease will undoubtedly reach a more advanced stage, according to everything I've read online. For my father's recovery, there is no hope." (Participant No. 2)

"Getting my mother to take a bath was really challenging. While taking a shower, I occasionally need to spend longer than an hour managing his behavior...huhhh... It's hopeless." (Participant No. 7)

In the subcategory responsibility, participants illustrate their experiences describing the experience of caring for a family with AD as a manifestation of responsibility. The role of the family is not to abandon parents or spouses who are sick. Even though it is difficult, it must be faced because the responsibility must be carried out. Participants reflect the following responses:

"I am aware of my responsibility as a child to take care of my parents. However, it is quite challenging to care for my father, whose capacity for thought is deteriorating. Dad has been in our care for six years, and things are becoming worse." (Participant No. 4)

"When we didn't have a domestic assistant, it was quite difficult to care for my mother; nonetheless, as a child, that was my responsibility" (Participant No. 6)

"I used to care for my husband by myself before moving in with my son. Helpers never feel at ease. They ask to cease working because they are terrified. I still had a responsibility as a wife when my husband was given the AD diagnosis." (Participant No. 12).

Caregiver's Life Learning

This theme is described by the experience of family caregivers as a life learning process in taking care of family members with AD. The process of taking care of a family member with AD involves many life experiences. Family caregivers learn about life values through their experiences. In the category on going caring for, participants shared experiences as life lessons that still have to be learned. The subcategory is still in the learning process, expressed by the participants as follows:

"I learned through discussions with friends who also experienced caring for their Alzheimer's parents. I received information about how to deal with my father's changing behaviors. My friend encourages me to be

patient and patient..heee" (Participant No. 10)

"In order to prevent disrespectful conduct toward the AD parents, the doctor advised us to hire an assistant to help with the care of the parents." (Participant No. 13)

In the category get through in caring for, participants describe life experiences gained after completing caring for AD family members. They explain the lessons learned from taking care of family members with AD. Family caregivers retained the life lessons learned from these situations. Memories as life lessons is a subcategory that some participants describe as follows:

"I've learned the value of patience and respect for parents from my experience taking care of my parents who have Alzheimer's disease. Even though it's not as simple as it seems, in actuality, while caring for my parents...I frequently acted impatiently toward my parents." (Participant No. 9)

"The spiritual journey is getting closer to God, the only prayer I offer to God, to deal with chaos conditions at that time...as a memory." (Participant No. 4)

"Despite the fact that there have been arguments amongst the brothers and sisters when taking care of our father, our mother warns against having constant arguments. Now our mother has passed away, only memories remain." (Participant No. 5)

Discussion

The experience of caring family members with AD in interviews with family caregivers emerged in themes of descent and ascent in caring for and caregivers life learning. The experience of family caregivers is found from the range of denial to acceptance. Hall and Sikes who investigated the negative experiences of having a parent with AD, found that participants said that getting a diagnosis was frequently a drawn-out process that led to misunderstandings, uncertainty, and increased family strife.¹⁹ The family's financial situation was affected by a misdiagnosis or lack of diagnosis. Despite the fact that being given a diagnosis was typically viewed as a "shock" and was extremely difficult to accept, it served as a crucial turning point in understanding the unsettling personality and behavioral changes that the parent with dementia was exhibiting.²⁰ On the other hand with a better understanding of dementia, the caregivers were better able to relate to the resignation and disease-related problems experienced by dementia patients. To help their loved ones cope with dementia, caregivers frequently decided to accept the patients' fate and tried to alter their own perspectives. Moreover, the certain carers were able to better appreciate the dementia patient's residual capacities as they adjusted to their duties.²¹

The caregivers under the present investigation mentioned lack of patience to compassion. Caring for family members who are behaving badly more frequently causes feelings of rage, tears, dread, and anxiety. However, when AD patients' conditions are stable, caregivers

frequently experience sadness and regret at witnessing their loved ones' suffering. In this context, several studies have indicated that family caregivers care burden results from the poor behavior of patients with AD.²² The care burden results from emotional and mental problems such as depression, hopelessness, tension, impatience and violence. It further led to negative changes in the family, eventually resulting in mental regression. This cognitive condition was also a significant risk factor for inappropriate behavior toward elderly patients suffering from AD.²³ Moreover, caregivers psychological pathology demonstrated that tensions caused by emotional and mental issues resulted in negligence and misbehaviors toward patients AD.²⁴ This condition results in feelings of guilt for family caregivers. Guilt has been defined as the feeling experienced by Alzheimer carers when they believe they have violated or have the potential to violate, a moral or societal standard relating to family care in both their thoughts and actions.²⁵ Guilty feeling led to compassion feeling demonstrated by family caregivers. Compassion in care seen as a building block of high-quality health care by patients, families and healthcare professional.²⁶

Another experience in caring for family members with AD is using or not using medications. In the current pharmaceutical treatment options for AD are still limited to symptomatic interventions. The N-methyl-D-aspartate receptor antagonist memantine and cholinesterase inhibitors, both of which have been shown to improve functional and cognitive outcomes in a significant proportion of AD patients.²⁷ In fact, the AD dementia condition is incurable. It is becoming more widely accepted that the intricate and poorly understood pathological processes leading to AD dementia can start decades before any clinical symptoms appear. By this point, extensive and probably irreversible processes have caused extensive damage on many different levels, including molecular, intracellular, cellular, network, and system levels.²⁸ The current paradigm for treating AD focuses on managing symptoms in a variety of ways in order to preserve quality of life, lessen the toll of the disease, and slow down long-term clinical decline.²⁹ Undoubtedly, this is what causes family caregivers to consider using medications or not in caring for family members of AD.

The family caregivers experienced with desperate yet responsibility in this study. The hopelessness behaviors resulted from their care responsibility. This finding is incongruent with the current research. In some countries, only a few families provide AD care, much more AD care by professional caregivers. However, efforts have been made to develop home and community-based care services to reduce the burden and pressure of caregivers.^{30,31} However in Indonesia, where there are close ties between family members and a significant focus on family values that include care for the elderly, family caregivers are solely responsible for caring for patients with AD because there are no home care facilities and

no official, professional caregivers to provide healthcare services.¹⁴ Consequently, families are given a heavier responsibility for providing care, and caregivers must deliver challenging care services. Families must also provide more consideration and support to the primary caregiver as a result.³²

The family caregivers under the present study expressed their life learning process in taking care of family members with AD. Consistent with results of this, it was suggested that due to the lack of experience of family caregivers who are still in the process of caring for AD family members, it is important to continue learning or seek support from various beneficial activities. Consult with professionals such as neurologists or psychologist and also engage in group discussions to share experiences caring for family members suffering from Alzheimer's.³³ Moreover, according to studies, providing care for an elderly person is strongly influenced by the values, priorities, and beliefs of the people providing the care as well as their past and present connections with one another. The impacts, the companionship, that is, the significance of upholding the ties and continuity of life, are also a significant sensitizer/motivator of the family to provide the care. Human dignity, solidarity, and, most importantly, the affectivity principle serve as the foundation for moral support that is built on love, care, respect, and cooperation.³⁴ Certainly, family caregivers experience various challenges in caring for family members of AD. In this study family caregivers acquire memories after ending these difficult times. Accordingly, family caregivers emphasized that their morals, such as conscientiousness, gratitude, and awareness of the patient's self-sacrifice, as well as their religious practices and beliefs, and social values, such as family norms, have a significant impact on their resilience in dealing with care stress. This, in turn, improves their capacity to respond appropriately to the situation and lessens the negative effects of the care burden. In stressful circumstances, religion offers elements that are helpful for enhancing a person's health and well-being.³⁵⁻³⁷ Previous research has demonstrated that religion strengthens a person's fortitude in the face of difficulties and gives them greater control over their actions and behavior. In general, religious people's distinctive way of life gives them the ability to view unpleasant situations as opportunities to grow and build their spirits.³⁸

Conclusion

This study provides an overview of experience of family caregivers caring for patients with AD. Our findings support the idea that family caregivers posed to the experience of descent and ascent in caring for AD and gain a life learning in caring for AD. The experience of descent and ascent in caring for AD is related to experience from being denial to acceptance, from lack of patience to compassion, from using to not using medications and desperate yet responsibility. The experience of caregivers'

life learning is related to experiencing ongoing caring for AD and getting through in caring for AD. Expressed concerns have shown that family caregivers not only face challenges in caring for family members suffer from AD, but also gain a lesson for life.

There were no particular limitations for carrying out this investigation. However, one the limitation of qualitative research may be the inability of the findings to be generalized. Besides, the results of this study can highlight the need to provide the necessary support to Indonesian family caregivers at home and abroad through the knowledge gained from their experiences and living conditions. Further research using in-depth focus group interviews in a wider population may provide more explanatory and useful information for family caregivers to better manage caring processes.

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Author's Contribution

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Competing Interests

The authors have no conflicts of the interest to declare.

Data Availability Statement

The datasets are available from the corresponding author on reasonable request.

Research Highlights

What is the current knowledge?

It has been argued that awareness of the family caregivers experiences of caring family members with AD could be informative to better manage caring processes for family members who suffer from AD.

What is new here?

Expressed concerns have shown that family caregivers not only face challenges in caring for family members suffer from AD including physical, psycho-social and financial burden, though also they gain a lesson for life such as values and spirituality.

Ethical Approval

This study was approved by the Ethics Committee Faculty of Nursing Science Universitas Advent Indonesia, Bandung Indonesia (code: 314/KEPK-FIK.UNAI/EC/V/23).

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References

1. United Nations, Department of Economic and Social Affairs, Population Division. World Population Prospects 2019: Highlights (ST/ESA/SER.A/423). Available from: https://population.un.org/wpp/Publications/Files/WPP2019_Highlights.pdf.
2. World Health Organization (WHO). Global Status Report in the Public Health Response to Dementia [Internet]. USA: WHO; 2021. Available from: <https://www.who.int/publications/i/item/9789240033245>. Accessed August 20, 2023.
3. Trevisan K, Cristina-Pereira R, Silva-Amaral D, Aversi-Ferreira TA. Theories of aging and the prevalence of Alzheimer's disease. *Biomed Res Int*. 2019; 2019: 9171424. doi: [10.1155/2019/9171424](https://doi.org/10.1155/2019/9171424)
4. Petersen RC. How early can we diagnose Alzheimer disease (and is it sufficient)? The 2017 Wartenberg lecture. *Neurology*. 2018; 91(9): 395-402. doi: [10.1212/WNL.0000000000006088](https://doi.org/10.1212/WNL.0000000000006088)
5. Co M, Couch E, Gao Q, Martinez A, Das-Munshi J, Prina M. Differences in survival and mortality in minority ethnic groups with dementia: a systematic review and meta-analysis. *Int J Geriatr Psychiatry*. 2021; 36(11): 1640-63. doi: [10.1002/gps.5590](https://doi.org/10.1002/gps.5590)
6. Huang SS. Depression among caregivers of patients with dementia: associative factors and management approaches. *World J Psychiatry*. 2022; 12(1): 59-76. doi: [10.5498/wjpv.12.i.1.59](https://doi.org/10.5498/wjpv.12.i.1.59)
7. Greaney ML, Kunicki ZJ, Drohan MM, Ward-Ritacco CL, Riebe D, Cohen SA. Self-reported changes in physical activity, sedentary behavior, and screen time among informal caregivers during the COVID-19 pandemic. *BMC Public Health*. 2021; 21(1): 1292. doi: [10.1186/s12889-021-11294-7](https://doi.org/10.1186/s12889-021-11294-7)
8. Pinyopornpanish M, Pinyopornpanish K, Soontornpun A, Tanprawate S, Nadsasarn A, Wongpakaran N, et al. Perceived stress and depressive symptoms not neuropsychiatric symptoms predict caregiver burden in Alzheimer's disease: a cross-sectional study. *BMC Geriatr*. 2021; 21(1): 180. doi: [10.1186/s12877-021-02136-7](https://doi.org/10.1186/s12877-021-02136-7)
9. Lindeza P, Rodrigues M, Costa J, Guerreiro M, Rosa MM. Impact of dementia on informal care: a systematic review of family caregivers' perceptions. *BMJ Support Palliat Care*. 2020. doi: [10.1136/bmjspcare-2020-002242](https://doi.org/10.1136/bmjspcare-2020-002242)
10. Chen L, Yin G, Lin S, Li Y. The perspectives of family caregivers of people with Alzheimer's disease regarding advance care planning in China: a qualitative research. *BMC Psychiatry*. 2022; 22(1): 464. doi: [10.1186/s12888-022-04106-8](https://doi.org/10.1186/s12888-022-04106-8)
11. Duplantier SC, Williamson FA. Barriers and facilitators of health and well-being in informal caregivers of dementia patients: a qualitative study. *Int J Environ Res Public Health*. 2023; 20(5): 4328. doi: [10.3390/ijerph20054328](https://doi.org/10.3390/ijerph20054328)
12. Yu H, Wu L, Chen S, Wu Q, Yang Y, Edwards H. Caregiving burden and gain among adult-child caregivers caring for parents with dementia in China: the partial mediating role of reciprocal filial piety. *Int Psychogeriatr*. 2016; 28(11): 1845-55. doi: [10.1017/s1041610216000685](https://doi.org/10.1017/s1041610216000685)
13. Hinton L, Tran D, Nguyen TN, Ho J, Gitlin L. Interventions to support family caregivers of people living with dementia in high, middle and low-income countries in Asia: a scoping review. *BMJ Glob Health*. 2019; 4(6): e001830. doi: [10.1136](https://doi.org/10.1136)

bmjgh-2019-001830

14. Turana Y, Kristian K, Suswanti I, Sani TP, Handajani YS, Tran K, et al. Adapting the World Health Organization iSupport dementia program to the Indonesian socio-cultural context. *Front Public Health*. 2023; 11: 1050760. doi: [10.3389/fpubh.2023.1050760](https://doi.org/10.3389/fpubh.2023.1050760)
15. Smith JA, Osborn M. Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *Br J Pain*. 2015; 9(1): 41-2. doi: [10.1177/2049463714541642](https://doi.org/10.1177/2049463714541642)
16. Creswell JW, Creswell JD. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. 6th ed. Los Angeles: SAGE Publications; 2022.
17. Lindseth A, Norberg A. A phenomenological hermeneutical method for researching lived experience. *Scand J Caring Sci*. 2004; 18(2): 145-53. doi: [10.1111/j.1471-6712.2004.00258.x](https://doi.org/10.1111/j.1471-6712.2004.00258.x)
18. Lincoln YS, Guba EG. *Naturalistic Inquiry*. Newbury Park, CA: SAGE Publications; 1985.
19. Hall M, Sikes P. "It would be easier if she'd died": young people with parents with dementia articulating inadmissible stories. *Qual Health Res*. 2017; 27(8): 1203-14. doi: [10.1177/1049732317697079](https://doi.org/10.1177/1049732317697079)
20. Woods B, Arosio F, Diaz A, Gove D, Holmerová I, Kinnaid L, et al. Timely diagnosis of dementia? Family carers' experiences in 5 European countries. *Int J Geriatr Psychiatry*. 2019; 34(1): 114-21. doi: [10.1002/gps.4997](https://doi.org/10.1002/gps.4997)
21. Yohannes AM, Willgoss TG. Rydym Eisiau Gwybod—the dementia diagnosis disclosure preferences of people in North Wales. *Int J Geriatr Psychiatry*. 2014; 15(30): 105-10.
22. Tulek Z, Baykal D, Erturk S, Bilgic B, Hanagasi H, Gurvit IH. Caregiver burden, quality of life and related factors in family caregivers of dementia patients in Turkey. *Issues Ment Health Nurs*. 2020; 41(8): 741-9. doi: [10.1080/01612840.2019.1705945](https://doi.org/10.1080/01612840.2019.1705945)
23. Ashrafizadeh H, Gheibizadeh M, Rassouli M, Hajibabae F, Rostami S. Explain the experience of family caregivers regarding care of Alzheimer's patients: a qualitative study. *Front Psychol*. 2021; 12: 699959. doi: [10.3389/fpsyg.2021.699959](https://doi.org/10.3389/fpsyg.2021.699959)
24. Raggi A, Tasca D, Panerai S, Neri W, Ferri R. The burden of distress and related coping processes in family caregivers of patients with Alzheimer's disease living in the community. *J Neurol Sci*. 2015; 358(1-2): 77-81. doi: [10.1016/j.jns.2015.08.024](https://doi.org/10.1016/j.jns.2015.08.024)
25. Prunty MM, Foli KJ. Guilt experienced by caregivers to individuals with dementia: a concept analysis. *Int J Older People Nurs*. 2019; 14(2): e12227. doi: [10.1111/opn.12227](https://doi.org/10.1111/opn.12227)
26. Sinclair S, Beamer K, Hack TF, McClement S, Raffin Bouchal S, Chochinov HM, et al. Sympathy, empathy, and compassion: a grounded theory study of palliative care patients' understandings, experiences, and preferences. *Palliat Med*. 2017; 31(5): 437-47. doi: [10.1177/02692163166663499](https://doi.org/10.1177/02692163166663499)
27. Dou KX, Tan MS, Tan CC, Cao XP, Hou XH, Guo QH, et al. Comparative safety and effectiveness of cholinesterase inhibitors and memantine for Alzheimer's disease: a network meta-analysis of 41 randomized controlled trials. *Alzheimers Res Ther*. 2018; 10(1): 126. doi: [10.1186/s13195-018-0457-9](https://doi.org/10.1186/s13195-018-0457-9)
28. Poulin SP, Bergeron D, Dickerson BC. Risk factors, neuroanatomical correlates, and outcome of neuropsychiatric symptoms in Alzheimer's disease. *J Alzheimers Dis*. 2017; 60(2): 483-93. doi: [10.3233/jad-160767](https://doi.org/10.3233/jad-160767)
29. Atri A. Current and future treatments in Alzheimer's disease. *Semin Neurol*. 2019; 39(2): 227-40. doi: [10.1055/s-0039-1678581](https://doi.org/10.1055/s-0039-1678581)
30. Walsh S, O'Shea E, Piersie T, Kennelly B, Keogh F, Doherty E. Public preferences for home care services for people with dementia: a discrete choice experiment on personhood. *Soc Sci Med*. 2020; 245: 112675. doi: [10.1016/j.socscimed.2019.112675](https://doi.org/10.1016/j.socscimed.2019.112675)
31. Low LF, Fletcher J. Models of home care services for persons with dementia: a narrative review. *Int Psychogeriatr*. 2015; 27(10): 1593-600. doi: [10.1017/s1041610215000137](https://doi.org/10.1017/s1041610215000137)
32. Kim B, Noh GO, Kim K. Behavioural and psychological symptoms of dementia in patients with Alzheimer's disease and family caregiver burden: a path analysis. *BMC Geriatr*. 2021; 21(1): 160. doi: [10.1186/s12877-021-02109-w](https://doi.org/10.1186/s12877-021-02109-w)
33. Lövenmark A. How children of parents with dementia can make their subject positions understandable and meaningful. *Qual Health Res*. 2020; 30(5): 704-16. doi: [10.1177/1049732319873051](https://doi.org/10.1177/1049732319873051)
34. de Souza IP, Santos de Araújo LF, Bellato R. [The experience of being chronically sick by Alzheimer and the arborescence of family care]. *Ciênc Cuid Saúde*. 2016; 15(4): 599-606. doi: [10.4025/ciencucidsaude.v15i4.34580](https://doi.org/10.4025/ciencucidsaude.v15i4.34580)
35. Hosseini L, Sharif Nia H, Ashghali Farahani M. Hardiness in family caregivers during caring from persons with Alzheimer's disease: a deductive content analysis study. *Front Psychiatry*. 2021; 12: 770717. doi: [10.3389/fpsyg.2021.770717](https://doi.org/10.3389/fpsyg.2021.770717)
36. Siregar D, Manurung EI, Sihombing RM, Pakpahan M, Sitanggang YF, Rumerung CL, et al. *Keperawatan Keluarga*. Medan: Yayasan Kita Menulis; 2020. Available from: <http://repository.uki.ac.id/7874/1/KeperawatanKeluarga.pdf>. Accessed August 20, 2023.
37. Amiri P, Gholipour M, Hajesmaeel-Gohari S, Bahaadinbeigy K. A mobile application to assist Alzheimer's caregivers during COVID-19 pandemic: development and evaluation. *J Caring Sci*. 2023; 12(2): 129-35. doi: [10.34172/jcs.2023.30679](https://doi.org/10.34172/jcs.2023.30679)
38. Simbolon I, Sacha C, Hemme E, Widyarti SH. Life experience of seventh-day adventist church members in caring for their parents who suffer from Alzheimer's dementia. *Abstr Proc Int Scholars Conf*. 2019; 7(1): 674-84. doi: [10.35974/isc.v7i1.2008](https://doi.org/10.35974/isc.v7i1.2008)