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Original research article

"Let's just die together, Mom": Family caregivers' responses to caring for elderly people with dementia

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Abstract
Introduction: Elderly people with dementia are highly dependent on caregivers; they require more assistance and supervision as the disease progresses and its severity increases. Family caregivers have different responses to caring for elderly people with dementia. This study aimed to explore Indonesian family caregivers' responses to caring for elderly people with dementia.
Methods: A qualitative research design was selected for this study. On the basis of semi-structured interviews, a descriptive phenomenological study was conducted among 15 purposively-recruited family caregivers.
Results: Three main themes and eight sub-themes emerged from the data. The first theme was family caregivers' perceptions of dementia. The sub-themes were that dementia is a common disease due to the aging process, and dementia is a disease due to Parkinson's, stroke, stress, and loneliness. The second theme was the meaning of caring for elderly people with dementia. The sub-themes were that obligation to care for older people with dementia, form of filial piety and the spiritual meaning of caring for older people with dementia. The third theme was the process of acceptance in taking on the role of caregiver to an elderly person with dementia. The sub-themes were that denial, depression, and acceptance.
Conclusion: Each of these themes has a cultural and spiritual dimension, and caregivers require professional assistance from health workers that accounts for these dimensions of caregiving. Likewise, it is important to identify depression in family caregivers so that suitable interventions can be provided.

Keywords: Dementia; Elderly people; Family caregiver; Indonesia; Response

Introduction

Dementia is a serious disease that is ranked as the seventh leading cause of death worldwide by the World Health Organization (WHO). It is also a significant cause of disability and dependency in terms of daily living activities, so elderly people with dementia require long-term or permanent care (Gauthier et al., 2022; World Health Organization, 2022). The WHO (2022) estimates an increased global population of elderly people with dementia, reaching 139 million in 2050. Half of elderly people with dementia live in the Asia Pacific region, which includes Indonesia. It is estimated that this number will rise to 71 million in 2050 (ADI, 2014; World Health Organization, 2022).

The number of elderly people with dementia in Indonesia is predicted to reach two million in 2030 and four million in 2050 (Alzheimer Indonesia, 2019). The prevalence of dementia in Indonesia, especially in the Special Region of Yogyakarta and Central Java, is 20.1%, which is higher than the global percentage of 10% (Suriastini et al., 2020). Most older people in Indonesia are cared for at home by their children (27.85%) and other relatives (39.10%) with their children and grandchildren (Statistik BP, 2020). Therefore, the projected increase in the number of elderly people with dementia will present challenges for family caregivers.

Family caregivers have many roles and responsibilities in caring for elderly people with dementia (Ducharme et al., 2011; Henriksen et al., 2020) and play a significant part in providing them with direct daily care (Cohen et al., 2001). Caring for elderly people with dementia affects both the elderly person and their caregivers. Caregivers not only provide care but also manage symptoms related to dementia, the most common of which are apathy, depression, and agitation (Chen and Lin, 2022; Gaugler et al., 2016; Lyketsos et al., 2011). Elderly people with dementia are highly dependent on caregivers, and require more assistance and supervision as the disease progresses and the severity of the dementia increases (Cohen et al., 2001; Ducharme et al., 2011). Therefore, family caregivers will respond differently when caring for elderly people with dementia.

Caregivers' responses to symptoms in elderly people with dementia are related to their caregiving burdens (Zauszniewski et al., 2018). In Indonesia, the total dependence of elderly peo-

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ple with dementia on their family caregivers can be a physical and emotional burden on the latter (Widyastuti et al., 2011). Caregivers bear a relatively high burden, especially in dealing with family dynamics, isolation, and financial problems, and in accepting their roles as caregivers along with their elderly relatives' conditions (Roberts and Struckmeyer, 2018). Family caregivers often lack the necessary skills or knowledge to provide care, and have difficulty planning for future care needs (Vaingankar et al., 2013). Family caregivers who experience role changes during caregiving will be vulnerable to the negative effects of caring. Therefore, they require adequate knowledge, skills, self-efficacy, and social support to be able to provide quality care (Ducharme et al., 2011; Leocadie et al., 2020; Meleis et al., 2000).

Adequate understanding of the experiences and responses of family caregivers in carrying out their roles can help ensure proper support for them (Lee et al., 2019). Exploring caregivers' responses to their roles can help identify the best way to facilitate support. It can also help inform interventions aimed at preventing the adverse effects of negative caregiving responses, thereby improving the quality of care. However, information about family caregivers' responses in caring for older people with dementia is still limited, as no previous research has attempted to investigate this issue. Therefore, this study aimed to explore family caregivers' responses to caring for elderly people with dementia in the Indonesian context.

Materials and methods

This qualitative study was conducted using a descriptive phenomenological research design to extract direct descriptions of participants' experiences and perceptions. The findings, *i.e.*, the participants' different experiences, are presented in a way that directly reflects (or is very similar to) the terminology used in the original research question (Sandelowski, 2010).

Sample

The participants were family caregivers to elderly people with dementia. They were recruited by means of a purposive sampling technique. This is used to identify participants who are able and willing to provide information based on their knowledge or experience, and who can communicate their experiences and opinions in an articulate, expressive, and reflective manner to individuals of a variety of ages, backgrounds, and cultures. Additionally, purposive sampling is used to identify specific participant characteristics that align with the research objective (Etikan, 2016). Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong et al., 2007) was used to report the study's findings.

The participants were recruited through non-governmental organizations (NGOs) about dementia care, Alzheimer Indonesia (ALZI) and health cadres in Semarang City, Central Java Province by WhatsApp. They were recruited based on the following inclusion criteria: adult primary caregivers with a family relationship with an elderly person with dementia who understand the Indonesian language; have been providing care for more than four hours a day for at least six months; and accompany and assist elderly people in performing their daily activities. In total, fifteen family caregivers were recruited.

Data collection and analysis

The research protocol was approved by the Human Ethics Committee of the Faculty of Nursing, Universitas Indonesia, West Java, Indonesia (reference number KET-132/UN2.F12.D1.2.1/PPM.00.02/2022). Data were collected using semi-structured individual interviews between August and September 2022. The principal investigator was involved in the data collection process. The interviews were conducted via telephone video calls and Zoom video conferences as there were face-to-face restrictions due to the Covid-19 pandemic. Before the interviews were conducted, the researchers clearly explained the purpose of the study to all of family caregivers and obtained their consent to participate. This ensured that all participants were fully informed and willing to take part in the study. All steps were conducted via WhatsApp. Each interview began with an opening question to build trust between the participant and the interviewer. The questions were about family caregivers' views on dementia and on caring for elderly people with dementia. All interviews were conducted in the Indonesian language and both audio- and video-recorded. Each interview lasted between 45 and 60 minutes.

The interviews were transcribed by the first author and reviewed by the other authors to ensure the accuracy of the transcripts. All authors performed coding and analysis based on the transcripts. The data were analyzed using Colaizzi's descriptive phenomenological method (Morrow et al., 2015). Colaizzi's (1978) seven-step method was used to analyze the data the method consisted of (1) reading all participant descriptions in the interview transcripts; (2) selecting significant statements from the transcripts according to the research objectives; (3) articulating the meaning of each significant statement by determining codes and developing categories; (4) thematically grouping meanings by compiling a theme table that groups categories into themes and sub-themes using Atlas Ti Software; (5) writing an in-depth description of the phenomenon; (6) validating participants' descriptions post-data analysis; and (7) merging the data that resulted during validation into a final description. These stages provided the researchers with clear, logical, and sequential steps for phenomenological research, thereby increasing the reliability of the findings. This strategy differs from other phenomenological data analysis methods in that it requires participants to validate the findings to ensure their accuracy and credibility. In the final validation, all authors verified the data to arrive at a complete description of the phenomenon based on the results of the data analysis. Data trustworthiness included credibility, dependability, confirmability, and transferability (Polit and Beck, 2014).

Results

Participants' characteristics

Table 1 shows the characteristics of the participants in this study (n = 15). Thirteen participants were daughters who cared for parents with dementia. One participant was a wife caring for a husband with dementia, and another one was a daughter-in-law caring for a mother-in-law with dementia. All participants were females aged 24 to 75 years, and most of them held undergraduate degrees. The participants were of two ethnicities, namely Javanese and Chinese, and two religions, namely Muslim and Catholic. All participants had family relationships with the elderly people for whom they were caring. They had been providing care for one to six years. All the elderly people for whom the participants had been caring had experienced moderate to severe changes in their degree of dementia, but mostly behavioral changes due to memory loss. Some of them were reported to have experienced worsening behavioral changes (compared to the first of such changes they experienced).

Three themes emerged relative to the caregivers' responses to caring for older people with dementia: (1) family caregivers' perceptions of dementia, (2) the meaning of caring for older people with dementia, and (3) the process of acceptance in taking on the role of caregiver to an elderly person with dementia.

Table 1. Characteristics of the family caregivers

No	Age	Education	Gender	Duration of care	Religion	Relationship with care recipient	Ethnicity
1	50	Bachelor	Female	6 years	Muslim	Daughter	Javanese
2	50	Bachelor	Female	3 years	Muslim	Daughter	Javanese
3	53	High school	Female	7 years	Catholic	Daughter	Chinese
4	48	High school	Female	6 years	Muslim	Daughter	Javanese
5	45	Bachelor	Female	2 years	Catholic	Daughter	Javanese
6	45	Bachelor	Female	6 years	Catholic	Daughter	Chinese
7	75	High school	Female	6 years	Muslim	Wife	Javanese
8	24	Bachelor	Female	3 years	Muslim	Daughter	Javanese
9	55	High school	Female	2 years	Muslim	Daughter	Javanese
10	32	Bachelor	Female	4 years	Catholic	Daughter	Chinese
11	31	Bachelor	Female	5 years	Catholic	Daughter	Chinese
12	42	Bachelor	Female	4 years	Muslim	Daughter	Javanese
13	42	High school	Female	5 years	Muslim	Daughter	Javanese
14	33	High school	Female	4 years	Catholic	Daughter	Chinese
15	37	Bachelor	Female	1 years	Catholic	Daughter-in-law	Javanese

Family caregivers' perceptions of dementia

Data analysis showed that family caregivers perceived dementia as a disease common to the aging process and caused by other factors (Parkinson's, stroke, stress, loneliness). The perception that dementia is a disease common to the aging process was expressed by P10 and P12. Here, P12 states that dementia occurs naturally in old age: *"At that time, I thought it is a symptom of aging. I didn't think about seeking treatment for my mother for her dementia. I thought this was a symptom of old age"* (P12).

The view that dementia is part of the aging process also made it difficult for participants to accept the changes that occur in the elderly with dementia, such as the expression of the daughter who cares for her mother:

"I think that senile dementia is just forgetting due to the aging process... If you forget, it is indeed something that can be considered natural for parents, because sometimes we also forget even though we are not old... so I think it's just forgetting due to the aging process. If you forget it, it is indeed something that can indeed be considered natural. It's just that Mom doesn't remember me and even thinks I'm her enemy, so this condition makes it difficult for me to accept Mommy's condition" (P12).

Meanwhile, P1 and P7 had different perceptions of dementia: they thought it was caused by other factors such as Parkinson's, stroke, stress, and loneliness. One family caregiver stated that her husband's dementia was caused by his Parkinson's disease. *"My husband previously suffered from Parkinson's disease, well, because of his Parkinson's disease, his advanced disease became dementia"* (P7). While another said her father's stroke had caused his dementia. *"My father suffered a stroke, after which he underwent a completely different change in behavior and his condition progressed to dementia"* (P1).

Other caregivers perceived dementia as caused by the psychological conditions of elderly people, such as stress and feelings of loneliness after the death of their spouse. For example, one participant stated: *"When my mother died, my father became alone. Gradually, my father's memory declined and became the dementia we see today. It is likely that my father's dementia condition occurred due to loneliness after my mother's death"* (P13). Another participant stated:

"My mother's dementia was caused by prolonged stress. My mother had to take care of my father who had cancer for 1.5 years so she felt tired and stressed, so it became a trigger for my mother to become dementia as it is today" (P10).

The theme of family caregivers' perceptions of dementia, participants in this study emphasized that the perception that dementia is a process of aging causes participants difficulty in accepting changes in the elderly with dementia.

Family caregivers' perceived meaning of caring for elderly people with dementia

The family caregivers experienced caring for elderly people with dementia as an obligation and a form of devotion to parents, they also perceived a spiritual meaning. A wife caring for her husband expressed the obligation to care as follows: *"This is my time to serve. In the past, my husband did everything for me. Now, I have to return the favor. I have to take care of* [my husband], *you know"* (P7).

Some family caregivers perceived caring for elderly people with dementia as a form of devotion to their parents. Two family caregivers interpreted devotion to parents as fulfilling their parent's wishes, while others perceived it as making their parents happy and making them smile: *"Now, I do whatever Mom likes, everything we do, just to make her happy, to make my mom happy and to make her laugh"* (P12).

Another caregiver, who had previously been separated from her father for a long time, took the opportunity to care for him as a form of filial piety. This was mentioned by the following participant: *"I am grateful for being given the opportunity to care for my father who has dementia"* (P9). Caring for older people

with dementia as a form of dedication was to be done patiently and sincerely as expressed in the following statement: *"Caring for the elderly with dementia was to be done patiently and sincerely so if we are caring for elder people with dementia, you have to do it patiently and sincerely"* (P12).

Other family caregivers found spiritual meaning in caring for elderly people with dementia. One interpreted the provision of care as receiving blessings from God. Another interpreted it as being rewarded by God. A daughter caring for her father after a long separation stated: *"May Allah give me health, a patient and sincere heart. I hope this all is not in vain. It can be my good deeds"* (P9).

The acceptance process in carrying out the role of caregiver for an elderly person with dementia

The acceptance process began with denial, then moved through depression to acceptance. Some caregivers expressed denial through shock when they discovered that the elderly family member had dementia. Others expressed denial through confusion about their family members' behavioral changes. One caregiver's denial manifested as rejection of the diagnosis because her father was physically healthy: *"My father should be able to travel and enjoy the moment, but he can't do it because he is a person with dementia"* (P1).

A daughter who was caring for her mother continued to hope that there was no dementia, even though her mother did not recognize her as her daughter: *"Sometimes I hope that my mother recognizes me as before. If I remember that my mother still have good memory to know me as her daughter, I want this moment"* (P12).

More than half the participants expressed depression in accepting their roles as caregivers. One withdrew into herself. Another felt sad because her life had changed since her father had dementia. Others were saddened by the changes they observed in the people for whom they were caring, and some also experienced sadness due to the family member's declining condition, the disease's progression, and the severity of the dementia: *"I know the decline is like that. Every stage of the decline always makes me cry"* (P1).

In the process of accepting the role of caregiver, some participants experienced depression in the form of frustration, hopelessness, and even the death wishes. For example, a caregiver who cared for her mother alone felt depressed about her mother's behavioral changes. She even felt the death wishes together with her mother: *"Mom, let's just die together, mom. I'm getting desperate. That's how it is…"* (P6).

Other caregivers showed acceptance of caring for older people with dementia. They enjoyed the current conditions, every change that occurred, the characteristics of older people with dementia, and every action that should be taken when caring for them. *"Yes, indeed, dementia is different for everyone. They have different characteristics, different changes, so just enjoy it"* (P5).

Some showed acceptance by being grateful that the people for whom they were caring were still physically healthy. P14 stated that they try to accept their role even though the process is difficult. Other family caregivers stated that accepting the role is a destiny bestowed upon them by God. Meanwhile, certain caregivers stated that acceptance made it easier for them to act as caregivers: *"Yeah, well… what can I do? It has already happened. If you accept it, it's easier to live with that"* (P10).

All themes that emerged from the data are described in Diagram 1.

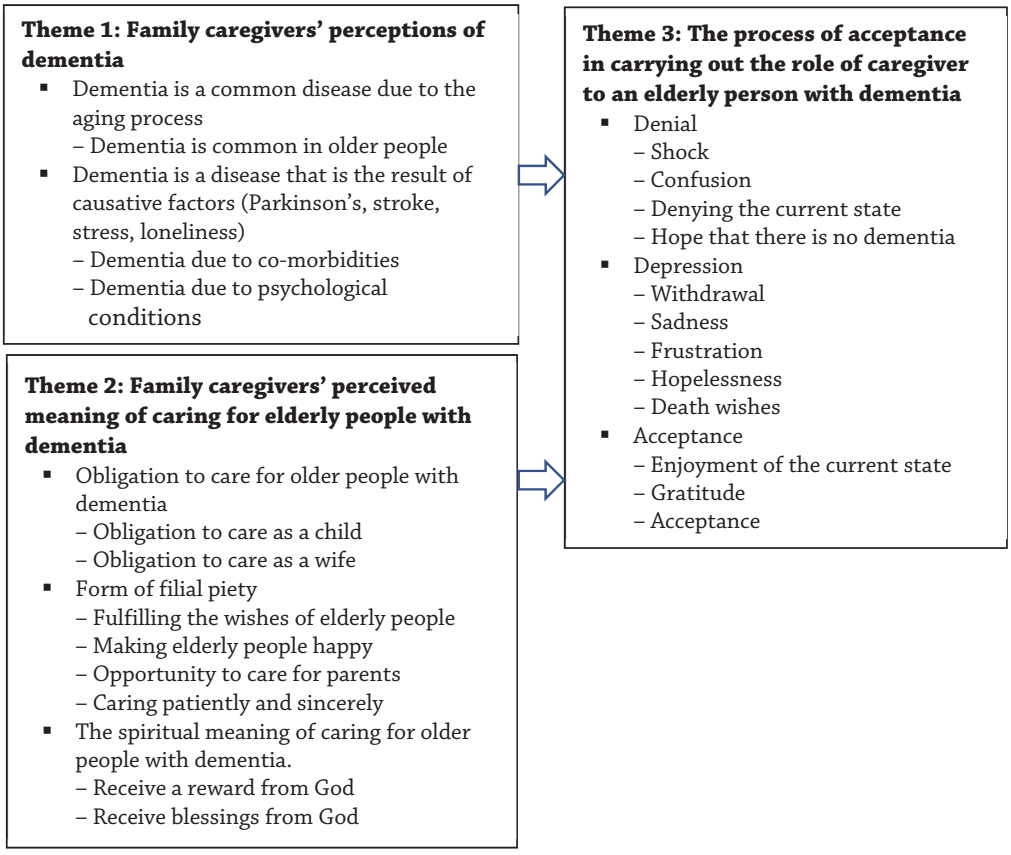

Diagram 1. Themes and sub-themes

Discussion

This study explored family caregivers' responses to their roles as caregivers to elderly people with dementia. A descriptive qualitative approach was used to generate a detailed account of the phenomenon. Three main themes were identified: family caregivers' perceptions of dementia, the meaning of caring for elderly people with dementia, and the process of accepting the role of caregiver to an elderly person with dementia.

The study found that family caregivers perceived dementia as a disease common to aging. Family caregivers shared the changes they experienced in the elderly people they cared for, such as the elderly people being forgetful, talkative, talking about the past, repeatedly asking similar questions, and having mood swings. They perceived these behaviors as natural parts of old age. It is known that elderly people will experience a decline in function (*e.g.*, cognitive) as they age: this is a natural process that cannot be prevented. Previous research among family caregivers of elderly people with dementia in China found that the caregivers had similar perceptions to the caregivers interviewed in this study of cognitive impairment, also associating it with the aging process (Dai et al., 2015). This may explain why family caregivers perceive their family members' dementia symptoms as normal. This study also found that some family caregivers perceived dementia as a disease caused by other factors (Parkinson's, stroke, stress, loneliness). In line with the Research on European-American family caregivers that also has found that dementia is related to the disease process (Dilworth-Anderson and Gibson, 2002).

Family caregivers' perceptions of the disease contribute significantly to their ability to respond to symptoms, seek health care or other help, and independently manage the disease or its general symptoms (Gregg et al., 2021; Hagger and Orbell, 2003). This was expressed by one of the study's participants, who thought that her mother's condition was natural and therefore did not bring her to the health service for further examination. This condition may cause delays in identifying problems, along with a lack of awareness, knowledge, and trust in dementia services. Hence caregivers face many challenges while carrying out their caregiving tasks. A lack of understanding about dementia can cause family caregivers not to seek help, which can exacerbate the progression of the disease. This can lead to increased levels of depression, stress, and burden on family caregivers (Gregg et al., 2021; Laparidou et al., 2019). Family caregivers' perceptions of the disease contribute significantly to their acceptance of the disease, the conditions they face while providing care, their role as primary caregiver, as well as their higher awareness, self-confidence, and ability to improve their skills (Nguyen and Levkoff, 2020). A person's perception is influenced by his or her cultural beliefs (Kastanakis and Voyer, 2014).

Participants perceived caring for older people with dementia as an obligation, a form of devotion to parents, and a spiritual matter. Most participants were Javanese, Javanese is a culture that holds the obligation to and responsibility for caring for one's parents as signs of devotion and respect for the parents' services (Aryati et al., 2019). The meaning ascribed to caring for elderly people is a cultural one. Family caregivers of elderly people with dementia in Iran, for instance, perceived caring as reciprocal compensation, a moral commitment to providing care to elderly family members in need as a way of repaying their kindness. This concept of family caregiving is more common in Asian communities than in Western ones. In the nuclear family system in Asian families, there is a commitment to parents that is essential to accept the role of caregiver (Farhadi et al., 2022).

This study also identified a spiritual element in caring for elderly people with dementia, *i.e.*, the wish for blessings and rewards from God. Caregivers have faith in religious teachings about caring for elderly people. A previous study reported that caregivers of elderly people believe in the love and the power of God, whereby God will control their lives. They also believe that by caring for older people with dementia they will receive blessings from God (McGee et al., 2022). The spiritual meaning ascribed by caregivers supports them in accepting their role, allowing them to find meaning while providing care and reducing stress (Acton and Miller, 2003; Márquez-González et al., 2012). The results of the present study demonstrate the importance of understanding the cultural and spiritual beliefs that underly the perceptions of dementia and of caring for elderly people with this illness. With such understanding, interventions to support family caregivers can be determined.

This study also revealed that the acceptance process in taking on the caregiving role is first expressed through denial, then depression, and finally acceptance. Denial manifests as shock, confusion, rejection, and hope. Denial is a form of grief that goes hand-in-hand with disease progression (Meuser and Marwit, 2001; Tatangelo et al., 2018). The caregivers felt confused because they had lost their loved ones due to dementia-related behavioural changes. They hoped that there was no dementia given that their elderly family members were still physically healthy. This study found that daughters more often experienced denial when caring for their parents than wives caring for their husbands. This is because children who care for their parents are more focused on their parents' capacities than on the early symptoms of dementia, and they avoid discussing what will happen in the future. Meanwhile, spouses are more open, accepting, and realistic about their partners' condition and the future burdens they face (Meuser and Marwit, 2001). Denial can be an inhibiting factor in the acceptance process. Family caregivers' acceptance is necessary to identify their needs and improve their welfare, as well as that of the elderly people for whom they care (Boots et al., 2015).

All participants in this study were female, and the majority expressed depression in relation to their role as caregivers. A cross-sectional study has found that female caregivers are more depressed than male caregivers (Clyburn et al., 2000). Previous research has determined that elderly people's behaviors of refusal of care, aggression, and agitation have high risks of causing depression in family caregivers (Choi et al., 2019). The depression experienced by the participants in this study in fulfilling their roles manifested itself in the form of sadness, frustration, hopelessness, detachment and death wishes due to the deteriorating condition of their elderly family members and behavioural changes as the illness progressed (Collins and Kishita, 2020). This study found that one participant who had to care for her elderly mother alone after the death of her older sibling and, further, who wished she could die with her mother, exhibited such signs of depression. Caregivers who wishe to die have more severe symptoms of depression, less family support, and more feelings of loneliness than those who do not (Joling et al., 2018). This study suggests that identifying depression in caregivers is an important step in taking preventive measures against its adverse effects.

The process of accepting the role of caregiver to an elderly person with dementia is associated with the positive aspects of caring (Larochette et al., 2020). Family caregivers with greater acceptance were found to enjoy the family member's current condition, to be grateful, and to willingly adopt their role de-

spite the difficult process of acceptance. Acceptance also made it easier for caregivers to carry out their roles. This is the final stage of the adjustment process and, in caregiving, it relates to individual perceptions, beliefs, and commitments to caring, which also relate to cultural values and norms (Nguyen and Levkoff, 2020).

Conclusion

The study provides important insights into the responses of family caregivers to caring for people with dementia. Family caregivers have different perceptions of dementia, and perceptions of dementia can lead to delays in identifying the problem. The study results emphasize that the meaning of caring for an elderly person with dementia supports caregivers in accepting their new role and developing a commitment to care. The study also emphasizes that caregivers who demonstrate greater acceptance find positive aspects in caring. They enjoy the current condition of family members, are grateful, and willing to adopt the role of caregiver despite going through a complicated acceptance process.

The new knowledge that this study contributes can be used for understanding the cultural and spiritual factors that underlie perceptions of dementia and the meaning of caring for elderly people, as well as the need for identifying the acceptance process among caregivers. That way, effective interventions can be provided for supporting caregivers in adapting to their roles.

Our study has several limitations. For example, the interview method was video and zoom calls, which can sometimes be challenging due to poor internet connections. The study explored the responses of caregivers to elderly people with varying degree of severity in their dementia, and all participants were female. Therefore, it is important that future studies examine the responses of carers in fulfilling their roles in relation to the severity of dementia, with greater variation in gender and types of family relationships.

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Ethical aspects and conflict of interest
The authors have no conflict of interest to declare.

„Zemřeme spolu, mami“: Reakce rodinných pečovatelů na péči o seniory s demencí

Souhrn
Úvod: Senioři s demencí jsou vysoce závislí na pečovatelích; jak nemoc postupuje a její závažnost se zvyšuje, vyžadují větší pomoc a dohled. Rodinní pečovatelé mají různé reakce na péči o seniory s demencí. Cílem této studie bylo prozkoumat reakce indonéských rodinných pečovatelů na péči o seniory s demencí.
Metody: Pro tuto studii byl vybrán kvalitativní výzkumný design. Na základě polostrukturovaných rozhovorů byla provedena deskriptivní fenomenologická studie mezi 15 účelově vybranými rodinnými pečovateli.
Výsledky: Z dat vyplynula tři hlavní témata a osm podtémat. Prvním tématem bylo vnímání demence ze strany rodinných pečovatelů. Dílčími tématy bylo, že demence je běžné onemocnění způsobené procesem stárnutí a demence je onemocnění způsobené Parkinsonovou chorobou, mrtvicí, stresem a osamělostí. Druhým tématem byl smysl péče o seniory s demencí. Dílčími tématy byly povinnost pečovat o seniory s demencí, forma filiální zbožnosti a duchovní smysl péče o seniory s demencí. Třetím tématem byl proces přijetí do role pečovatele o seniora s demencí. Dílčími tématy byly popírání, deprese a přijímání.
Závěr: Každé z těchto témat má kulturní a duchovní rozměr a pečovatelé vyžadují odbornou pomoc zdravotníků, která odpovídá těmto rozměrům péče. Stejně tak je důležité identifikovat depresi u rodinných pečovatelů, aby mohly být poskytnuty vhodné intervence

Klíčová slova: demence; Indonésie; reakce; rodinný pečovatel; senioři

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