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ORIGINAL RESEARCH

Barriers and Support for Family Caregivers in Caring for Older Adults with Dementia: A Qualitative Study in Indonesia

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Abstract

Background: Understanding the barriers and support that family caregivers face when caring for older adults with dementia is critical for improving the quality of dementia care. However, research in this area remains limited in Indonesia.
Purpose: This study aimed to explore the barriers and support for family caregivers in caring for older adults with dementia in Indonesia.
Methods: A descriptive phenomenological study was conducted among 15 family caregivers who cared for older adults with dementia. Purposive sampling was used to recruit the participants. Inclusion criteria included primary family caregivers who provided care for four hours per day for at least six months, were proficient in Indonesian, assisted older adults in daily activities, and were capable of expressing their experiences. Data were collected using in-depth semi-structured interviews and analyzed using the Colaizzi method.
Results: This study found that family caregivers faced barriers during the care of older adults with dementia, which have decreased the quality of care. These barriers included inadequate knowledge and skills of family caregivers regarding dementia, stigma, lack of knowledge and awareness in the community, limited availability of healthcare services, and healthcare professionals' lack of knowledge about dementia. On the other hand, support received by family caregivers within the family, support from other family caregivers, and education provided by NGOs about caring for someone with dementia have shown a positive impact in reducing the burden on caregivers and improving the quality of care. Therefore, appropriate support is essential for family caregivers caring for older adults with dementia.
Conclusion: This study showed that barriers originating from family caregivers, community awareness, access to health services, and barriers from health workers have impacted poor quality of care, while the support of families, fellow family caregivers, and NGOs have contributed to good quality of care. Further studies are needed to explore the perspectives of family caregivers representing different cultures in Indonesia.

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1. Introduction

Dementia is a chronic, long-term illness characterized by a cognitive decline that affects memory, communication, and behavior, leading to disability and dependency in activities of daily living (ADLs) and progressive memory impairment for 3 to 20 years (Gauthier et al., 2022; Ineu de Oliveira et al., 2017; World Health Organization, 2022). The increasing elderly population and life expectancy contribute to the growing number of older adults affected by dementia, both regionally and globally. More than 55 million people worldwide have dementia in 2020, and it is projected to increase by 70% in 2050 (World Health Organization, 2022). The exact prevalence of dementia in Indonesia is not yet known. However, it is estimated that there will be two million older adults with dementia by 2030, which will increase to four million by 2050 (Alzheimer Indonesia, 2019). Central Java is among the top five provinces in Indonesia with the highest number of older adults, which implies a potential increase in the number of elderly individuals with dementia, and over 30% of older adults in Indonesia receive care from their families (Alzheimer Indonesia, 2019; Indonesia Central Bureau of Statistics, 2020).

The growing number of older adults with dementia poses challenges as they require continuous care, which can impact family caregivers providing that care (Prince et al., 2016). Caring for older adults with dementia can have positive and negative effects on individuals with dementia and their family caregivers. Studies in Western and Asian countries identified the positive effects and negative effects felt by family caregivers in caring for older adults with dementia. The positive effects include role satisfaction, increased self-care awareness, emotional rewards, personal growth, opportunities to demonstrate piety, closer relationships with people with disabilities, competence and mastery, relationship benefits, a sense of duty, and reciprocity (Devi et al., 2020; Lloyd et al., 2016). The negative effects of caregiving comprise emotional and social aspects. Caregivers often experience fear, worry, stress, sadness, social isolation, and problems accepting dementia diagnosis. Furthermore, carers frequently worry about the future because they are unsure of what lies ahead and how long they can provide monetary and emotional support to care for older adults with dementia (Lindeza et al., 2020).

Previous studies conducted in Indonesia have explored the positive and negative effects of caring for older adults with dementia. The positive effects encompass feelings of gratitude, enhanced closeness with the individuals being cared for, increased patience and resilience, strengthened affection for older adults (Pradana et al., 2022), and the establishment of meaningful relationships (Kristanti et al., 2018). Positive effects of caregiving occurred because of the acceptance of the caregiver role and support system (Devi et al., 2020; Pradana et al., 2022). On the other hand, the adverse effects include increased burden during caregiving (physical, economic, social, and psychological burdens) (Widyastuti et al., 2011), feelings of boredom in caregiving, loss, and increased stress (Kristanti et al., 2018; Pradana et al., 2021). These adverse effects were often linked to a lack of knowledge to take care of the behavioral and psychological problems of older adults with dementia, financial difficulties, and high workload from assisting in the activities of daily living (Lindeza et al., 2020). The barriers and support experienced by families during the care of individuals with dementia and mental illness are related to the emerging effects of caregiving (Lot et al., 2023; Putri et al., 2021).

Existing qualitative studies in Indonesia have predominantly focused on exploring the negative and positive impacts of caring for older adults with dementia (Pradana et al., 2022; Widyastuti et al., 2011), while the exploration of barriers and support for caregivers remains limited, despite their close association. Therefore, identifying the barriers and support that family caregivers experience while caring for older adults with dementia can significantly assist in the development of national dementia programs, promoting family empowerment and enhancing the quality of dementia care. Additionally, to our knowledge, no research has been conducted in Central Java, Indonesia, regarding the barriers and support for family caregivers while caring for older adults with dementia. This study aimed to investigate the barriers and support experienced by family caregivers while caring for older adults with dementia in Central Java, Indonesia.

2. Methods

2.1 Research design

A qualitative study with a descriptive phenomenological approach was conducted to explore the first-hand experiences of family caregivers regarding the challenges and support they have while caring for older adults with dementia. The descriptive phenomenological approach was chosen to capture the unique experiences and perspectives of the participants, allowing the researchers to explore in-depth individual lived experiences of a phenomenon, which represents the true nature of the phenomenon (Shorey & Ng, 2022). By employing this approach, the researchers were able to gather in-depth information about the phenomenon of interest as perceived by the family caregivers. Moreover, the approach allowed caregivers to freely express their experiences and perceptions concerning the challenges and support they encounter in caring for older adults with dementia.

2.2 Setting and participants

In a phenomenological study, participants must have first-hand experience with the phenomenon under investigation (Creswell & Creswell, 2018). This study utilized a purposive sampling technique to select the participants. This technique allows for selecting participants from various age groups, cultures, and backgrounds and assists in identifying participants who are willing to participate, articulate their experiences and opinions effectively, and meet specific characteristics relevant to the research objectives (Etikan, 2016). Family caregivers caring for older adults with dementia were recruited from five regions in Central Java Province, Indonesia, according to the availability of participants and the fulfillment of inclusion criteria. The inclusion criteria included: (1) primary family caregivers who have a familial relationship with older adults with dementia, (2) being of adult age and proficient in the Indonesian language, (3) providing care to an older adult with dementia for a minimum of four hours per day for at least six months, and (4) family caregivers accompanying and assisting older adults in performing their daily activities. Purposive sampling emphasizes achieving saturation to gain a comprehensive understanding of the phenomenon by continuously taking the participants until no new information emerges (Etikan, 2016). In this study, the interviews were conducted until saturation was reached; at this point, neither new debate topics nor themes nor any new conceptions developed. The total participants were 15 family caregivers.

2.3 Data collection

Data collection in descriptive qualitative research aims to identify who, what, and how the phenomenon is (Sandelowski, 2010). In this study, data were collected through semi-structured individual interviews conducted between August and September 2022 to explore the challenges faced by family caregivers while caring for older adults with dementia. A semi-structured interview guide was used to explore the participants' experiences and perceptions. The interviews were conducted via telephone with video calls or video conferences using Zoom meetings, as agreed upon with the family caregivers. Prior to the interviews, the researcher explained the research objectives through WhatsApp, and participants provided their consent. The interviews and explanation of research objectives were not conducted face to face because there were face-to-face restrictions due to the COVID-19 pandemic. It was RHW and JS who developed the interview guide by referring to the relevant literature review. The interview guide was developed from three open-ended questions, "Tell us your perspectives while caring for older adults with dementia?", "What are the challenges experienced received by family caregivers in providing the care." and "What resources can help you face the challenges?". Probing questions such as: "Could you please provide some examples of the barriers you have faced while caring for older adults with dementia...?" and "How were the barriers in dementia caregiving?" were used to obtain in-depth information about their experiences and the significance attached to those experiences. Additional investigative questions were also provided depending on the flow of the participant's responses. Interviews were conducted once time. On average, each interview lasted between 45 and 60 minutes. Field notes were taken during the interview via Zoom. All interviews were conducted in Indonesian, recorded using an audio recorder, and transcribed verbatim by the primary researcher.

2.4 Data analysis

All interview recordings were transcribed verbatim within 24 hours after each interview to avoid memory bias and initiate the initial data analysis process. RHW has transcribed the verbatim. The subsequent transcript was coded and analyzed by RHW, JS, and ER. The seven-step Colaizzi method (Colaizzi, 1978) was used for data analysis in this study, including (1) reading and rereading all interview transcripts, (2) selecting significant statements related to the studied phenomenon for extraction, (3) formulating the meanings of the significant statements based on the previous step, (4) integrating the previously formulated meanings into thematic clusters, (5) developing a comprehensive description of the essential phenomena (comprehensive depiction of challenges and support experienced by participants while caring for older adults with dementia), (6) describing the fundamental structure of the phenomena, and (7) validating the research findings with the participants and seeking their feedback to enhance the analysis. The transcripts were translated from the original Indonesian language into English for publication purposes. The research report utilized the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong et al., 2007). An example of the theme-developing process for the sub-theme can be seen in Table 1.

Table 1. Example of the theme development process

Significant Statement	Sub-theme	Theme
I don't understand, I didn't know that the stages were like that, I don't understand the stages. That's what we don't know; the actions that should be taken for each stage, we don't know.	Family caregivers lack knowledge about the stages of dementia	Limitations of knowledge and skills of family caregivers in caring for older adults with dementia

2.5 *Trustworthiness*

In a qualitative study, the trustworthiness of the data includes credibility, dependability, confirmability, and transferability (Polit & Beck, 2014). Credibility was ensured by submitting the interview transcripts to the participants for verification. Dependability was achieved by transparently describing the research steps undertaken from the beginning of the study to the development and reporting of the research findings. Dependability was also ensured by establishing clear study stages, developing a daily research journal, and ensuring accurate data coding. Confirmability refers to the data's objectivity, accuracy, relevance, or meaningfulness. This criterion relates to establishing that the data are information from the participants and that the interpretation of the data is not biased or based solely on the researcher's perspective. This was achieved by providing the research findings to the entire research team to ensure the absence of bias in the data analysis and theme development. All researchers agreed on the research findings. Meanwhile, transferability refers to the extent to which qualitative findings can be transferred or applied to other contexts. This criterion was achieved by summarizing the research findings and providing a narrative explanation of the interview results to facilitate clear understanding for readers, enabling the application of the findings in other contexts.

2.6 *Ethical considerations*

Ethical approval was obtained from 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), prior to commencing the study in 2022. During recruitment and interviews, the researchers explained the research objectives, and participants provided written consent through a Google form and verbal consent via WhatsApp before the interviews. The interview transcripts were stored in a password-protected master folder in anonymized and disguised Microsoft Word documents. Only the researchers involved in the study had access to the data. Additionally, participants were informed that they could receive further recommendations if their condition required additional actions.

3. Results

3.1 *Characteristics of participants*

All participants in this study are women, with an average age of 44.1. Most of them have a bachelor's degree in education background and are married. The participants come from two ethnic groups, namely Javanese and Chinese descent. All participants have a familial relationship with dementia patients, with the majority being daughters of these patients. The participants have an average duration as primary caregivers of 4.5 years. All dementia patients have comorbidities such as heart disease, diabetes mellitus, and stroke (Table 2).

3.2 *Analytical findings*

The data analysis yielded six themes that captured the barriers and support experienced by family caregivers of older adults with dementia. The identified barriers encompassed: (1) stigma and lack of awareness and knowledge of dementia among the wider community; (2) the limited knowledge and skills of family caregivers in caring for older adults with dementia; and (3) the inadequate availability of healthcare services for older adults with dementia. On the other hand, the support for family caregivers included: (1) active involvement of family members in the caregiving process, (2) support from fellow family caregivers who shared similar experiences, and (3) education from non-governmental organizations (NGOs) specializing in dementia care. These themes represent the barriers and support experienced during the care of older adults with dementia from the perspective of family caregivers. The themes are described in Figure 1

Table 2. Characteristics of family caregivers caring for older adults with dementia (n=15)

Characteristics	Mean	f	%
Gender			
Male		0	0
Female		15	100
Age (years)	44.1		
Education			
High school		6	40
Bachelor degree		9	60
Marital Status			
Married		11	70
Single		4	30
Duration of caring for older adults with dementia	4.5		
Comorbidities in older adults with dementia			
Yes (heart disease, diabetes mellitus, and stroke)		15	100
No		0	0

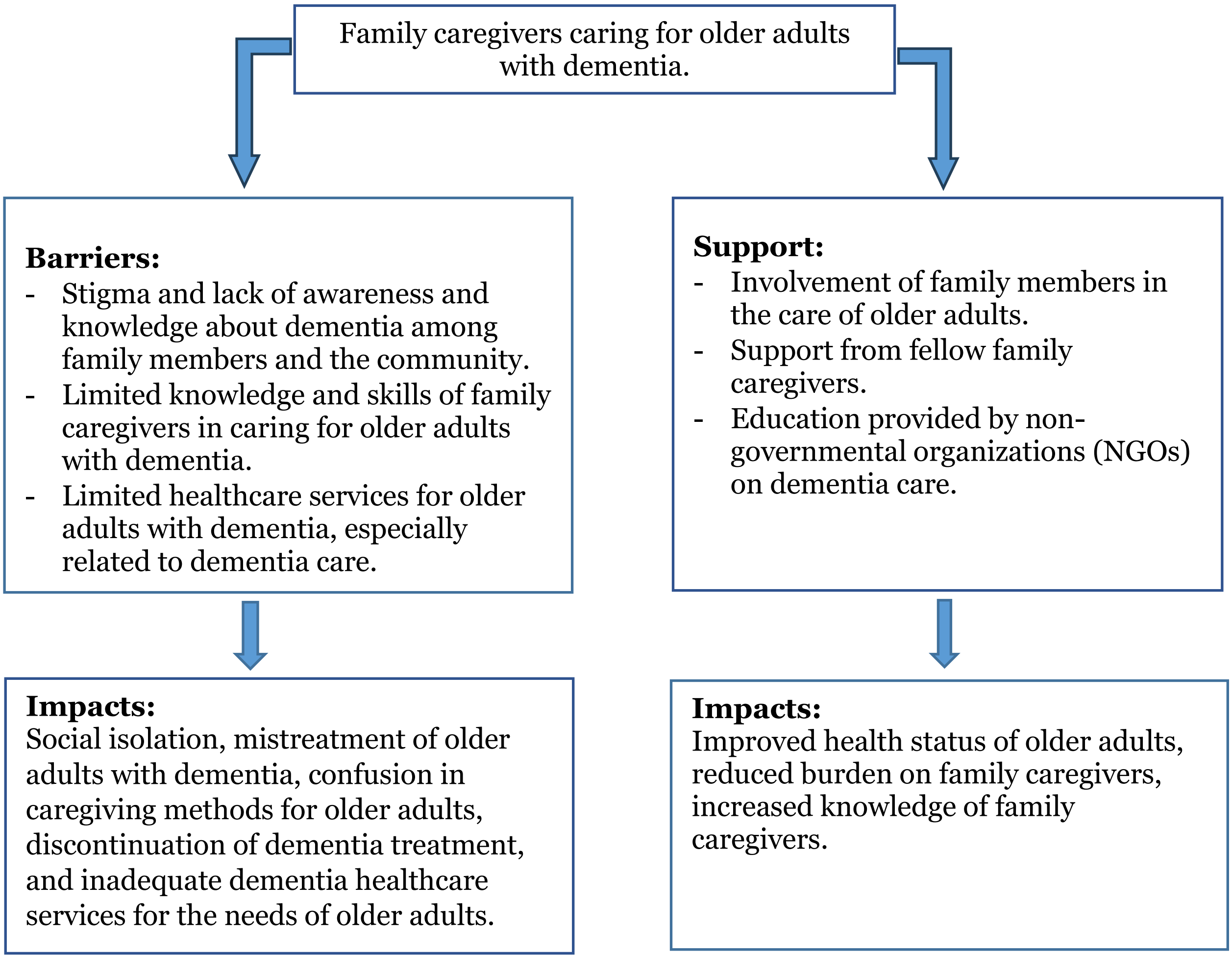

Figure 1. Schematic diagram of barriers and support experienced by family caregivers while caring for older adults with dementia

3.2.1 Theme 1: Stigma and lack of awareness and knowledge of the community about dementia

Some family caregivers stated that they face stigma from the community regarding the older adults they care for. The community stigmatizes older adults with dementia who experience behavioral changes as “crazy/mentally ill” individuals. This was mentioned by the following participant: *Some of those people think that my mother is crazy. Their response is like that. My mother was told to stay at home and not allowed to go out* (Daughter, P10). The community also lacks awareness and knowledge about dementia, leading to a lack of understanding of the behavioral changes in older adults with dementia. The stigma results in social isolation for dementia patients. The participants expressed it in the following statements: *The neighbors cannot accept the behavioral changes in older adults with dementia. They perceive that dementia patients are mentally ill. They do not understand dementia patients, so there are many negative stigmas from the community* (Daughter, P13).

Even more, there were cases in which older adults with dementia experienced physical violence from the community due to the lack of awareness and knowledge about dementia. This was mentioned by the following participant (P2):

> *Well, at that time, my father went out, and when he returned, he was in a terrible condition, especially in his face. It looked like he had been beaten; there were cuts on his legs and his eyes. It seems like people didn’t know and got angry at my father because he defecated indiscriminately. Since then, my father was not allowed to leave the house.* (Daughter, P2)

3.2.2 Theme 2: Limitations of knowledge and skills of family caregivers in caring for older adults with dementia

Almost all participants stated that they have limitations in knowledge and skills in caring for older adults with dementia. These family caregivers lack knowledge about the stages of dementia and how to care for patients according to its stages. For example, one participant stated the following: *I don’t understand, I didn’t know that the stages were like that, I don’t understand the stages. That’s what we don’t know; the actions that should be taken for each stage, we don’t know* (Daughter, P1). Family caregivers also stated that they relied on trials and error for the actions taken during the care of dementia patients, as expressed in the following statement: *It’s more about how to handle it because I have no knowledge, no experience, so it’s like trial and error* (Daughter, P10).

Furthermore, the family caregivers felt confused when faced with behavioral changes in older adults with dementia due to their limited knowledge and skills in caring for such individuals. One participant expressed this condition as follows: *Sometimes I don’t know what to do when my mom shows behavioral changes…*(Female child, P11).

3.2.3 Theme 3: Limitations of healthcare services for older adults with dementia

Family caregivers perceived that healthcare services for older adults with dementia are still limited. Not all areas have healthcare services, particularly for dementia patients. There is a lack of healthcare services specifically tailored to the condition of older adults with dementia, resulting in them receiving similar treatment as older adults with other diseases. Not all healthcare providers have sufficient knowledge and skills to care for older adults with dementia. Another barrier experienced by family caregivers is that healthcare services for older adults with dementia are only available in major cities and not in all small towns. As a result, family caregivers living far from major cities choose to discontinue treatment for older adults due to the long distance that causes them to become exhausted. This was expressed by the following participant:

> *After returning from the hospital, my mother refused to eat for three days; she only slept and drank. The distance between Semarang and Demak was far, and we had to wait in line at the hospital, which made my mother exhausted. Eventually, our family decided not to have my mother undergo further examinations as long as she wasn’t in pain.* (Female child, P12)

The absence of healthcare services specifically tailored to the individual condition of older adults with dementia led to increased aggressive behaviors when they had to be cared for without the presence of family members. This was experienced by several participants, as described in the following statements:

> *So, at that time, my mother was hospitalized and placed in the high-care unit. The staff said that I couldn't accompany my mother. My mother felt uncomfortable because she felt alone, and there was no one taking care of her. She kept calling me, shouting, and asking me to go home. She even pulled out the infusion tube twice.* (Female child, P6)

Furthermore, family caregivers also mentioned that not all healthcare providers have sufficient knowledge and skills to care for older adults with dementia, as expressed by one participant below:

> *Drawing from our personal experience when my father was hospitalized, we encountered a situation where the nurse would frequently become frustrated whenever my father requested to use the bathroom despite him already wearing diapers. Nevertheless, my father persistently expressed the need to go to the bathroom, and as a result, I felt compelled to apologize. Unfortunately, his bowel movements ended up being uncontrollable, which further angered the nurse. It appeared evident that she lacked comprehension of my father's condition and the challenges associated with his dementia.* (Female child, P2).

3.2.4 Involvement of family members in elderly care

Active involvement of family members in the care of older adults with dementia is paramount. Family caregivers receive financial assistance and support in caregiving, which improves the quality of care for older adults. This was expressed by the following four participants: *The primary family members consistently offer support, even if not all of them reside in Semarang. Those living outside the city provide financial assistance* (Female child, P10); *If I need to be away from home for three days, my sister takes over the responsibility of caring for our mother* (Female child, P12); *Now, my father's physical health is stable because he regularly sees a doctor. I have a brother-in-law who assists in accompanying my father to medical appointments* (Female child, P8); *Every month, the children take turns visiting their father, which greatly motivates him* (Wife, P7)

3.2.5 Theme 5: Support from fellow family caregivers

Most family caregivers felt supported by fellow caregivers who cared for older adults with dementia. The support they received includes information and emotional support, which positively impacts family caregivers. Some participants expressed the following statements: *With fellow family caregivers, we can share information and strategies in caring for older adults with dementia, which increases our knowledge in providing care* (Female child, P2); *Family caregivers encourage each other* (Female child, P12).

Family caregivers also received emotional support from other fellow caregivers, which positively impacted their ability to cope with the emotional burden associated with caring for older adults. This was exemplified by the following statements: *The stories shared by fellow caregivers of older adults with dementia are nearly identical, so I no longer feel alone. There is a sense of similarity between me and other caregivers, which alleviates the sadness I experience* (Wife, P7).

3.2.6 Theme 6: Education from Non-Governmental Organizations (NGOs) on dementia care

Some family caregivers received educational support from NGOs (non-governmental organizations) through direct and online education on dementia. NGOs play a critical role in helping them improve their knowledge and skills in caring for older adults with dementia. Some participants mentioned the following: *Having no prior knowledge about dementia, I attended various activities at Alzheimer's Indonesia (ALZI) to receive an education. It significantly enhanced my understanding of how to care for older adults with dementia* (Female child, P9);

When I initially felt stressed about my mother's condition, I sought support from ALZI. I wanted to learn effective strategies for managing the situation, so I started reading articles on the ALZI website (Female child, P10).

4. Discussion

This study aimed to explore the barriers and support for family caregivers in caring for older adults with dementia in Indonesia. Six themes were revealed from the data obtained in this study, including (1) stigma and lack of awareness and knowledge of the community about dementia, (2) limitations of knowledge and skills of family caregivers in caring for older adults with dementia, (3) limitations of healthcare services for older adults with dementia, (4) involvement of family members in elderly care, (5) support from fellow family caregivers, and (6) education from non-governmental organizations (NGOs) about dementia care.

4.1 Stigma and lack of awareness and knowledge in the community about dementia

The findings of this study indicate that some family caregivers experience stigma from society, perceiving dementia in older adults as a mental illness. In this study, stigma from society shown by the community used the terms "crazy" or "insane" to refer to older adults with dementia. The everyday language used by the community to refer to dementia reflects the community's attitudes and stigma toward individuals with dementia (Swaffer, 2014). The communities develop their own everyday terms based on their understanding of the symptoms and behavioral changes resulting from the disease. Previous studies have indicated stigma from society labeling older adults with dementia as "crazy" was reported in a study conducted in South Africa (Mfene & Pillay, 2023). Meanwhile, dementia is not a mental illness but a pathological or neurological condition (Mukadam & Livingston, 2012).

Family caregivers in this study reported that negative stigma towards older adults with dementia leads to social isolation for individuals with dementia and their families. This is in line with previous studies, which show that negative stigma has resulted in increased social isolation and reduced quality of life for older adults with dementia (Lion et al., 2020). Family caregivers in this study also expressed that the community also lacks awareness and knowledge, it has triggered physical violence to older adults with dementia. The present study indicates that stigma arises due to the lack of public knowledge about dementia, which aligns with previous research showing that a lack of knowledge in society can contribute to the emergence of stigma toward older adults with dementia (Burgener et al., 2015). Stigma and the lack of knowledge and awareness about dementia in the community can lead to the mistreatment of older adults with dementia (Alzheimer's Disease International, 2019; Khonje et al., 2015), including physical violence against them. Increasing awareness and education in the community about dementia can help prevent stigma. The strategies can include national dementia campaigns, the use of social media, changing public attitudes towards dementia through television advertisements on national channels, and early education about dementia (Hung et al., 2021; World Health Organization, 2015).

4.2 Limitations of knowledge and skills of family caregivers in caring for older adults with dementia

The results of this study showed that almost all participants stated that they have limitations in knowledge and skills in caring for older adults with dementia. Well-prepared caregivers with appropriate skills and knowledge can reduce the burden of care. Family caregivers of patients with non-communicable diseases in Indonesia reported feeling moderately prepared for caregiving, which means family caregivers need help in certain situations (Sari & Nirmalasari, 2020). Previous research has shown a low knowledge level about early symptoms of dementia among family caregivers in Indonesia who care for older adults with dementia (Suriastini et al., 2020), which aligns with the interview findings in this study that limited knowledge and skills in caring for older adults with dementia are barriers faced by family caregivers. Similar findings have been reported among caregivers in Iran, China, the United Kingdom, and the United States (Lot et al., 2023). This situation can be attributed to low health literacy, particularly in the context of dementia care among family caregivers (Putri et al., 2022). Family caregivers' lack of knowledge and skills in caring for older adults with dementia can negatively impact the quality of care provided (Leocadie et al., 2020). Higher knowledge has been found to lead to positive attitudes toward dementia, increased confidence in dementia care, and positive impacts on the care of older adults with dementia (Teichmann et al., 2022). Limited access to educational resources is a significant factor contributing to the lack of knowledge and skills among family caregivers. Currently, most information about dementia is available in English (Lot et al., 2023), with a scarcity of scientifically valid and updated materials in the Indonesian language. Therefore, developing appropriate, scientifically sound, and credible educational materials tailored to the needs of family caregivers in Indonesia is necessary to improve their health literacy regarding dementia and positively impact their knowledge and caregiving skills.

4.3 Limitations of healthcare services for older adults with dementia

In this study, family caregivers felt that healthcare service providers do not understand the condition of elderly individuals, leading to increased aggression in patients when they are hospitalized. Increased disorientation in older adults with dementia during hospitalization can worsen dementia-related behaviors (Dementia Australia, 2019). Person-centered care (PCC) is an approach that can provide healthcare services that meet the needs of individuals with dementia (Kim & Park, 2017). Healthcare professionals may lack an understanding of PCC, and the implementation of this knowledge is influenced by the care environment and the high demands placed on healthcare providers (Røsvik & Rokstad, 2020). Healthcare professionals often lack an understanding of the specific needs of elderly individuals with dementia and may not be adequately trained to meet those needs, resulting in impatience when dealing with their behaviors. Lack of knowledge about dementia causes healthcare professionals to be unaware that their communication style can affect the psychosocial needs of older adults with dementia (Beardon et al., 2018; Dementia Australia, 2019). This study also revealed that healthcare professionals' impatience with the conditions of older adults with dementia could create discomfort and trigger increased aggression in these individuals. Therefore, dementia healthcare services should focus on strengthening professional training on dementia for healthcare providers and developing training guidelines tailored to the national culture. Various training interventions for healthcare providers can improve healthcare professionals' knowledge of dementia and their positive attitudes toward managing individuals with dementia (Røsvik & Rokstad, 2020).

The lack of healthcare services for older adults with dementia can be considered a significant factor influencing their care. This study has identified that family caregivers living far from major cities choose to discontinue treatment for their elderly relatives because the distance exhausts the elderly individuals, while individuals with dementia need continuous care due to the complexity and impact of the disease on the elderly individuals and their caregivers (Prince et al., 2016). Although the number of older adults with dementia in Indonesia is increasing, healthcare services for these individuals are currently only available in major cities. Elderly care has not yet become a top priority in Indonesia, leading to a lack of healthcare programs for older adults (Kadar et al., 2013). This poses a challenge for family caregivers living farther away from urban centers, as it hampers access to services and adds a financial burden to the family (Putri et al., 2021)

4.4 Involvement of family members in elderly care

This study showed that the involvement of family members in elderly care is significant support for family caregivers, leading to improved quality of care. Financial support from other family members is crucial for family caregivers since they have to accompany elderly individuals with dementia, making it difficult for them to meet their financial needs adequately. Family caregivers can focus more on caring for older adults with dementia with financial support from other family members. This is consistent with research in Iran, which found that one family member usually cares for elderly individuals with dementia and receives financial support from other family members (Lot et al., 2023). The involvement of other family members in caring for older adults with dementia allows family caregivers to have time to rest from their caregiving role, enabling them to have more time and energy for the tasks involved in elderly care. The support received by family caregivers of older adults with dementia in Indonesia reduces the burden of caregiving (Putri et al., 2022).

4.5 Support from fellow family caregivers

The study found that the support from fellow family caregivers comes in the form of informational and emotional support; family caregivers have accepted knowledge about dementia care from another family caregiver and feel a sense of similarity with other family caregivers. Which positively impacted their ability to cope with the emotional burden associated with caring for older adults. This is in line with previous studies that show peer support can reduce the psychosocial stress experienced by caregivers, as reported by the participants in this study. The support from peers is perceived as more effective because caregivers feel they share similar experiences; having shared experiences can create empathetic relationships through exchanging experiences among family caregivers caring for older adults with dementia (Carter et al., 2020). A previous study also showed that support from fellow family caregivers offers valuable opportunities for caregivers to share their concerns, provide mutual encouragement, enhance their understanding and management of the disease, identify common problems, develop problem-solving skills, improve their physical and psychological well-being, reduce the burden of caregiving, and strengthen social support networks among caregivers (Armstrong & Alliance, 2019; Bernabéu-Álvarez et al., 2020),

4.6 Education from Non-Governmental Organizations (NGOs) on dementia care

The findings of this study show that family caregivers received educational support on dementia care from non-governmental organizations (NGOs), both directly and through online platforms. Family caregivers reported they get materials for dementia offline and online education from NGOs. This NGO activity is crucial for increasing knowledge and skills about dementia care. The government plays a significant role in setting priorities and policies and providing the necessary resources for implementation. The Ministry of Health launched the national dementia strategy in March 2016, which includes dementia education programs. However, the recent progress of this national strategy and its outcomes remains unclear (Suriastini et al., 2023). Alzheimer Indonesia is one of the NGOs that is currently involved in providing dementia services in Indonesia. They offer direct education and online webinars, as well as materials on dementia care and family caregiving that can be accessed through their website; however, not all activities are freely accessible, and some may require payment, which can contribute to improving knowledge about dementia (Immanuel & Natalia, 2021). NGOs play a vital role in providing care and support services due to their accessibility to communities and their understanding and responsiveness to community needs. The government can collaborate with NGOs to provide dementia-related education to family caregivers and the general public. Through this ongoing collaboration, NGOs and government can be more effective in providing education, healthcare services, nutrition, medications, financing, and policy-making (Sajadi et al., 2022; Thara & Patel, 2010).

5. Implications and limitations

The findings of this study provide new insights into the barriers and support experienced by family caregivers in caring for older adults with dementia and offer inputs to nurses to identify the appropriate strategies to overcome barriers and enhance support during dementia caregiving in Indonesia from the family caregivers' perspectives. Nurses should consider dementia education and training for families, communities, and health professionals to increase knowledge and awareness. The care team can coordinate to implement group process strategies through self-help groups. The government must increase collaboration with non-governmental organizations to conduct sustained activities that enhance knowledge and awareness of dementia.

This study has limitations. It was conducted only in Central Java Province, so it may not fully represent the support and barriers experienced by family caregivers across the cultural contexts in Indonesia. Only females were the subjects of the study. While males and females may have different points of view, this study could not describe the men's perspectives on the barriers and support while caring for older adults with dementia. This study involved data collection using as video and Zoom calls. However, because of sluggish internet connections, video and Zoom calls might occasionally be difficult, which could be a limitation of this research.

6. Conclusion

This study provides insights into the perspectives of family caregivers regarding the barriers and support during caregiving. The findings of this study shed light on the barriers faced by family caregivers caregivers' insufficient knowledge and skills regarding dementia impacting the quality of care provided. In addition, stigma, lack of knowledge and awareness in society, limited availability of healthcare services, and healthcare professionals' lack of knowledge about dementia exacerbate dementia quality of care. Meanwhile, the support received by family caregivers, support from fellow family caregivers, and education provided by NGOs on dementia care have shown a positive impact on reducing caregiver burden and improving the quality of care. Considering the multicultural aspects of Indonesia, future studies should encompass the perspectives of family caregivers representing different cultures in Indonesia.

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Author contribution

All authors contributed to the study conception and design (RHW, JS, ER, AK), data collection (RHW), data analysis (RHW, JS, ER), and manuscript preparation and revision (RHW, JS, ER, AK).

Conflict of interest

The authors declare no potential conflict of interest concerning this research, authorship, and/or publications of this article.

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