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Dementia care' needs regarding dementia care services in Indonesia: A qualitative study

Necesidades de atención de la demencia con respecto a los servicios de atención de la demencia en Indonesia: un estudio cualitativo

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ABSTRACT:
Introduction: In Indonesia, approximately 30% of older adults with dementia are treated by family caregivers. These caregivers require supportive dementia care services to provide effective care. However, research on family caregivers' expectations regarding dementia care services that facilitate optimal caregiving remains limited.
Objective: This study aimed to explore the needs of family caregivers concerning dementia care services in Indonesia.
Methods: This qualitative study employed a descriptive phenomenological approach using semi-structured interviews. Data were collected from purposively selected family caregivers who provide care to older adults with dementia (n=15). The data were analyzed using Colaizzi's method to identify themes.
Results: Three themes were developed from the data, reflecting the expectations of family caregivers regarding dementia care services in Indonesia. Family caregivers expressed a need for health programs that enhance their knowledge and skills in caring for older adults with dementia. However, they also reported limited dementia care services in the community.
Conclusion: Dementia care services in Indonesia are not yet adequately prepared to meet the challenges of dementia care. These findings underscore the need to develop comprehensive dementia care services that support family caregivers, thereby improving the quality of care for older adults with dementia.

Keywords: Health Services Needs and Demand; Dementia; Family Caregiver.

RESUMEN:
Introducción: En Indonesia, aproximadamente el 30% de los adultos mayores con demencia son tratados por cuidadores familiares. Estos cuidadores requieren servicios de atención de apoyo para la demencia para brindar una atención eficaz. Sin embargo, la investigación sobre las expectativas de los cuidadores familiares con respecto a los servicios de atención de la demencia que facilitan un cuidado óptimo sigue siendo limitada.
Objetivo: Explorar las necesidades de los cuidadores familiares con respecto a los servicios de atención de la demencia en Indonesia.
Métodos: estudio cualitativo con enfoque fenomenológico descriptivo mediante entrevistas semiestructuradas. Se recopilaron datos de cuidadores familiares seleccionados intencionalmente que brindan atención a adultos mayores con demencia (n = 15). Los datos se analizaron utilizando el método de Colaizzi para identificar temas.
Resultados: Se desarrollaron tres temas a partir de los datos, que reflejan las expectativas de los cuidadores familiares con respecto a los servicios de atención de la demencia en Indonesia. Expresaron la necesidad de programas de salud que mejoren sus conocimientos y habilidades en el cuidado de adultos mayores con demencia. Sin embargo, también informaron servicios limitados de atención de la demencia en la comunidad.
Conclusión: Los servicios de atención de la demencia en Indonesia aún no están adecuadamente preparados para enfrentar los desafíos de la atención de la demencia. Estos hallazgos subrayan la necesidad de desarrollar servicios integrales de atención de la demencia que apoyen a los cuidadores familiares, mejorando así la calidad de la atención para los adultos mayores con demencia.

Palabras clave: Necesidades y demanda de servicios de salud; Demencia; Cuidador familiar.

INTRODUCTION

The prevalence of older adults in Indonesia has increased over the years, accounting for 12% of the total population in 2024, and is projected to reach 65.82 million or 20.31% of the total population in 2045(1). The increase in the older adult population is also associated with a significant rise in the number of older adults with dementia. Globally, dementia is one of the fastest-growing causes of disability and death and presents serious social, health, and economic challenges(2). While national data on dementia prevalence in Indonesia are lacking, it is estimated that the number of older adults with dementia will increase from 1.2 million in 2016 to 2 million by 2030 and 4 million by 2050. More than 30% of these individuals are cared for by family members(3).

In Indonesia, approximately 30% of individuals with dementia are cared for by family members, including adult children, daughters-in-law, and spouses(3,4). Family caregivers play a crucial role in providing quality care as the disease progresses. The progression of dementia will result in memory loss and changes in personality and behaviour, leading to increased dependence on activities of daily living(5,6). This progressive nature of dementia requires daily support from family caregivers, posing significant challenges for them(7). Caring for older adults with dementia can have various impacts on family caregivers. Previous studies in Indonesia have reported both positive and negative effects of caregiving. Family caregivers have reported increased patience and resilience, as well as closer relationships and more meaningful connections with their care recipients(8). However, they also face negative impacts such as stress, depression, burden, and caregiving fatigue(9,10). Family caregivers of individuals with dementia experience higher levels of stress, burden, and depression compared to those caring for older adults without dementia(11,12).

Mental health issues experienced by family caregivers are closely related to the level of support they receive during the caregiving process(13,14). Thefore, interventions aimed at supporting family caregivers of individuals with dementia are essential in addressing these challenges. For this reason, understanding the specific needs of family caregivers is a crucial step in supporting them effectively(7).

Most qualitative studies in Indonesia have focused on the impacts of caregiving, barriers, and sources of support in dementia care(15–17). However, little research has explored the specific needs of family caregivers related to dementia care services. Previous findings indicate that family caregivers in Indonesia often have limited knowledge about dementia and lack the necessary skills and support for dementia care(17). Therefore, investigating the needs of family caregivers regarding dementia care services can play a significant role in developing national programs that support older adults with dementia and their caregivers, thereby improving their quality of life. Additionally, based on a review of the existing literature and to the best of the authors' knowledge, no studies in Indonesia have specifically explored the service needs of family caregivers for dementia care. Therefore, this study was conducted to explore the needs of family caregivers regarding dementia care services in Indonesia that can support them in providing high-quality care for older adults with dementia.

MATERIAL AND METHODS

This study employed a descriptive phenomenological design, which aims to explore the lived experiences and perceptions of a defined phenomenon, allowing researchers to gain insights that reflect each participant's unique condition(18,19). This research serves as a preliminary study for developing dementia care services based on the needs of family caregivers in Indonesia. All authors (RHW, JS, and ER) have experience in conducting qualitative research.

Participants were individuals who had experienced the phenomenon under investigation(20). A purposive sampling technique was employed to select the participants. This technique was chosen to ensure the recruitment of participants with diverse experiences relevant to the phenomenon, as well as the ability to articulate, self-reflect, and express their experiences meaningfully in relation to the research purposes he participants included 15 family caregivers from one province in Indonesia, selected from five different areas(19,21) . The inclusion criteria were having a familial relationship with the older adult with dementia, being an adult, being communicative, being fluent in Indonesian, and providing at least 4 hours of daily care for older adults for more than 6 months.

Before the study began, ethical approval was obtained from the Human Ethics Committee of the Faculty of Nursing, University of Indonesia, West Java, Indonesia (reference number: KET-132/UN2. F12. D1.2.1/PPM.00.02/2022). Before the interviews, participants provided verbal consent via WhatsApp and written consent via a Google form after the researchers explained the purpose of the study during recruitment and interviews. Anonymized and disguised Microsoft Word documents containing interview transcripts were stored in a password-protected master folder. The data could only be accessed by researchers participating in this study. Participants were also informed that if their condition required further action, they could receive additional recommendations.

Data collection was conducted between August and September 2022 through video calls or Zoom meetings, based on the participants' preferences, as they needed to accompany the older adults they cared for. Only the researcher and the participant were present during the interviews. Participants were informed that they had the right to withdraw from the study at any time without consequence. In-depth unstructured interviews were the primary data collection method, in line with the descriptive phenomenological approach(22,23). Interview questions were open-ended, allowing participants to explore their experiences in depth(22). The interview guide was developed based on Bevan's phenomenological structure, which includes three main domains: contextualization, apprehension of the phenomenon, and clarification of the phenomenon(22). Sample questions included: "Tell me about the dementia care services you expect," "Please describe the types of dementia care services you need in caring for an older adult with dementia," and "Can you explain your experience and how such services are needed in dementia care?" Each interview lasted approximately 45 to 60 minutes and was audio-recorded. The interview was then transcribed verbatim by the first author (RHW).

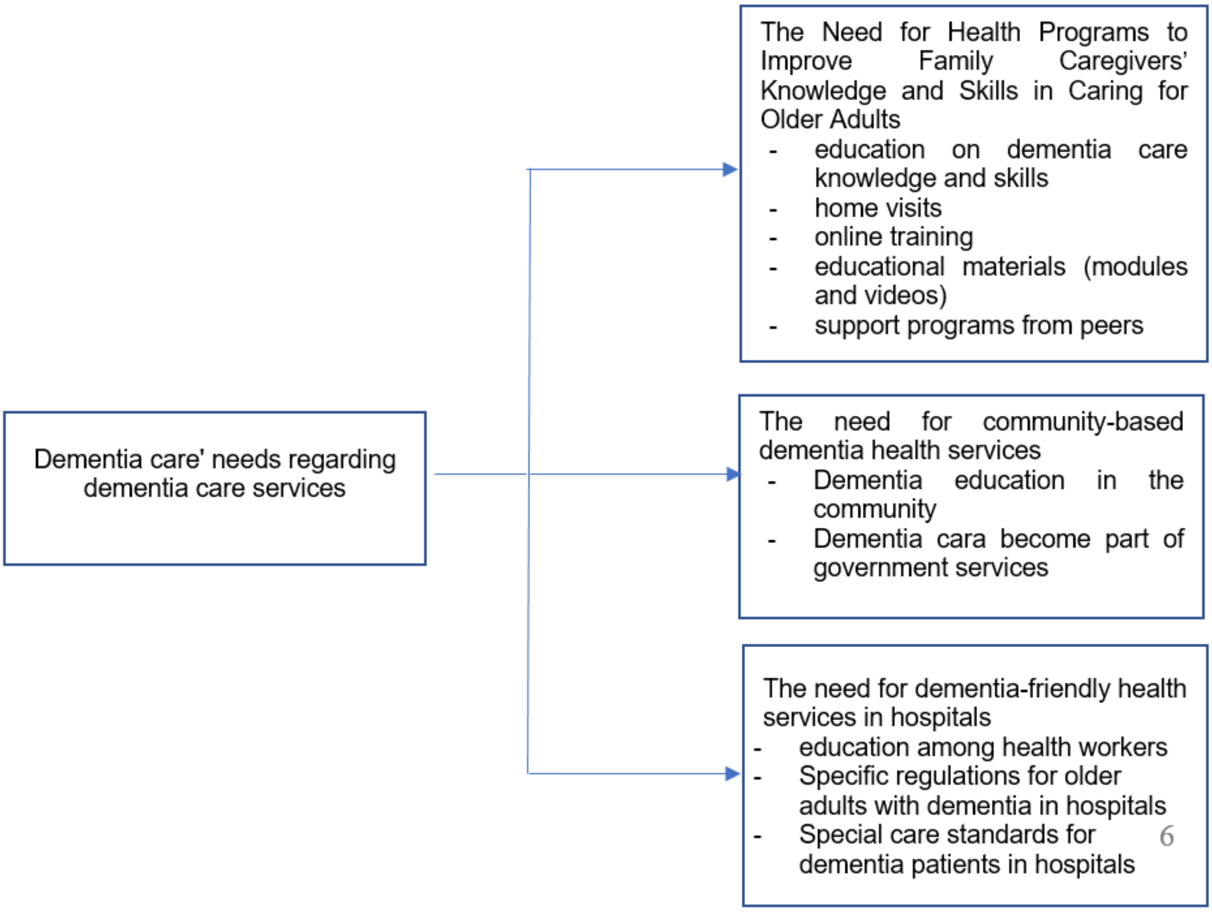
The researchers transcribed the interviews verbatim and analyzed the data using Colaizzi's method(24), which involves the following steps: (1) Re-reading all interview transcripts, (2) Extracting significant statements related to the phenomenon, (3) Formulating meanings from these significant statements, (4) Organizing the formulated meanings into theme clusters, (5) Developing an exhaustive description of the phenomenon, (6) Constructing the fundamental structure of the phenomenon, and (7) Validating the findings with participants and requesting feedback to ensure completeness. All researchers participated in categorizing the data and defining the themes. Initial findings informed subsequent data collection through an iterative process, which continued until data saturation was achieved. This study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist(25). To ensure the trustworthiness of the findings, the researchers adhered to the criteria of credibility, dependability, confirmability, and transferability(26).

RESULTS

All participants were female, with an average age of 44.1 years. Most had a university degree, were married, and belonged to the Javanese and Chinese ethnicities. The majority were daughters of older adults with dementia, with an average caregiving duration of 4.5 years.

Three themes emerged from the data collected in this study, including (1) the need for health programs to improve the knowledge and skills of family caregivers in caring for older adults, (2) the need for dementia care services to increase public awareness and reduce negative stigma toward dementia in the community, and (3) the need for dementia-friendly healthcare services in hospitals. These themes are explained in Figure 1.

Figure 1. Schematic diagram of dementia care' needs regarding dementia care services and the relationships between themes described by participants.



THEME 1: THE NEED FOR HEALTH PROGRAMS TO IMPROVE FAMILY CAREGIVERS' KNOWLEDGE AND SKILLS IN CARING FOR OLDER ADULTS

Family caregivers expressed that they lacked sufficient knowledge and skills in caring for older adults with dementia. To provide quality care, they felt the need for health programs that could enhance their caregiving competencies. Participants expressed the importance of education on dementia care knowledge and skills, as stated below:

"When my father had difficulty swallowing, I didn't know what to do. He often choked, and his speech became unclear. I wish I had been taught about that—the emergency actions to take when my father choked. We need clear guidelines and some instruction on how to help him speak clearly, maybe like speech therapy, just simple things." (P1)

Family caregivers also expressed a need for home visits to help them learn practical skills in caring for older adults with dementia, as stated by the following participant:

"My mother just likes to sit around. I really wish there were hands-on activities to assist with ODD (older adults with dementia). I hope someone can come to the house to teach us. At least teach us how to engage in activities with ODD." (P3)

“Yes, what we need is a health service that provides assistance directly at home to help us. That way, I can understand how to care for my mother.” (P11)

Participants stated that they had to accompany older adults for 24 hours every day to meet their needs. Therefore, they expressed the need for online training to improve their knowledge and skills without leaving the older adult alone. Participants stated the following:

“I want to have online training so I can still accompany my father. It’s very important. I want to learn about the stages of dementia and how to care for older adults with dementia according to each stage. I also want to learn how to care for those in the late stage of dementia.” (P1)

“To keep accompanying my mother without leaving her alone, I really hope there’s online training about dementia care strategies.” (P11)

Family caregivers also stated that they need educational materials that they can use as care guides, as expressed by the following participant:

“We really need training modules and videos on how to care for older adults with dementia that show examples and illustrations. So, they can serve as a guide that fits my father’s condition.” (P2)

Furthermore, family caregivers also experience stress and burden in caring for older adults with dementia and, therefore, need support programs from peers. Some participants stated:

“I hope we can have forums, like the caregiver support group we created, where we can meet once a week or once a month to share knowledge.” (P2)

“We need psychological support groups. It is some kind of assistance; we really need that. Sometimes, it's not just the patient who needs care but also the caregiver. We feel sick, too; we need support. I often cry. It’s very stressful caring for my father.” (P8)

THEME 2: THE NEED FOR COMMUNITY-BASED DEMENTIA HEALTH SERVICES

Family caregivers felt that they had not received positive acceptance from the community due to a lack of understanding and awareness about dementia. Therefore, they emphasized the need for dementia education in the community, as stated by participants:

“People in the community don’t know what dementia is. They think it’s just normal aging, just forgetfulness. So, they assume there's no need to talk to the older adult because they're just senile. There is also a lack of socialization within the community. People need to be educated about what dementia really is—many don’t understand.” (P3)

“Many people don’t know the difference. They need to be informed. They can’t distinguish between people with dementia and those with mental illness or considered ‘crazy’. People need to be educated about Alzheimer’s.” (P6)

Participants also noted that dementia care is not yet included in government public health programs, and they hoped it would become part of government services. Some participants stated:

“I hope the Ministry of Health will include dementia in their programs at community health centers, just like other diseases. I hope that the ‘Puskesmas’ [community health center] provides services for older adults with dementia.” (P8)

“We already have elderly ‘Posyandu’ [Integrated Health Service Post], but maybe they shouldn’t only focus on physical health. There should also be services for emotional and mental well-being for older adults with dementia.” (P14)

THEME 3: THE NEED FOR DEMENTIA-FRIENDLY HEALTH SERVICES IN HOSPITALS

From the caregivers' perspective, current hospital services are not yet dementia-friendly, as many health workers still lack the knowledge and skills to care for older adults with dementia properly. Participants stated that there is a need for education among health workers, as mentioned below:

“Older adults with dementia are different. Nurses need to be patient with them. There should be education for nurses on how to effectively care for patients with dementia. What often happens to me is that nurses get angry because my father keeps pulling out the IV line. Maybe they aren’t patient enough.” (P2)

“Healthcare workers need to understand the condition of older adults with dementia. Some nurses are patient, while others are not. They should be introduced to dementia and what ODD is—at least the basics.” (P1)

Family caregivers also need care services that focus on the unique conditions of older adults with dementia. They wish to have specific regulations for older adults with dementia when undergoing treatment in hospitals. This was experienced by participants when older adults had to be hospitalized without family companions, as stated below:

“When my mom was admitted to the high care unit, I wasn’t allowed to accompany her. She became anxious, felt alone, kept yelling to go home, and pulled out the IV line. Considering that older adults feel calmer when accompanied by family caregivers, I hope that there will be a policy allowing family members always to accompany elderly patients during hospitalization.” (P6)

Older adults with dementia have specific characteristics, as they may become agitated or aggressive in unfamiliar environments. Therefore, caregivers need special care standards for dementia patients in hospitals. Participants stated:

“Older adults with dementia are different from general patients. If they're alone, they can panic or get angry. Their care shouldn't be the same as others. The care provided should be tailored to their condition. Right now, everything is treated the same, and that shouldn’t be the case. Hospitals, especially in the emergency department, still lack this kind of service. There should be special signs or indicators for dementia patients.” (P1)

“Dementia involves a decline in thinking ability in older adults. As a result, they become confused about what to do. So, I think there should be special treatment for people with dementia.” (P8)

DISCUSSION

This study identified the needs for dementia care services by family caregivers, which include (1) health programs to improve the knowledge and skills of family caregivers in caring for older adults, (2) dementia health services to enhance public understanding of dementia and reduce negative stigma in the community, and (3) dementia-friendly health services in hospitals. Improving knowledge and skills in caring for older adults with dementia through educational programs was a significant expectation of family caregivers in this study. Participants expressed the need for information related to the management of older adults with dementia. This aligns with research stating that family caregivers require training that includes both knowledge about dementia and caregiving skills(27). Enhancing knowledge through specialized training in dementia care can also reduce stress and caregiver burden, improve caregivers’ well-being, and enhance the quality of care(28). Educational programs for family caregivers can enhance their knowledge and skills in dementia care, alleviate psychological stress, strengthen social networks, and increase their confidence in understanding older adults with dementia(29).

Family caregivers also need online training and learning modules on caring for older adults with dementia and coping with the caregiving burden. Training for caregivers has a positive impact on their physical health when caring for older adults with dementia(30). Care-related training, combined with counseling and health education interventions, can improve the quality of care provided and reduce the caregiver overload burden(31). The present study also identified that participants need home visits to provide education and support in caring for older adults with dementia. This is supported by previous research, which reports that home visits by nurses make family caregivers feel more at ease and reduce their stress. Caregivers also receive information about dementia and its management, which results in positive changes and improves their quality of life(32).

This study also found a need for support programs from fellow caregivers. This aligns with previous findings that peer support groups can increase caregivers’ knowledge about dementia and improve the support they receive(33). Community nurses can facilitate peer support groups for caregivers of older adults with dementia, allowing them to share caregiving experiences, receive education, and offer mutual support.

Furthermore, caregivers in this study expressed disappointment regarding the lack of dementia care services in public health programs, especially those offered by community health centers. Although the Indonesian Ministry of Health has introduced policies to support dementia management, its implementation at the primary healthcare level remains limited. Screening programs and dementia care coverage remain low, with only a small proportion of community health centers (36%) providing care for older adults with dementia(34). Dementia has not been fully integrated into Indonesia’s health policies and regulations, which is also a common issue in other low- and middle-income countries(35). This condition contrasts with countries like the UK, where comprehensive dementia care services have been developed, including adult day health services (ADS), social adult day centers (SADCs), memory cafés, and caregiver support groups.

In Indonesia, elderly health programs are still not a primary focus, as health efforts remain centered on maternal and child health(36).

The results of the present study also emphasize the need for specific hospital policies that accommodate the needs of older adults with dementia to ensure dementia-friendly care. Providing care that understands and supports the unique needs of older adults with dementia can be achieved through patient-centered care (PCC)(37). Family caregivers emphasized the importance of involving family members in the care of older adults with dementia during hospitalization. This is supported by previous research, which reports that caregivers' knowledge of older adults' conditions and the strategies they use can improve care in hospital settings(38). However, this study found that family involvement in dementia care in Indonesian hospitals is often overlooked. Therefore, there is a need for specific regulations that allow family members to accompany older adults, especially in isolation units, to enhance their comfort and ensure care that aligns with their specific conditions.

This research has some limitations. This article may not accurately reflect the needs for dementia care services by family caregivers in Indonesia's various cultural contexts because research was limited to the Central Java Province. The study only included female participants. Although men and women may have distinct viewpoints, this study was unable to provide men's opinions on the needs for dementia care services by family caregivers. Zoom calls and video were used to collect data for this investigation. However, video and Zoom calls may occasionally be challenging due to slow internet connections, which could be a limitation of this study.

Future studies should focus on how health service systems for older adults with dementia can be improved to meet the growing needs of both individuals with dementia and their caregivers. Strong political commitment and leadership are needed to improve the provision of healthcare services for people with dementia.

CONCLUSIONS

This study found that family caregivers of older adults with dementia have not yet received dementia health services that meet their caregiving needs. The findings underscore the importance of enhancing education and training for family caregivers, as well as the urgent need to develop targeted health services and policies related to dementia care in order to deliver high-quality care and provide better support to family caregivers.

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