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Research Article

Unveiling Spousal Challenges and Expectations in Caring for Elderly Dementia Patients in Indonesia

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Abstract

Aims: Dementia is a progressive, terminal condition causing cognitive decline and dependency on caregivers, often spouses. Spousal caregivers face unique challenges, including physical, emotional, social, and financial burdens. However, limited research in Indonesia has explored the lived experiences, challenges, and expectations of spousal caregivers for elderly dementia patients.
Objective: This study aims to uncover the challenges and expectations of spousal caregivers for elderly dementia patients in Bekasi, Indonesia, to inform tailored support interventions.
Methods: Using a qualitative descriptive phenomenology approach, in-depth semi-structured interviews were conducted with 10 spousal caregivers. Participants were selected purposively, meeting inclusion criteria such as caregiving duration of over six months. Data were analyzed systematically through thematic analysis, validated via peer review and participant feedback.
Results: Two main themes emerged: (1) Optimal conditions expected of a partner, including hopes for condition improvement and miraculous recovery; and (2) Improving self and family conditions, involving desires to maintain caregiving responsibilities, avoid burdening children, and foster harmonious household relationships. Participants emphasized the importance of societal and governmental support for dementia care.
Conclusion: Spousal caregivers in Indonesia face significant challenges yet maintain optimistic expectations for their partners and families. This highlights the need for community-based monitoring systems and tailored interventions to reduce caregiver burden and improve dementia care quality.

Keywords:
Caregiver burden, caregiver expectations, dementia, elderly care, Indonesia, spousal qualitative study, caregiving,

INTRODUCTION

Dementia is a progressive, terminal, and irreversible disease characterized by a decline in cognitive function that necessitates increasing dependence on others over the course of 5–20 years (1). Despite its profound impact on individuals and families, dementia often receives less public attention compared to other non-communicable diseases (2). This condition, which develops gradually, leads to irreversible brain damage and renders the elderly unproductive and fully reliant on family members for daily care (3).

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Globally, dementia poses significant challenges to individuals, families, communities, and nations. The associated caregiver burden is multifaceted, encompassing physical, psychological, social, and financial dimensions. Physically and psychologically, caregivers are at a higher risk of health issues due to the prolonged and demanding nature of care provision (4). Socially, caregivers often face isolation, with limited opportunities to participate in community activities or maintain social connections. The financial strain on families, communities, and healthcare systems further underscores the need for heightened attention to dementia care (5).

Caregiver burden is a complex interplay of stressors resulting from the physical, emotional, social, and economic challenges associated with caring for individuals with dementia (6). Spouses, who frequently assume the role of primary caregivers, experience profound changes in their physical and psychological well-being due to the evolving nature of their responsibilities. Previous studies highlight key challenges faced by spousal caregivers, including feelings of depression, isolation, lack of support, limited knowledge about dementia care, and dissatisfaction with available healthcare services (7,8). These factors can exacerbate the caregiver’s burden, especially in communities where awareness and understanding of dementia are low.

The onset of dementia in one partner often marks a significant shift in marital dynamics. According to the Alzheimer’s Association (2018), the traditional role of equal partners in a marriage may transform into a parent-child relationship in the context of caregiving (9). Spousal caregivers are tasked with managing a wide range of responsibilities, including assisting with activities of daily living (e.g., bathing, eating, dressing), making decisions on behalf of their partners, and providing emotional and social companionship (10). These role changes demand continuous adaptation and pose unique challenges to the marital relationship, potentially transforming it from a reciprocal partnership to a one-sided caregiver-client dynamic (11).

In Indonesia, spousal caregiving for elderly dementia patients remains underexplored, particularly in terms of the specific challenges and expectations faced by caregivers. Existing studies predominantly focus on the general caregiver burden, often overlooking the nuanced experiences of spousal caregivers. This research aims to address this gap by examining the lived experiences, challenges, and expectations of spousal caregivers for elderly dementia patients in Indonesia. By shedding light on these dynamics, this study seeks to inform interventions that better support caregivers and improve the overall quality of dementia care.

METHODS

Study Design

This study employed a qualitative research design using a descriptive phenomenology approach. The study aimed to explore the challenges and expectations experienced by spouses providing care for elderly individuals with dementia in Bekasi, Indonesia. This approach was chosen to gain an in-depth understanding of participants' lived experiences, perceptions, and emotions.

Sample

The study population consisted of spouses (husbands or wives) who served as the primary caregivers for elderly individuals diagnosed with dementia in Bekasi, Indonesia. A purposive sampling technique was employed to ensure the selection of participants who could provide rich, relevant, and diverse information. Participants were included in the study if they met the following criteria were the main caregiver (spouse: husband or wife) for the elderly dementia patient, could communicate effectively in the Indonesian language, and ad been providing care for a dementia client for more than six months.

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Caregivers who were unwilling or unable to participate in the interviews or those who exhibited significant communication barriers were excluded from the study.

The study involved 10 participants, which was deemed sufficient to achieve data saturation. Data saturation occurred when no new themes or insights emerged from the interviews, ensuring the comprehensiveness of the findings.

Interview Guideline

The interview guideline was developed based on a review of relevant literature and consultation with experts in geriatric nursing and qualitative research. The initial draft was prepared in a semi-structured format to allow flexibility while maintaining a clear focus on the research objectives. Key questions were designed to explore participants' experiences, challenges, and expectations in caregiving. The guideline was reviewed by three independent experts in dementia care and qualitative research to ensure clarity, relevance, and appropriateness of the questions. The guideline was piloted with two caregivers who met the inclusion criteria but were not part of the main study. Feedback from the pilot testing was used to refine the questions for better comprehensibility and flow.

Procedure

Ethical approval for the study was obtained from the Ethics Review Board of the Faculty of Nursing, University of Indonesia. Following ethical approval, a research permit was sought from the Bekasi City Government, which was granted in March 2020. Participants were recruited through community networks and local health centers in the Bekasi City area. Eligible individuals were contacted, provided with detailed information about the study, and asked for informed consent. Data were collected through in-depth, semi-structured interviews conducted from November 2019 to May 2020. Each interview lasted between 45 and 60 minutes and was conducted in a private and comfortable setting chosen by the participant. Verbatim transcriptions of the interviews were reviewed and cross-checked by peers for accuracy and consistency. Observational field notes were also taken during the interviews to capture non-verbal cues and contextual information. After completing the interviews, participants were invited to review the findings relevant to their contributions to ensure that their experiences were accurately represented.

Data Analysis

The data analysis followed a systematic approach based on descriptive phenomenology.

Verbatim transcription of audio-recorded interviews. Identification of meaningful statements and coding them into categories. Categorized codes were organized into themes that reflected the participants' lived experiences. A synthesis of the themes was conducted to identify key insights and derive essential meanings. The analysis process and results were validated through peer review to enhance credibility and reduce potential biases.

Trustworthiness

To ensure the trustworthiness of the study, the following strategies were employed: Prolonged engagement with participants and triangulation of data from interviews and field notes ensured the accuracy of the findings. An audit trail was maintained, documenting all decisions, procedures, and processes undertaken during the study. Peer debriefing and participant feedback were used to confirm the accuracy and neutrality of the findings. Detailed descriptions of the research context, participants, and methodology were provided to enable readers to assess the applicability of the findings to similar contexts.

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RESULTS

Table 1 presents the characteristics of participants and dementia patients, highlighting their age, marital duration, and employment status. The participants, aged 60 to 78, had varying lengths of marriage, ranging from 28 to 60 years. Most participants were housewives, while others included entrepreneurs, private employees, and a laundry worker, reflecting diverse employment backgrounds within the sample.

Table 1. Characteristics of Participants and Dementia Patients

No.	Name of participants (age)	Period of marriage	Employment status
1.	Mrs. T (64 years old)	42 years	Housewife (IRT)
2.	Mrs. J (65 years old)	40 years	Housewife (IRT)
3.	Mrs. E (67 years old)	40 years	Housewife (IRT)
4.	Mrs. S (78 years old)	60 years	Housewife (IRT)
5.	Mrs. R (67 years old)	47 years	Entrepreneur
6.	Mr. R (65 years old)	45 years	Entrepreneur
7.	Mrs. C (60 years old)	28 years	Housewife (IRT)
8.	Mr. E (68 years old)	43 years	Private employees
9.	Mrs. I (60 years old)	35 years	Laundry Worker
10.	Mrs. N (65 years old)	49 years	Housewife (IRT)

The specific goal obtained by the researcher is the expectations of the caregivers while caring for their partner who suffers from dementia. In this specific objective, there are 2 themes, namely the optimal condition expected of a partner supported by 2 sub-themes (the condition of the partner expected by the caregiver and the desired condition by the caregiver), and expectations for self and family which are supported by 3 sub-themes (the desire to remain able to carry out the role as caregiver, the desire not to trouble children in caring for their partner, and wanting a conducive relationship).

Theme 1: Optimal conditions expected of a partner

This theme appears supported by 2 sub-themes, namely the expected condition of the partner and the desired condition by the caregiver. The explanation of the sub-themes and categories is as follows.

The sub-theme of the expected condition of the partner is divided into 2 categories, namely the partner experiencing improvement in his condition and the condition of the disease not getting worse, the category of condition improvement can be seen in several significant statements which include:

"Em.. hopefully there will be improvements later on in the next step, yes. I would prefer to consult a neurologist……" (P1)

".....The hope is that he will be healthy again………… Yes, he will be healthy again ……" (P9)

While the next category can be seen in the statement

"….*I'm hoping that the setbacks don't continue, that's all*…." (P1)

"In his condition, I really want him to live a long life… I'm not insistent though" (P5)

"….Yes... if he really won't recover, what people say is yes, at least this way, don't get worse…." (P8)

The second sub-theme is the condition desired by the caregiver, this can be seen from the 2 categories found that the desire for the disease to be cured and get a miracle is found. The desire to be cured can be seen from several statements, including:

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"…..Yes, we ask Allah, if Allah really want to heal him, he will heal……" (P2)
"…….It just depends on Allah…. the important thing is to heal" (P3)
"……The hope is that his condition will improve quickly…. Get well" (P4)

While in the second category, the hope to get a miracle can be seen from the following statements:
"……Yes, I have a thought, oh God, I hope someone can help me this time….." (P6)
"……….but we don't know, God's miracle……" (P7)

Theme 2: Improving self and family condition

The theme of improving self and family conditions desired by caregivers is depicted into 3 sub-themes, including the desire to remain able to carry out the role as caregivers, the desire not to bother children in caring for their partners, and wanting a conducive relationship. The following is an explanation of each sub-theme and category:
The first sub-theme is the desire to remain able to carry out the role as caregivers. This sub-theme is obtained from 2 categories, namely being able to carry out the wife's obligations and having the independence to take care of her partner. For the category of wife's obligations, here are some supporting statements:
""…It's already the wife's obligation to strengthen it, the neighbors say, be patient, be patient, you'll go to heaven…." (P2)
"….Yes, because I said it was part of me before, it's already part of my life….." (P3)
"…….both are obligations as wives who else if not the wife who takes care of them…." (P4)
"….but all I have to do is take care of him to find money for his needs…." (P5)
"….Yes, as a wife. Wife's responsibility to take care of husband…." (P10)

Meanwhile, regarding the category of independence to take care of their partner, it can be seen in the following statements:
"….The kids are busy too, right, who else if not me?….." (P1)
"………Yes, it's my own business, yes, it's definitely my responsibility……" (P3)
"…..Well, I'll just take care of it myself, so the condition really requires me to take care of it" (P8)
"…….whether he dies or lives, let it be, let me take care of it here" (P9)

The second sub-theme, Desire not to bother children in caring for their partner, was obtained after examining several related categories, namely not wanting to be a bother. For the category of not wanting to be bothered, it is obtained from the following statements:
"…If possible, I don't want to disturb the children. They also have their own needs. If possible, be independent……" (P1)
"It's difficult for them to take care of their 3rd grade child. It's even more difficult if they have to take care of their father... how are we going to take care of their father…." (P3)
"…..can't give burdens to children, they have their own activities, we are wrong if we give burdens to children……." (P5)

The next sub-theme is wanting a conducive relationship which consists of 2 categories, namely household conditions remain stable and caregivers remain healthy. the category of stable household conditions can be seen in the statements below.
"The best is our household, hopefully it will be fine, just like that, Istiqomah….." (P2)
"……Yes, so that my wife can obey what we want……." (P8)

Meanwhile, the category of expectations for caregivers to remain healthy can be seen in the following statements.
"……The important thing is that I am healthy, I can take care of my husband in the hereafter…." (P3)
"……At least I just think like this, God, it's difficult for me, I hope that God will prolong my life, it's already like that" (P4)
"Yes, so I can live long, so I can take care of my husband….." (P4)

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DISCUSSION

Understanding the expectations of couples caring for a spouse with dementia provides valuable insight into the desires and challenges faced by caregivers in their current circumstances. These expectations often include a clear understanding of the partner's condition and aspirations for the family's well-being. Dementia is a progressive decline in cognitive function, marked by personal and behavioral changes in affected individuals (8). A widespread lack of public awareness about the irreversible nature of dementia can heighten unrealistic hopes for a partner's recovery. Miller (2012) highlighted that insufficient knowledge and awareness among caregivers about the nature of the disease can lead to ineffective caregiving practices (11).

Cheung et al. (2018) reported that spouses who care for partners with dementia experience higher levels of sadness and caregiving burden compared to adult children who take on this role. Their study also emphasized the critical role of social capital in alleviating caregiver burden among spouses (12). Social capital, rooted in cultural ethics and morals, fosters positive societal conditions and plays a significant role in supporting caregivers' biological and psychological well-being, particularly in the complex dynamics of dementia care (3).

Research by Jang and Yi (2017) identified a recurring theme among caregivers: the hope for their partner's recovery, even after enduring significant emotional challenges during the caregiving journey (13). Community-based informal caregivers are predominantly family members or spouses (14), with spouses frequently being the primary caregivers for elderly individuals with dementia (15). Supporting this, Juntunen (2018) found that most dementia patients reside in community settings with their spouse acting as their primary caregiver (16).

Interviews and supporting theories reveal that caregivers often harbor hopes for their partner's condition to improve or for a miraculous recovery, largely driven by limited understanding of dementia's irreversible nature. This lack of knowledge fosters unrealistic expectations and contributes to feelings of resignation. Consequently, caregivers may cling to the belief that their partner's condition can be cured, despite the progressive nature of dementia.

The caregiving role is deeply ingrained in socio-cultural values, where providing care for a spouse is viewed as a moral obligation, irrespective of health challenges. In Indonesian society, it is often considered taboo to relinquish caregiving responsibilities or to openly discuss the hardships and fatigue associated with the role. Social norms reinforce the expectation that harmonious couples will navigate caregiving together seamlessly.

Caregivers often express a desire for a harmonious household environment and hope to maintain their own health to continue providing care. This aligns with findings by Wang et al. (2017), who noted that caregivers often take over their partner's household responsibilities, leading to an inseparable bond between the two (17).

Another common expectation among caregivers is to avoid burdening their children, viewing caregiving as their personal responsibility as a spouse. Bielsten et al. (2018) found that elderly couples often prefer to spend time together, share household tasks, and remain mutually independent (18). Similarly, Tuomola et al. (2016) observed that caregiver spouses are more likely to accept their role as the primary caregiver, seeing it as an inherent duty as a spouse (19). Rigby et al. (2018) further supported this, noting that adult children who assume caregiving roles tend to perceive dementia as a more destructive and exhausting condition, leading to a

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higher risk of depression compared to caregiving spouses (20).

Caregivers' reluctance to involve their children often stems from an awareness of their children's personal challenges, a recognition that children may lack the patience and dedication of a spouse, and a desire to shield them from the emotional toll of caregiving. However, caregivers are generally open to receiving help when offered, particularly in the form of emotional or financial support initiated by their children.

This study has several limitations. First, the qualitative design limits the generalizability of findings to broader populations. The sample size, while adequate for thematic analysis, may not capture the full spectrum of experiences among diverse caregivers. Second, cultural factors specific to the study's location may influence the findings, which might not be applicable to other cultural or geographical contexts. Finally, the reliance on self-reported data may introduce biases, such as social desirability bias, affecting the authenticity of participants' responses. Future research should include larger, more diverse populations and consider longitudinal designs to explore changes in caregivers' experiences over time.

CONCLUSION

This study identified two main themes regarding the experiences and expectations of caregivers for individuals with dementia: (1) Optimal conditions expected of a partner, encompassing hopes for health improvement and miraculous recovery; and (2) Improving self and family conditions, reflecting the desire to uphold caregiving responsibilities, reduce dependency on children, and maintain harmonious household dynamics. Caregivers expressed a profound need for societal and governmental support to enhance the quality of dementia care and alleviate the challenges they face . These findings highlight the multifaceted nature of caregiving for dementia, emphasizing both personal and systemic factors influencing caregivers' well-being and caregiving capacity.

The findings underscore the importance of holistic support systems for dementia caregivers. Healthcare professionals should prioritize providing education and emotional support tailored to caregivers' needs, addressing their hopes and concerns. Interventions should focus on strengthening caregivers' resilience, offering practical strategies to manage caregiving responsibilities, and facilitating access to resources. Additionally, policies aimed at improving societal and governmental support—such as subsidized care programs, respite services, and awareness campaigns—are crucial to alleviating the burden on caregivers and fostering a supportive caregiving environment.

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Conflict of Interest

The authors have no conflict of interest to declare.

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