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Research Article

Factors Associated with Resilience Family Caregiver of Patients with Dementia

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Abstract

Aims: Dementia represents a critical public health issue. Family caregivers play a vital role in providing care due to limited healthcare resources, yet they face significant bio-psycho-social challenges that impact their resilience. Understanding the factors influencing caregiver resilience is crucial for developing targeted interventions.
Objective: This study aimed to analyze factors associated with the resilience of family caregivers of PwD in Bekasi City, Indonesia.
Methods: A cross-sectional study was conducted among 42 family caregivers of PwD. Resilience was measured using the Connor-Davidson Resilience Scale (CD-RISC). Descriptive and bivariate analyses were performed to examine associations between demographic characteristics, caregiving duration, dementia knowledge, and resilience.
Results: The majority of caregivers were female (71.4%), aged 18–59 years (83.3%), and unemployed (71.4%). Most caregivers had a moderate level of resilience (71.4%), while 28.6% demonstrated high resilience. Bivariate analysis showed no significant associations between resilience and demographic factors, including gender, age, education level, employment status, caregiving duration, and dementia-related knowledge ($p > 0.05$).
Conclusion: Resilience among caregivers is not significantly influenced by demographic variables, highlighting the importance of focusing on psychosocial and environmental factors to strengthen resilience. Future efforts should prioritize community-based interventions, stress management programs, and social support systems to enhance the well-being of caregivers and the quality of care for PwD.

Keywords:
Dementia, family caregivers, resilience, caregiver burden, social support, Indonesia, cross-sectional study

INTRODUCTION

Dementia is a significant public health challenge, with global reports indicating that approximately 50 million people are currently affected, with 7.7 million new cases emerging annually (1). This figure is projected to rise to 80 million by 2030 and 152 million by 2050, with nearly 60% of individuals with dementia (PwD) residing in low- and middle-income countries (LMICs) (2). In Indonesia, Alzheimer's Indonesia reported that the population of PwD in 2010 was approximately 1.2 million, a number expected to quadruple to 4 million by 2050. These escalating statistics highlight the urgent need to address the challenges faced by PwD and their caregivers, particularly in LMIC contexts like Indonesia, where resources for dementia care are often limited.

The needs of PwD are complex, necessitating holistic support from family

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members and informal caregivers. These caregivers play a pivotal role, as financial constraints and limited access to healthcare services often prevent PwD from receiving professional care. However, the complete dependence of PwD on their caregivers can lead to caregiver exhaustion, especially when compounded by socio-demographic and psychological challenges (3). Caregivers frequently experience bio-psycho-social stressors, which collectively contribute to what is termed "caregiver burden"—a multidimensional condition encompassing physical, emotional, and financial stress (4).

Research conducted in high-income countries has highlighted the challenges faced by caregivers of PwD. Studies by Ivey et al. (2012) and Clissett et al. (2013) found that caregivers often develop positive coping mechanisms to adapt to their changing routines and the demands of caregiving. However, evidence also indicates that high levels of caregiver burden can lead to adverse outcomes, including depression, feelings of isolation, and even suicidal ideation (5). Despite these findings, much of the existing literature focuses on individualistic societies, where cultural values differ significantly from collectivist societies like Indonesia. This cultural distinction underscores the need for context-specific research to explore how caregivers in collectivist cultures experience and cope with caregiving burdens (6).

Caregiver burden is influenced by several factors, including socio-demographic characteristics, the progression of dementia, and the caregiver's psychological resilience. Resilience, defined as the ability to adapt positively in the face of adversity, plays a crucial role in mitigating caregiver burden and improving the quality of care provided to PwD (7). Studies have shown that higher resilience levels can help caregivers manage stress effectively and maintain a better quality of life (8). However, resilience is a subjective process and can vary among individuals based on their perceptions and external support systems, such as social networks and healthcare services (9). Despite these insights, there is a notable research gap in understanding the factors that influence caregiver resilience in LMICs, particularly in Indonesia. Preliminary research conducted by the authors in Bekasi City, Indonesia, revealed several challenges: the absence of comprehensive data on PwD and their caregivers, limited governmental and community support, and a lack of dementia-specific healthcare services. Furthermore, caregivers in Bekasi City are predominantly family members, with minimal access to professional caregiving services. These findings suggest that the resilience of caregivers in this setting is shaped by unique cultural, social, and systemic factors that require further exploration.

While global research has extensively documented the challenges of caregiving for PwD, there is limited evidence from LMICs, where caregiving dynamics differ significantly due to cultural and systemic factors. In Indonesia, where collectivist values emphasize familial responsibility, caregivers may experience different resilience-building processes compared to those in individualistic societies. Additionally, the lack of dementia-specific resources and support services in cities like Bekasi further exacerbates caregiver burden. Existing studies have primarily focused on the burden and coping mechanisms of caregivers but have not comprehensively examined the factors influencing resilience in such settings. This gap highlights the need for research that not only identifies these factors but also informs culturally relevant interventions to support caregivers. The present study aims to identify and analyze the factors associated with the resilience of family caregivers of PwD in Bekasi City, Indonesia. By addressing this research gap, the study seeks to provide insights that can inform the development of targeted interventions to enhance caregiver resilience and improve the overall quality of dementia care in similar settings.

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METHODS

This research used a cross sectional approach to determine the level of resilience of the family of caregivers for PwD in Bekasi City using the Caregiver Resilience Scale (CRS). The population in the implementation of this research is the family of caregivers of PwD in the city of Bekasi. The inclusion criteria applied in this study were (1) the caregiver is the family member of the PwD, (2) the family has been a caregiver for at least 6 months, (3) the caregiver is able to speak Indonesian well (4) the caregiver have an android-based cellphone/smartphone, (5) the caregiver does not have cognitive problems, and (6) is signing the informed consent as a willingness to become participants. The exclusion criteria were (1) using formal/informal assistance in caring for PwD, and (2) domiciled outside the city of Bekasi, and (3) not willing to be a respondent. This research has received approval from the Ethics Committee of Binawan University (NO 026/PE/FKK-KEPK/VIII/2021).

Study Design

This study employed a cross-sectional design to investigate factors associated with the resilience of family caregivers of patients with dementia. Data were collected through a structured survey administered to caregivers meeting the study criteria.

Sample

The study targeted family caregivers of patients diagnosed with dementia who were providing direct care for at least three months. A total sample of 42 caregivers was determined based on sample size calculation. Inclusion Criteria: Family caregivers aged 18 years or older, Caregivers who had been providing care for at least three months, and Caregivers capable of providing informed consent. Exclusion Criteria: caregivers diagnosed with severe physical or mental health conditions, caregivers who were paid professional caregivers, and participants unwilling or unable to complete the survey. Participants were recruited using a purposive sampling technique. Recruitment took place at dementia care centers and through community support groups.

Instruments

The resilience of family caregivers was measured using the Connor-Davidson Resilience Scale (CD-RISC). This instrument, developed by Connor and Davidson, consists of 25 items rated on a 5-point Likert scale (0 = not true at all to 4 = true nearly all the time). Higher scores indicate greater resilience. The total score ranges from 0 to 100, with higher scores reflecting higher levels of resilience. The original version of the CD-RISC demonstrated excellent internal consistency with a Cronbach's α of 0.89. The Bahasa Indonesia version, adapted through forward-backward translation, showed good reliability with a Cronbach's α of 0.87 in a prior validation study.

Procedure

Ethical clearance was obtained from the Institutional Review Board (IRB) of Binawan University (NO 026/PE/FKK-KEPK/VIII/2021). Eligible participants were identified through dementia care centers and community organizations. Written informed consent was obtained before participation. Surveys were administered in a supervised setting by trained research assistants to ensure comprehension and accuracy. Data were anonymized and securely stored to maintain confidentiality. After completing the survey, participants were debriefed and encouraged to provide feedback on the research process.

Data Analysis

Data were analyzed using SPSS version 24. Descriptive statistics summarized demographic characteristics, while linear regression analysis was used to identify factors associated with caregiver resilience. Predictor variables included caregiver burden, social support, and demographic factors. Significance was set at $p < 0.05$.

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RESULTS

The data analysis for the univariat analysis used depends on the data measuring scale. In this study, data on gender, age, education level, length of care for PwD, occupation, information about dementia used a categorical measuring scale so that the data were displayed in the form of a frequency distribution.

Table 1. Demographic Distribution of Caregivers' Characteristics Based on the sex of the caregiver, age of the caregiver, occupation, education, length of time as a caregiver and information about dementia (n=42)

Variable	Frequency (n)	Percentage (%)
Gender of caregiver		
Man	12	28,6
Woman	30	71,4
Age of caregiver		
18-59 years old	35	83,3
> 60 years old	7	16,7
Work status		
Doesn't work	30	71,4
Work	12	28,6
Level of education		
Basic education	29	69,00
Higher education	13	31,00
Length of time being a caregiver		
< 5 years	29	69
≥ 5 years	13	31,
Information about dementia		
No	20	47,6
Yes	22	52,4

The majority of caregivers in this study were female, 30 people (71.4%), the average age range is 18-59 years (adults) 35 people (83.3%), the majority are not working 30 people (71 ,4%), the most education is basic education 29 people (69%). The majority of the length of time caring for the PwD was < 5 years as many as 29 people (69%) with the median age of caring for the PwD was 65 (95% CI: 53-96, SD 8.53) (table 2). There are still caregivers who have not received information about dementia as many as 20 people (47.6%) (Table 1).

Table 2 shows that the majority of caregivers are at the moderate level of resilience as many as 20 people (71.4%) while the high ones are 12 people (28.6%).

Table 2. Frequency Distribution of Respondents Based on Resilience Levels (n=42)

Resilience Levels	Frequency (n)	Percentage (%)
Moderate	20	71,4
High	12	28,6

Caregivers shows that the education variable has a p-value = 0.245, the information variable about dementia has a p-value = 0.241, the variable length of time being a caregiver has a p-value = 0.342, the employment variable has a p-value = 0.746, the age variable for the caregiver has a p-value = 1,000 and the gender variable has a p-value = 0.745. This shows that all independent variables have no relationship to family resilience (p-value < 0.005) (Table 3).

Table 3. Cross Table of independent variables

Variable	Family resilience						P-Value	OR
	Moderate		High		Total			
	F	%	F	%	F	%		
Gender								
Man	9	75	3	25	12	100		
Woman	21	70	9	30	30	100	**0,745**	1,286
Jumlah	30	71,43	12	28,57	42	100		
Age of caregiver								
18-59 years old	25	78,13	7	21,87	32	100	**1,00**	1,00
> 60 years old	5	50	5	50	10	100		
Jumlah	30	71,43	12	28,57	42	100		
Level of Education								
Basic education	19	65,52	10	34,48	29	100		
Higher Education	11	84,62	2	15,38	13	100	**0,245**	0,345
Jumlah	30	71,43	12	28,57	42	100		
Work status								
Doesn't work	21	70	9	30	30	100		
Work	9	75	3	25	12	100	**0,746**	0,778
Jumlah	30	71,43	12	28,57	42	100		
Length of time being a caregiver								
< 5 years	22	75,86	7	24,14	29	100	**0,342**	1,964
> 5 years	8	61,54	5	38,46	13	100		
Jumlah	30	71,43	12	28,57	42	100		
Information								
Yes	16	80	4	20	20	100	**0,241**	2,286
No	14	63,64	8	36,36	22	100		
Jumlah	30	71,43	12	28,57	42	100		

DISCUSSION

The findings reveal that demographic factors such as gender, age, education level, employment status, and dementia-related information do not significantly influence family resilience. This highlights the importance of focusing on psychosocial and environmental factors in resilience-building efforts rather than demographic characteristics. Effective strategies to enhance resilience should prioritize tailored interventions that address caregivers' psychosocial needs and strengthen their capacity to cope with the demands of caregiving.

Families caring for persons with dementia (PwD) often experience heightened psychological burdens, such as depression, anxiety, and stress, compared to non-caregiving families. Despite these challenges, many families exhibit remarkable resilience, demonstrating their ability to adapt and provide effective care. For example, O'Dwyer et al. (10)found that caregiving families frequently perceive themselves as resilient and capable of enduring caregiving demands, although caregiving responsibilities often lead to social disengagement (10–12). Such resilience is essential for reducing caregiving burdens, improving caregivers' quality of life, and enhancing the quality of care for PwD (13,14).

Family resilience enables families to maintain stability and a sense of normalcy while fostering supportive relationships (15). This resilience often stems from protective factors such as acceptance of the caregiving role, positive communication patterns, optimism, strong family connections, social support, spirituality, and economic resources (16,17). These factors facilitate successful adaptation to caregiving challenges, allowing families to manage stress and fatigue effectively (18). However, the caregiving process can be fraught with stress, particularly due to the negative behaviors exhibited by PwD, such as severe cognitive impairments and behavioral disturbances. Prolonged caregiving hours and heavy caregiving burdens can exacerbate family strain, increasing the risk of neglect and abuse (19,20). Effective communication within families is critical, as it can either positively or negatively influence how families adapt to caregiving demands (9).

Interventions aimed at strengthening family resilience have demonstrated promising outcomes. Coordinated programs, including dementia care education, self-help groups, and enhanced family communication, have been shown to improve caregivers' understanding of dementia, foster supportive relationships, and promote healthier family lifestyles (18,19). Such interventions not only alleviate caregiving burdens but also improve perceived health status and caregiving experiences, enabling families to sustain their caregiving roles for longer periods (10,21). Protective factors like communication, adaptation, support networks, and coping mechanisms play a vital role in enhancing family resilience. Programs designed to address both risk and protective factors simultaneously are crucial, as these elements often coexist within caregiving families (8,22). Research by Conway et al. (2020) underscores the importance of family togetherness and reciprocity in sustaining resilience (23). Social support and caregiver self-resilience are particularly significant in mitigating caregiving burdens. Female caregivers, who often report higher levels of burden, benefit greatly from social support networks and effective coping mechanisms, which enhance their resilience and caregiving capacity (24). Access to multidimensional social support is thus essential for maintaining caregiver resilience and ensuring quality care for PwD (25).

CONCLUSION

The findings indicate that demographic factors such as gender, age, education level, employment status, and dementia-related information do not significantly affect family resilience. This suggests that resilience-building efforts should prioritize psychosocial and environmental factors rather than demographic variables. Future initiatives should focus on fostering resilience through targeted interventions, such as stress management programs, counseling, and skill-building workshops tailored to caregivers' needs. Additionally, community-based support programs and education campaigns should aim to strengthen coping mechanisms, promote social support networks, and enhance caregivers' overall well-being. These efforts have the potential to significantly improve the quality of care provided to persons with dementia (PwD) while ensuring a better quality of life for their caregivers.

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Conflict of Interest

The authors declare no conflict of interest.

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