

Caregiver Burden and Family Autonomy in Long-Term Elderly Care: A Correlational Study

Brilliant Yunita Adiratna¹, Nur Melizza^{2*}, Nadin Budiarti³, Suyesti Yossi⁴, Berlyan Surya P.P.S⁵, Roby Putra Hermanto⁶

^{1,2,3,4,5,6}Nursing Science Study Program, Faculty of Health Sciences, Universitas Muhammadiyah Malang, Bendungan Sutami Street No. 188, Sumber Sari, Lowokwaru District, Malang City, East Java, Indonesia, 65145

*Corresponding email: melizza@umm.ac.id

ABSTRACT

The increasing number of elderly people in Indonesia poses a major challenge in the provision of long-term care services. The elderly tend to experience a decline in physical and mental function so that they depend on the family as the main caregiver. However, the role as a caregiver can cause psychological, physical, economic, and social burdens known as caregiver burden. The purpose of this study was to analyze the relationship between caregiver burden and family independence in long-term care of the elderly. This study used a quantitative approach with a cross-sectional design, conducted from September 2024 to May 2025 in Malang City. A total of 59 family members who care for the elderly were selected through accidental sampling technique. The instruments used were the Zarit Burden Interview and the Family Independence Level questionnaire. Data analysis was performed with the Spearman Rank test using SPSS version 25.0. The majority of respondents came from large families (71%) and were female (90%). Most families showed high independence (KM 4), while caregiver burden was classified as mild to moderate. Statistical analysis showed no significant relationship between caregiver burden and family independence ($p = 0.741$; $r = -0.044$). Although some caregivers experienced burden, families were still able to care for the elderly independently. Caregiver burden is not the only factor that influences family independence and quality in providing services and long-term care for the elderly. Emotional support, family togetherness, and cultural values are thought to play a role in maintaining family independence.

Keywords: Caregiver Burden, Family Independence, Long-term Care, The Elderly

Cite this as: Adiratna BY., Melizza N., Budiarti N., Yossi S., Surya B and Hermanto RP. (2025). Caregiver Burden and Family Autonomy in Long-Term Elderly Care: A Correlational Study. *Dunia Keperawatan*; 13(3): 262-271. DOI: 10.20527/dk.v13i3.930

INTRODUCTION

Aging is a natural process characterized by a decline in physical and social functioning in older adults. As they age, the elderly tend to experience a decline in health, resulting in increased dependence on others, especially on family members as primary caregivers (20). This condition is in line with changes in the demographic structure in Indonesia. Indonesia has now entered an era of population aging, marked by an increase in the number of people aged 60 and above (12). The increase in the global population, particularly in developing countries, the need for

complex and sustainable health services has also increased. This situation has created a significant economic burden, not only for individuals and families but also for national health (30).

The increase in the elderly population is a global phenomenon that is significantly felt in developing countries. As the elderly population grows, the challenges faced by governments in providing adequate healthcare services become increasingly complex. According to the Indonesian Statistics Agency (2021), the elderly population continues to experience an increase. In 5 decades, it

has approximately doubled (1997-2020), with the elderly female population reaching 9.92% (26 million), exceeding the elderly male population (10.3%: 9.2%). Currently, the elderly population structure is concentrated in eight provinces with an aging rate of 10%, namely the Special Region of Yogyakarta at 15.52%, East Java around 14.52%, Central Java 14.17%, North Sulawesi 12.74%, Bali 12.71%, Lampung 10.22%, and West Java around 10.8% (24).

Independence in older adults is influenced by various interrelated factors, such as increasing age, general health conditions including chronic diseases, education level and socioeconomic status, as well as mental conditions that include symptoms of depression and cognitive function (11). A number of studies show that as they age, older adults tend to experience increased limitations in performing Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL), which are related to a decline in physical and mental function (7, 13, 21).

These findings are reinforced by a global meta-analysis stating that these factors play a significant role in the occurrence of ADL and IADL dysfunction in elderly populations in various countries (1). Additionally, daily health behaviors, including physical activity levels and the presence of chronic diseases, have also been reported to be associated with older adults' ability to maintain independence in daily activities (17).

In these circumstances, families play a central role as the primary providers of emotional, physical, and practical support for older adults in their daily lives (26). In this case, families act as caregivers. Caregivers are individuals who provide assistance to older adults with health or functional limitations. The

assistance provided can include helping with daily activities, providing emotional support, organizing and taking care of their needs (10). The role of caregiver often causes psychological, physical, social, and economic burdens known as caregiver burden.

Caregiver burden is described as the stress experienced by someone who cares for elderly parents, the sick, or people with limitations and disabilities. According to Zarit (1980), caregiver burden is defined as a subjective feeling and negative impact experienced by caregivers in terms of psychological, physical, economic, and social issues. Additionally, this burden includes other symptoms experienced by caregivers, such as , sleep disturbances, fatigue, anxiety, depression, and social isolation, which can persist even after the caregiving period has ended (31).

A study in Singapore showed that approximately 31.3% of caregivers experienced stress, 24.7% experienced an increase in social burden, and approximately 26.7% experienced disruptions to their daily routines as a result of their caregiving role (Loo et al., 2022). Caregivers caring for patients with dementia have a high prevalence of burden, around 49.26% (18). A study conducted in the Netherlands found that around 39% of elderly caregivers who came to the emergency unit experienced high caregiving burden, which was related to cognitive impairment and patient dependence (32).

The activities of the elderly are highly dependent on the social support they receive from their families or the people around them. In this context, family independence is an important aspect in meeting the needs of family members or the elderly without assistance from others. Many children who have families of their own must care for their parents

as well as their immediate families. This situation is common in developing countries, including Indonesia (29).

Understanding the relationship between caregivers and family independence is very important for identifying the factors that influence the burden on caregivers and the impact on the quality of elderly care. In the context of family independence, the ability to meet daily needs without relying on others is very important. However, the role of the family as a caregiver carries its own burden in caring for the elderly. The burden experienced by caregivers is a multidimensional response to the pressures felt by caregivers in the form of physical, emotional, and psychosocial (16).

The role of the family is very important in long-term care. If family dysfunction occurs, the caregiver's burden will increase, which will potentially result in a decline in the quality of care for the elderly (23). Therefore, it is important to examine the relationship between caregiver burden and family independence in order to understand the factors that influence the quality of long-term care for the elderly (20). When caregivers must bear the entire responsibility without assistance from other family members, the caregiving burden becomes even heavier. Therefore, the active role of the family is crucial to support caregivers so they do not feel alone, reduce stress, and improve the quality of care for the elderly (19).

Based on the above discussion, it can be concluded that the increasing elderly population in Indonesia poses a challenge in providing healthcare services and long-term care. Elderly individuals who experience a decline in physical and mental condition will become increasingly dependent on their

families or caregivers. Therefore, this study aims to analyze the relationship between caregiver burden and family independence in long-term care for the elderly, in order to contribute to the development of independent and sustainable elderly care strategies.

METHODS

This study applies a quantitative approach with a cross-sectional design to analyze the relationship between caregiver burden and family independence in long-term care for the elderly. The research was conducted from September 2024 to May 2025 in Malang City. The population in this study was families living with elderly people in long-term care. The sampling technique used in this study was accidental sampling with the criteria of families living with elderly people, minimum age of 17 years, and willingness to participate as respondents in the study.

The instruments used in this study consisted of two questionnaires. The first instrument was the 12-item Zarit Burden Interview (ZBI), which was used to measure caregiver burden. This instrument covered physical, emotional, and psychosocial dimensions, such as fatigue in caregiving, emotional pressure, stress, and the impact of the caregiving role on the social life and health of caregivers. Each item is rated using a 0–4 Likert scale with the following scoring criteria: Total score range: 0 to 48, 0–10: no to mild burden, 10–20: mild to moderate burden, >20: high burden (27). This instrument has been tested for validity and reliability and is considered suitable for measuring caregiver burden in this study.

The second instrument used the Family Independence Level Questionnaire, which was used to assess the level of

family independence in caring for family members, especially the elderly. This instrument consists of four levels, namely Family Independence Level 1 to Family Independence Level 4, which describe the family's ability to recognize health problems, make decisions, provide care, and utilize health services. The data were analyzed using the Spearman Rank statistical test with SPSS version 25.0 software.

RESULTS AND DISCUSSION

Table 1 shows that caregivers in this study were generally women who were

adults to elderly, came from large families, and had sufficient educational and economic backgrounds to support their role in caring for the elderly at home.

Table 2 shows the relationship between caregiver burden, and family independence in caring for the elderly. The majority of respondents with high family independence (KM 4) experienced a light burden (n=17), followed by a moderate burden (n=15), and only a few experienced a heavy burden (n=4). Meanwhile, in the KM 1 to KM 3 independence categories, the

Table 1. Demographic Characteristics of Respondents

Respondent Characteristics	Frequency	Percentage (%)
Caregiver age		
17 – 25	2	3
26 – 35	6	10
36 – 45	11	19
46 – 55	16	27
56 – 65	17	29
>65	7	12
Gender		
Male	6	10
Female	53	90
Family Type		
Nuclear family	13	22
Extended family	42	71
Single parent	4	7
Income		
Below Minimum Wage	3	5
Minimum wage	15	25
Above minimum wage	41	70
Highest level of education		
No schooling	2	3
Elementary	11	19
Junior High School	10	17
High School	25	42
College	11	19
Ethnic		
Javanese	58	99
Madura	1	1
Religion		
Islam	57	96
Catholic	1	2
Protestan	1	2
Work		
Working	26	44
Not working	33	56

Table 2. Caregiver Burden Level and Family Independence Level

Factor	KM 1	KM 2	KM 3	KM 4	Sig.	R
<i>Factor Caregiver Burden</i>						
<i>Mild</i>	4	4	4	17	0,741	-0,044
<i>Moderate</i>	3	4	2	15		
<i>High</i>	1	0	1	4		

number of respondents was smaller and the distribution of burdens varied. The statistical test results showed a significant value of 0.741 ($p > 0.05$), meaning that there was no significant relationship between caregiver burden and family independence. A correlation of -0.044 also indicated a very weak and negative relationship. In other words, even though some caregivers felt burdened, families were still able to be independent in caring for the elderly.

The results of the study indicate that there is no significant relationship between the burden felt by caregivers and the level of independence of families in caring for the elderly ($p = 0.741$). This finding is in line with previous studies which show that the burden of caregiving is not entirely determined by the level of independence of the elderly, but is more influenced by health conditions or chronic diseases (22). Thus, family independence is not the only determining factor in the perception of the burden felt by caregivers.

In general, the burden experienced by caregivers does not always reduce the quality of care provided by the family. This is due to several supporting factors. Research by Cai et al. (2024) shows that familism and social support can act as mediators, enabling caregivers to provide optimal care despite facing pressure. Family support and strong family ties help caregivers manage the stress that arises while performing their roles (4).

The majority of respondents in this study had been caring for the elderly for a long period of time, ranging from more than one year to more than ten years. However, the burden of caregiving does not always increase over time. In some situations, the burden can remain the same or decrease, depending on the condition of the elderly and the caregiver's situation (25). These findings are in line with the conditions in Indonesian society, where family ties encourage families to continue providing care for the elderly.

In this study, most respondents came from large families and were predominantly women who had an emotional closeness to the elderly they cared for. In large family structures, the responsibility of caregiving is often not borne by one individual alone, but is shared collectively, thereby lightening the burden. A study shows that women from migrant communities, such as the Ahmadiyya Pakistanis in Norway, often become the primary caregivers for the elderly. This role is influenced by family responsibilities, religious teachings, and cultural values. These findings confirm that gender roles and social norms have a major influence on patterns of elderly care in various cultural settings (28).

Cultural and religious factors also play an important role in explaining the findings of this study. Almost all respondents came from cultural backgrounds that uphold the value of respect for elders. This value is reflected in the strong practice of mutual cooperation and family solidarity,

enabling families to maintain their independence in caring for the elderly despite facing various challenges (23).

Emotional support and family togetherness are key elements in the sustainability of elderly care. The social support provided by families generally includes emotional support, appreciation, practical assistance, and the provision of information, reflecting the strong cultural values in Indonesian society, where caring for parents is seen as a moral and social responsibility inherent in family life (23).

In this context, religious values also contribute to shaping caregivers' coping mechanisms. Research on Islamic coping shows that faith and religious teachings play a role in strengthening caregivers' psychological resilience when facing severe emotional stress (8). Similarly, the appreciation of local cultural values, such as those developed in Javanese society, also influences how individuals interpret life experiences, including the process of caregiving and loss.

The cultural value of *nrimo ing pandum* reflects an attitude of acceptance towards the conditions faced, which can help ease the emotional burden of caregivers and strengthen their resilience in providing long-term care (2,14). However, the effectiveness of cultural and religious support is also influenced by the individual characteristics of caregivers and the availability of socioeconomic resources within the family.

Most caregivers in this study were aged 46–65 years, a group that generally has better emotional maturity in performing the role of elderly caregiver. This finding is in line with a study in Taiwan which reported that the majority of caregivers were in the 50 to 59 age range, with an average age of 53.1 years, and this age

group was considered to be more emotionally prepared to face the demands of elderly care (15).

In addition, around 70% of them have an income above the minimum wage, which supports them in meeting care needs and accessing health services. Furthermore, most caregivers in this study have an income above the regional minimum wage, making them relatively more capable of meeting elderly care needs and accessing the necessary health services. This condition is an important resource for families in maintaining the sustainability of care.

These findings indicate that the burden of caregiving arising from the condition of the elderly does not necessarily reduce the quality or independence of care when caregivers receive adequate social support. The involvement of other family members, particularly through good communication and a clear division of roles, helps reduce the psychological pressure felt by caregivers, such as stress and emotional exhaustion. This family support plays a role in managing caregivers' psychological responses to caregiving demands, enabling them to cope with the burden in a more adaptive manner (6). Thus, an optimally functioning family can act as a protective factor that maintains independence in elderly care even when caregivers face considerable caregiving demands (3).

In addition, adaptive coping strategies and acceptance of the role as caregiver as a form of family responsibility can reduce the perception of the burden experienced. Adaptive coping strategies, such as focusing on emotions positively, seeking social support, and giving new meaning to the caregiving experience, help caregivers become mentally stronger in carrying out their roles with a better quality of life (9). Emotional

support from other family members and flexibility in the decision-making process also contribute to lightening the caregiver's responsibilities, so that the burden felt is not too heavy.

In a study by Zhang et al. (2024), it was shown that family resilience and perceived social support play an important role in reducing caregiver burden and increasing caregiving capacity. These findings emphasize the need for interventions that not only focus on the individual caregiver but also aim to strengthen family resilience and the social support system as part of efforts to optimize long-term care (33). In nursing practice, nurses play a strategic role through comprehensive assessments of family conditions, providing education on long-term care, and facilitating families in accessing available social support resources.

Thus, even though caregivers face pressure in caring for the elderly, strong family support, cultural and religious values, and stable economic and psychological conditions are protective factors that support family independence in long-term care. The role of nurses in strengthening these factors is important to ensure sustainable and family-oriented nursing care. However, these insignificant results also need to be reviewed for possible romanticization bias. Researchers are aware of the potential for respondents to give socially desirable answers.

In the Indonesian cultural context, complaining about the burden of caring for parents is often perceived as taboo or unethical. Therefore, the low reported burden scores may not only reflect the role of culture and religion as protective factors, but also reflect the respondents' reluctance to reveal their actual difficulties in order to maintain social

norms and values of filial piety towards their parents.

LIMITATIONS

The results of this study need to be interpreted with consideration of the existing limitations. Respondents in this study exhibited relatively homogeneous characteristics, with almost all caregivers being of Javanese ethnicity and Muslim religion. This condition limits the generalizability of the findings, as the results of the study are strongly influenced by a specific cultural and social context and may not necessarily reflect the experiences of caregivers with different cultural and religious backgrounds.

In addition, most caregivers had incomes above the regional minimum wage and came from large families, indicating the availability of relatively good economic and social support. This condition has the potential to cause sample bias, as caregivers with more adequate resources tend to be able to maintain family independence even when faced with the burden of caregiving. This may be one explanation for why the relationship between caregiver burden and family independence did not show significant results in this study.

This study also has limitations in its cross-sectional design, which cannot explain cause-and-effect relationships, as well as a sample size that is not representative of the wider population.

RESEARCH ETHICS

This study has obtained ethical approval with ethical number E.5.a/011/KEPK-UMM/I/2024.

CONFLICT OF INTEREST

There is no conflict of interest in this study.

ACKNOWLEDGEMENTS

The author would like to express their appreciation to Universitas Muhammadiyah Malang for the support and opportunity provided to conduct this research. Gratitude is also extended to the elderly caregivers who were willing to spare their time and participate in the research.

CONCLUSION

This study shows that the burden felt by caregivers is not the only factor that affects the independence of families in providing long-term care for the elderly. Despite facing pressure in the caregiving process, many families are still able to carry out this role independently with the support of culture, extended family solidarity, and adaptive coping strategies. Further studies are recommended using a longitudinal design and considering additional variables such as social support and spirituality.

On the other hand, health workers are expected to provide education, caregiving skills training, and emotional support for families. The formation of support groups in the community and the detection of caregiver burnout are also important to maintain the sustainability and quality of care for the elderly in a family environment.

REFERENCES

1. Amlak BT, Getinet M, Getie A, Kebede WM, Tarekegn TT. Functional disability in basic and instrumental activities of daily living among older adults

- globally: a systematic review and meta-analysis. 2025.
2. Azheema E, Alfina N. Nrimo in pandum: description of Javanese self-acceptance after the family died. *Int J Res Publ Rev.* 2023;4(7):1989–1993.
3. Brites R, Brandão T, Nunes O, Hipólito J, Tomé C. The impact of caregiving on informal caregivers of people with dementia: family functioning, burden, and burnout. *J Clin Psychol Med Settings.* 2025;32(2):325–335. doi:10.1007/s10880-024-10052-2.
4. Cai C, Zhou X, Chen S. Associations between perceived overload and quality of care in dementia family caregivers in China: mediating role of familism and social support. *Front Public Health.* 2024;12:1512778. doi:10.3389/fpubh.2024.1512778 /
5. Cham CQ, Ibrahim N, Siau CS, Kalaman CR, Ho MC, Yahya AN, et al. Caregiver burden among caregivers of patients with mental illness: a systematic review and meta-analysis. 2022.
6. Chan CY, De Roza JG, Teck G, Ding Y, Koh HL, Lee ES. Psychosocial factors and caregiver burden among primary family caregivers of frail older adults with multimorbidity. *BMC Prim Care.* 2023;24:198. doi:10.1186/s12875-023-01985-y.
7. Chen F, Huang S, Zhong W, Cheng Q, Shuai Y. Instrumental activities of daily living function and cognitive status among Chinese older adults: a serial multiple mediation model. *Front Public Health.* 2024;12:1378979. doi:10.3389/fpubh.2024.1378979

8. Çınaroğlu M. A tale of resilience and faith: understanding grief through Islamic coping mechanisms. *2024*;9:169–186.
9. Fairfax A, Brehaut J, Colman I, Sikora L, Kazakova A, Chakraborty P. Association between coping strategies and quality of life among caregivers of children with chronic illness and/or disability: a systematic review. *2019*.
10. Fingerman KL, Zhou Z, Haley WE, Zarit SH. Young adult caregivers for older family members: setting a new research agenda. *Gerontologist*. *2025*;65(1).
11. Haryati O, Banon E, Rahmawati I. Kemandirian lansia dalam pemenuhan activity of daily living. *2022*; 129–139.
12. Heri L, Cicih M. Older persons in the era of demographic dividend. *J Keperawatan Indones*. *2023*;17(1). doi:10.14203/jki.v17i1.636.
13. Jafari-Koulaee A, Mohammadi E, Fox MT, Rasekhi A, Akha O. Predictors of basic and instrumental activities of daily living among older adults with multiple chronic conditions. *2024*.
14. Karmiyati D. The influence of Javanese cultural internalization on the happiness of the elderly. *Adv Soc Sci Educ Humanit Res*. *2018*;231:43–46.
15. Liu C, Lee C, Chang T, Liao J. Exploring the relationship between caregiver stress load and dementia patient behavior: a case study from Taiwan. *2020*.
16. Liu F, Shen Q, Huang M, Zhou H. Factors associated with caregiver burden among family caregivers of children with cerebral palsy: a systematic review. *BMJ Open*. *2023*;13:e065215. doi:10.1136/bmjopen-2022-065215.
17. Liu K, Qin Z, Qin Y, Li Y, Liu Q, Gao F, et al. Effects of Reiki therapy on quality of life: a meta-analysis of randomized controlled trials. *Syst Rev*. *2025*;14:281. doi:10.1186/s13643-025-02811-5.
18. Loo YX, Yan S, Low LL. Caregiver burden: prevalence, measurement scales, predictive factors and impact—an Asian perspective. *Singapore Med J*. *2022*;63(11):593–603. doi:10.11622/smedj.2021033.
19. Mamom J. Listening to caregivers' voices: the informal family caregiver burden of caring for chronically ill bedridden elderly patients. *2022*.
20. Marinho S, Batista IB, Guimarães A, Santos-Orlandi AA, Saidel MG, Oliveira FD, et al. Family relations in informal caregivers of older adults. *2022*.
21. Moon S, Oh E, Chung D, Hong GR. Changes in instrumental activities of daily living limitations and associated factors by gender in community-residing older adults: a longitudinal cohort study. *PLoS One*. *2024*;19:e0296796. doi:10.1371/journal.pone.0296796.
22. Nubli M, Awang W, Hasanah P. Caregiving burden of older people with functional deficits and associated factors among Malaysian family caregivers. *2024*;31(1):161–171.
23. Nurrohmi. Dukungan sosial keluarga terhadap lansia. *2020*;2(1):77–88.
24. Oktarina R, Agustiani S. Life of older adults in institutional care settings in Pangkalpinang.

- 2024;5:11039–11049.
25. Ping Y, Lim-Soh J, Østbye T, Azman SDOA, Ting Y, Malhotra R. Trajectories of burden or benefits of caregiving among informal caregivers of older adults: a systematic review. 2025.
 26. Rahayu DYS, Usman RD, Putri DP. Optimizing independence of older adults in daily living activities through empowerment. 2024;6.
 27. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*. 1980;20(6):649–655.
 28. Shrestha S, Arora S, Hunter A, Debesay J. The morality of care: female family caregivers' motivations for providing care to older migrants. *Qual Health Res*. 2024;34:1–15. doi:10.1177/10497323241280239.
 29. Syifa FASY, Surjaningrum ER. Narrative review: caregiving burden among sandwich generation women and psychological well-being. *Buletin Riset Psikologi Kesehatan Mental*. 2021.
 30. Tang B, Li Z, Hu S. Economic implications of health care burden for the elderly population. *Policy Polit Nurs Pract*. 2022;23(4). doi:10.1177/00469580221121511.
 31. Wang J. Caregiver burden and associated factors among informal caregivers of hospitalized elderly patients in China: a latent profile analysis. 2025.
 32. Zaalberg T, Barten DG, van Heugten CM, Klijsma P, Knarren L, Hiemstra Y, et al. Prevalence and risk factors of burden among caregivers of older emergency department patients. *Sci Rep*. 2023;13:31750. doi:10.1038/s41598-023-31750-1.
 33. Zhang Y, Gan J. Family resilience and social support as mediators of caregiver burden and capacity in stroke caregivers: a cross-sectional study. *Front Psychol*. 2024;15:1435867. doi:10.3389/fpsyg.2024.1435867.