



CHARACTERISTICS OF CAREGIVERS CARING FOR ELDERLY PEOPLE WITH DEMENTIA

Syapri Pardiansah^{1*}, Rika Sabri¹, Tasman²

¹School of Nursing, Universitas Andalas, Limau Manis, Pauh, Padang, Sumatera Barat 25175, Indonesia

²Politeknik Kesehatan Kementerian Kesehatan Padang, Jl. Raya Siteba, Surau Gadang, Nanggalo, Padang, Sumatera Barat 25146, Indonesia

*syapri92@gmail.com

ABSTRACT

Elderly individuals often experience physical, social, and psychosocial decline, leading to various health issues, including dementia. In Padang City, the number of dementia cases increased significantly, reaching 458 in 2022. Caregivers play a crucial role in caring for elderly people with dementia, despite facing significant physical and psychological burdens. Objective: This study aims to describe the characteristics of caregivers caring for elderly people with dementia in Padang City in 2023. Method: This descriptive observational study involved 122 caregivers as respondents. Data were collected through direct interviews and analyzed using univariate tests to observe the frequency distribution of each variable studied. The study was conducted from June 2023 to April 2024. Results: The study results showed that the most common age group of respondents (52.5%) was young adults ≤ 40 years old. The majority of caregivers had a basic/secondary education level (97%), and 20.5% had higher education. Regarding marital status, 18.9% were unmarried, 27.9% were divorced, and 54.1% were married. Conclusions: The characteristics of caregivers in Padang City indicate that age, education, marital status, and gender are important variables influencing the quality of care for elderly people with dementia. This study highlights the need for specific support for caregivers to enhance their skills and knowledge, as well as interventions to alleviate the physical and psychological burdens they experience.

Keywords: caregiver characteristics; caregiver; dementia; elderly

First Received 28 Juni 2024	Revised 30 Juni 2024	Accepted 20 July 2024
Final Proof Received 30 July 2024	Published 01 December 2024	
How to cite (in APA style) Pardiansah, S., Sabri, R., & Tasman, T. (2024). Characteristics of Caregivers Caring for Elderly People with Dementia. <i>Indonesian Journal of Global Health Research</i> , 6(6), 3857-3864. https://doi.org/10.37287/ijghr.v6i6.3968 .		

INTRODUCTION

Elderly individuals experience gradual physical, social, and psychosocial decline, leading to various health problems, including dementia. Dementia is the most common mental health issue among the elderly (Suratmi & Budi Rahardjo, 2023a). According to the (Simonetti & Oggi, 2023), the global number of dementia sufferers is projected to increase to 55 million by 2030, a 40% rise. In the Asia-Pacific region, the number of cases is expected to grow by 53%, from 48 million in 2019 to 74 million in 2050 (Nichols et al., 2022). In Indonesia, it is estimated that there will be 2 million people with dementia by 2030, increasing to 4.3 million by 2050, a 100% increase (Hogervorst et al., 2021). Similarly, it is reported that there were about 1.2 million people with dementia in Indonesia in 2016, with the number expected to rise to 2 million by 2030 and 4 million by 2050 (Jumiarti et al., 2023). Data from the Health Office of Padang City shows that there were 458 cases of elderly individuals with dementia in 2022 (Dinkes Kota Padang, 2022).

The increase in dementia cases leads to changes in physical abilities, daily activities, psychological aspects, social relationships, and quality of life. These changes are often not supported by the family's ability, due to the increased mobility of productive age workers and the shift from extended family structures to nuclear families. These family changes make it increasingly difficult to care for elderly people with dementia within the family, as they are often seen as burdensome (Halid et al., 2023). The loss of independence in the elderly, especially those with dementia, makes them dependent on caregivers for daily activities (Kim et al., 2009). Elderly individuals with dementia require strict attention and control to prevent harmful situations. Dementia impacts public health (high incidence, prevalence, mortality rates), healthcare costs, and social life. Many families experience stress in caring for the elderly, both physically and psychologically. Some families even confine elderly individuals at home for safety reasons, which can worsen the condition of those with dementia (Simonetti & Oggi, 2023).

This situation is influenced by strong societal values in Indonesia, where children are expected to care for their elderly parents as a form of filial piety (Rahayu & Rahmawati, 2019). Care for the elderly with dementia is mostly provided by family members (informal caregivers). Without caregivers, elderly individuals with dementia would have a poor quality of life and would require institutional care, impacting the family's financial condition. Most elderly individuals with dementia needing caregiver support are in the moderate dementia stage (61.8%) (Anang Fardhyan et al., 2018). Caregivers face significant burdens in the form of psychological stress, identified through verbal expressions like stress, crying, and guilt, and emotional changes in patients who often become angry and behave poorly. Physical burdens are visible through expressions and statements of tiredness, boredom, and fatigue (Elmore, 2014). Previous research on the experiences of families in caring for the elderly at home (Prabasari et al., 2017) showed that caregivers face internal burdens like physical fatigue and psychological stress such as anger.

Caregivers often struggle to separate their role as caregivers from their roles as spouses, children, friends, or other close relationships (Raissa Hamidah & Siagian, 2021). Some caregivers place unreasonable burdens on themselves, considering caregiving as their exclusive responsibility. They might neglect their own responsibilities and become overwhelmed as primary caregivers (Yustisia et al., 2022). Caregivers play a crucial role in caring for elderly individuals with dementia by providing social protection, helping connect them with needed resources, and fulfilling basic needs to enhance their well-being (Halid et al., 2023). The type of care provided by caregivers requires patience, as it is physically, emotionally, and family-life demanding. Caregivers must balance caregiving with other demands such as raising children, developing careers, and maintaining relationships (Hadi Widiastuti et al., 2019). This study aims to describe the characteristics of caregivers caring for elderly individuals with dementia in Padang City in 2023.

METHOD

This observational descriptive study involves a population of caregivers who care for elderly individuals with dementia in Padang City, with a sample size of 122 respondents. The study examines the caregivers' characteristics, including age, educational level, marital status, and gender, over a period from June 2023 to the end of April 2024. Data were collected through direct interviews, assisted by research assistants who had been previously briefed. The data were analyzed using univariate tests to determine the frequency distribution of each studied variable. Prior to data collection, an ethical feasibility test was conducted with the number: No.203.layaketik/KEPKFKEPUNAND. The population in this study includes all elderly

individuals with dementia in Kota Padang in 2022, totaling 176 individuals. The sample size was determined using quota sampling, calculated with the allocation formula: $n=176/(1+ 176 (0,05)^2)=176/1,44=122$. Therefore, the minimum required sample size is 122 respondents.

RESULTS

Table 1.
Respondent characteristics (n= 122)

Respondent characteristics	f	%
Age of Caregivers		
Young Adults (≤ 40 years old)	64	52.5
Middle-Aged Adults (> 40 years old)	58	47.5
Education		
Basic and Secondary (Elementary School, Middle School, High School)	97	79.5
Higher Education (College/University)	25	20.5
Gender		
Male	46	37.7
Female	76	62.3
Marital Status		
Single	23	18.9
Divorced	33	27.0
Married	66	54.1

The study results indicate that the majority of respondents (52.5%) are young adults aged ≤ 40 years. Most caregivers have a basic/secondary education level (97%), with 20.5% having higher education. Regarding marital status, 18.9% are unmarried, 27.9% are divorced, and 54.1% are married. The characteristics of caregivers in Padang City show that age, education, marital status, and gender are important variables affecting the quality of care for elderly individuals with dementia.

DISCUSSION

The research results indicate that a significant portion of the respondents are in their young adulthood (under 40 years old). Young adulthood is described as a productive age group, yet it includes those who frequently care for elderly individuals with dementia. This data aligns with the findings of (Ma et al., 2024) which show that the average age of informal caregivers for elderly individuals with dementia is 38.5 years. (Rahayu & Rahmawati, 2019) research provides a perspective on age, indicating that the average age of caregivers for elderly individuals with dementia is 30 years. Analysis of this data concludes that most informal caregivers for dementia patients are productive-aged individuals, suggesting that dementia care is not only carried out by the older generation but also by young adults. Individuals aged between 20 and 40 years fall within the young adult category (Renwick et al., 2023) Research analysis shows that people within this age range continue to have high enthusiasm for caring for elderly individuals with dementia. In young adulthood, individuals often begin to prioritize family needs and interests over their personal desires or rights, which explains why many caregivers are found within this age range (Sya'diyah et al., 2022). Additionally, young adult caregivers are considered sufficiently mature in life experience, wise in decision-making, capable of rational thinking, able to control emotions, and increasingly tolerant of others.

Young adulthood is a sufficiently mature age for making decisions regarding the care of elderly individuals with dementia. (Kartika et al., 2023) state that as people age, they become more emotionally mature, wiser in decision-making, capable of rational thinking, better at controlling emotions, and more tolerant of others. Young adulthood is an important stage

following adolescence, during which individuals are in the early stages of building family relationships. It is crucial for individuals to make appropriate decisions to ensure the continued well-being of their families in the future. Poor decision-making in young adulthood may be influenced by failures to achieve previous developmental stages. It is hoped that young adult caregivers will maximize their role in providing care for elderly individuals with dementia. Notoatmodjo (2014) states that education is crucial as it influences an individual's cognitive processes in enhancing knowledge, absorbing information, and gaining experience. The researcher believes that education significantly affects caregivers in their actions and behaviors. Thus, individuals at certain educational levels can solve problems based on their understanding and experience. Education level determines one's broader knowledge, abilities, and skills. When informal caregivers provide health care for elderly individuals with dementia, they can better understand the conditions of those they care for (Issalillah & Aisyah, 2022).

The researcher analyzed the education levels of caregivers providing care for elderly individuals with dementia. The data shows that most caregivers have low education levels, with the majority having education equivalent to high school or below. It is essential for individuals to receive adequate education to understand how to care for elderly individuals with dementia effectively (Dos Santos et al., 2020). Caregivers who have received good education will be more aware of the needs of the elderly, thus being more capable of meeting the care needs of elderly individuals with dementia (Sussams et al., 2020). The research results show that the majority of respondents (62.3%) are female. This finding aligns with a study conducted by (Nichols et al., 2022) which found that most caregivers for elderly patients are women, accounting for 60.1%. This can be attributed to cultural and societal norms in Indonesia, where women are typically responsible for household chores such as cooking, cleaning, and caring for family members, while men are expected to earn a living. Consequently, women more often take on the role of caring for sick family members (Liu et al., 2022)

Other studies support the notion that women are better suited than men to serve as informal caregivers for elderly individuals with caregiving needs, such as those with dementia (Hogervorst et al., 2021) 2019). The numerous demands of caregiving for individuals with dementia and their impact on caregivers highlight gender differences in caregiving roles (Irwadi et al., 2021) When caring for elderly individuals with dementia, women face greater burdens and challenges compared to their male counterparts. Women often have to manage family responsibilities, including those related to their spouse, children, and other household matters, before addressing caregiving duties. The demanding nature of caring for elderly individuals with dementia requires significant physical and mental effort, leading to greater physical and mental fatigue among women. Moreover, societal expectations that women should play a more significant role in caring for elderly parents with dementia add to their stress (Del Pilar Carrera-Gonzalez et al., 2022). As a result, female caregivers frequently experience physical, mental, and emotional exhaustion, commonly referred to as burnout.

The research results show that more than half of the respondents (54.2%) have a marital status of being married. This indicates that caregivers live with their spouses; however, after marriage, they may still reside in their parents' home or live independently elsewhere. This marital status may lead caregivers to feel responsible for others, prompting them to care for elderly individuals with dementia to honor and support them in their final stages of life. The analysis further reveals that nearly half (45.9%) of the respondents are unmarried (either single or divorced). This status can negatively impact caregivers providing care for elderly

individuals with dementia. This finding aligns with (Yani Qurrota A'yun, 2019) research, which discovered that unmarried caregivers experience several adverse effects on their lives. The status of being a caregiver within the family can significantly impact individuals during early adulthood, often causing family members to feel ashamed and avoid interacting with their community. Additionally, caregivers may struggle to share their feelings or discuss issues and burdens related to caring for elderly individuals with dementia with their close ones.

CONCLUSION

The study reveals that a significant portion of caregivers are young adults under 40, a group mature enough to manage caregiving responsibilities and often enthusiastic about balancing personal and family needs, as supported by research from (Suratmi & Budi Rahardjo, 2023). Over half of these caregivers have basic or secondary education levels, consistent with findings by (Li et al., 2013) highlighting how educational background influences cognitive abilities and problem-solving skills essential for caregiving. The study also notes that 54.2% of caregivers are married, indicating that living with a partner might affect their sense of responsibility, while 45.9% are unmarried or divorced, which could impact their social support systems. Additionally, 62.3% of caregivers are female, reflecting societal norms in Indonesia where women predominantly assume caregiving roles, leading to increased physical and emotional strain, as observed by (Hogervorst et al., 2021). This underscores the need for supportive measures to prevent burnout and enhance the well-being of female caregivers

REFERENCES

- Anang Fardhyan, M. A., M Natumnea, J. P., Bachruddin, A., Jauhari, Y., Putra, A. W., Kartini, J. R., & Barat Jakarta Selatan, C. (2018). Analisis Kebutuhan ODD dan Family Caregiver dalam Komunitas ALZI (Vol. 01, Issue 2).
- Del Pilar Carrera-Gonzalez, M., Canton-Habas, V., & Rich-Ruiz, M. (2022). Aging, depression and dementia: The inflammatory process. In *Advances in Clinical and Experimental Medicine* (Vol. 31, Issue 5, pp. 469–473). Wroclaw University of Medicine. <https://doi.org/10.17219/acem/149897>
- Dos Santos, C. de S., de Bessa, T. A., & Xavier, A. J. (2020). Factors associated with dementia in elderly. *Ciencia e Saude Coletiva*, 25(2), 603–611. <https://doi.org/10.1590/1413-81232020252.02042018>
- Elmore, D. L. (2014). The Impact of Caregiving on Physical and Mental Health: Implications for Research, Practice, Education, and Policy (pp. 15–31). https://doi.org/10.1007/978-1-4614-8791-3_2
- Hadi Widiastuti, R., Ika setyowati Setyowati, A., & Ekivalent Setianingrum, D. (2019). Beban Dan Koping Caregiver Lansia Demensia Di Panti Werdha.
- Halid, S., Hadi, I., & Utomo, H. (2023). Pengaruh Psikoedukasi Terhadap Kemampuan Keluarga Dalam Melakukan Perawatan Demensia Pada Lansia. *Journal Nursing Research Publication Media (NURSEPEDIA)*, 2(1), 20–28. <https://doi.org/10.55887/nrpm.v2i1.31>
- Hogervorst, E., Schröder-Butterfill, E., Handajani, Y. S., Kreager, P., & Rahardjo, T. B. W. (2021). Dementia and dependency vs. Proxy indicators of the active ageing index in indonesia. *International Journal of Environmental Research and Public Health*, 18(16). <https://doi.org/10.3390/ijerph18168235>

- Irwadi, I., Murni, A. W., & Oktarina, E. (2021). Karakteristik dan Perilaku Caregiver Lansia dengan Comorbid dalam Pencegahan Infeksi Covid-19. *Jurnal Ilmiah Universitas Batanghari Jambi*, 21(2), 780. <https://doi.org/10.33087/jiubj.v21i2.1541>
- Issalillah, F., & Aisyah, N. (2022). The Elderly and the Determinants of Stress. In *Journal of Social Science Studies* (Vol. 2, Issue 1).
- Kartika, A., Kumboyono, K., Kristianingrum, N. D., & Hayati, Y. S. (2023). Pelatihan Caregiver untuk Meningkatkan Kesiapan Perawatan Lansia Sakit Kronis di Rumah. *Jurnal ABDINUS: Jurnal Pengabdian Nusantara*, 7(2), 568–578. <https://doi.org/10.29407/ja.v7i2.19236>
- Kim, M. D., Hong, S. C., Lee, C. I., Kim, S. Y., Kang, I. O., & Lee, S. Y. (2009). Caregiver burden among caregivers of Koreans with dementia. *Gerontology*, 55(1), 106–113. <https://doi.org/10.1159/000176300>
- Li, R., Cooper, C., Austin, A., & Livingston, G. (2013). Do changes in coping style explain the effectiveness of interventions for psychological morbidity in family carers of people with dementia? A systematic review and meta-analysis. In *International Psychogeriatrics* (Vol. 25, Issue 2, pp. 204–214). <https://doi.org/10.1017/S1041610212001755>
- Liu, R., Chi, I., & Wu, S. (2022). Caregiving Burden Among Caregivers of People With Dementia Through the Lens of Intersectionality. *Gerontologist*, 62(5), 650–661. <https://doi.org/10.1093/geront/gnab146>
- Ma, L., Azizah, rifatul, Zainuri, I., & Ilmu Kesehatan, F. (2024). Pemberdayaan Caregiver dalam Meningkatkan Kesehatan Jiwa Lanjut Usia di Wilayah Kerja Puskesmas Mentikan.
- Nichols, E., Steinmetz, J. D., Vollset, S. E., Fukutaki, K., Chalek, J., Abd-Allah, F., Abdoli, A., Abualhasan, A., Abu-Gharbieh, E., Akram, T. T., Al Hamad, H., Alahdab, F., Alanezi, F. M., Alipour, V., Almustanyir, S., Amu, H., Ansari, I., Arabloo, J., Ashraf, T., ... Vos, T. (2022). Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *The Lancet Public Health*, 7(2), e105–e125. [https://doi.org/10.1016/S2468-2667\(21\)00249-8](https://doi.org/10.1016/S2468-2667(21)00249-8)
- Prabasari, N. A., Linda Juwita, P., Ayu, I., Fakultas, M., Universitas, K., Widya, K., Surabaya, M., Raya, J., & Selatan, K. (2017). Pengalaman Keluarga Dalam Merawat Lansia Di Rumah (Studi Fenomenologi) (Family Experience in Caring For Eldery At Home (Phenomenological Study)). In *Jurnal Ners LENTERA* (Vol. 5, Issue 1).
- Rahayu, S., & Rahmawati, T. (2019). Karakteristik Dan Kesiediaan Caregivers Keluarga Dari Pasien Dengan Penyakit Kronis Tentang Pembentukan Support Group. *Jurnal Ilmiah Keperawatan Altruistik*, 3(2).
- Raissa Hamidah, P., & Siagian, N. (2021). Pengalaman Caregiver Dalam Merawat Pasien Paliatif Di Panti Werdha Tulus Kasih.
- Renwick, L., Susanti, H., Brooks, H., Keliat, B. anna, Bradshaw, T., Bee, P., & Lovell, K. (2023). Culturally adapted family intervention for people with schizophrenia in

- Indonesia (FUSION): a development and feasibility study protocol. Pilot and Feasibility Studies, 9(1). <https://doi.org/10.1186/s40814-023-01280-8>
- Simonetti, C., & Oggi, P. (2023). Active ageing with proper, healthy and active lifestyles: healthy ageing in Europe Invecchiamento attivo con stili di vita corretti, sani e attivi: l'invecchiamento sano in Europa. *Pedagogia Oggi | XXI |*, 1, 280–286. <https://doi.org/10.7346/PO-012023-33>
- Suratmi, T., & Budi Rahardjo, T. W. (2023). Beban Kerja Caregiver Dalam Mendampingi Lansia Dengan Demensia di Sasana Tresna Werdha RIA Pembangunan Jakarta Tahun 2022. In *Jurnal Untuk Masyarakat Sehat (JUKMAS) e-ISSN (Vol. 7, Issue 1)*. <http://ejournal.urindo.ac.id/index.php/jukmas>
- Sussams, R., Schlotz, W., Clough, Z., Amin, J., Simpson, S., Abbott, A., Beardmore, R., Sharples, R., Raybould, R., Brookes, K., Morgan, K., Culliford, D., & Holmes, C. (2020). Psychological stress, cognitive decline and the development of dementia in amnesic mild cognitive impairment. *Scientific Reports*, 10(1). <https://doi.org/10.1038/s41598-020-60607-0>
- Sya'diyah, H., Nursalam, Mahmudah, & Efendi, F. (2022). Effectiveness of home care intervention on family ability to do caregiving at home and increase the independence among elderly with dementia. *Journal of Public Health Research*, 11(3). <https://doi.org/10.1177/22799036221115774>
- Yani Qurrota A'yun, D. (2019). Pengalaman Caregiver Informal dalam Merawat Lansia pada Masa Pandemi.
- Yustisia, N., Aprilatutini, T., Saleha, N., & Sari, N. (2022). Perbedaan Status Pekerjaan Dan Penyakit Lansia Dengan Dukungan Caregiver Dalam Pemenuhan Aktivitas Lansia. *Jurnal Keperawatan Muhammadiyah Bengkulu*, 10(2), 132–138. <https://doi.org/10.36085/jkmb.v10i2.3881>.

