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Original research article

The relationship between family burden, environment, and quality of life among caregivers of older adults with chronic diseases: a cross-sectional study

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Abstract
Aim: The number of older adults with chronic diseases is growing. When caring for and accompanying their family members, the quality of life (QoL) of elderly family caregivers is highly affected. The aim is to find the relationship between family burden, family environment, and QoL among caregivers of older adults with chronic diseases.
Methods: The study involved 409 caregivers in Samarinda (East Kalimantan), Makassar, and Gowa (South Sulawesi), Indonesia. It analyzed family burden, family environment, and QoL using descriptive, Spearman, Kruskal–Wallis, Mann–Whitney, and hierarchy regression analysis using SPSS version 21.
Results: Family burden was negatively associated with QoL physical domain (r = –0.05, p = 0.26), psychological domain (r = 0.05, p = 0.31), and social domain (r = –0.02, p = 0.55), Family burden was positively associated with QoL environmental domain (r = –0.09, p = 0.05). Family environment was positively associated with QoL physical domain (r = –0.24, p = 0.00), psychological domain (r = 0.39, p = 0.00), social domain (r = 0.30, p = 0.00), and environmental domain (r = 0.41, p = 0.00). Hierarchy regression analysis shows that family environment has a tremendous positive correlation on QoL physical domain (β = 0.21, p = 0.00), psychological domain (β = 0.31, p = 0.00), social domain (β = 0.23, p = 0.00), and environmental domain (β = 0.33, p = 0.00).
Conclusion: Family burden and family environment are crucial factors in the QoL of caregivers of older adults with chronic diseases. Family and public health nurses should develop interventions to relieve the burden and enhance family environments, ultimately improving caregiver's QoL.

Keywords: Chronic diseases; Elderly; Family burden; Family caregiver; Family environment; Quality of life

Introduction

The global elderly population is experiencing steady growth, with projections showing an annual increase. The reports show a 48% increase in people aged 60 and above. Indonesia is experiencing a notable trend, with a 10.6% increase in the proportion of individuals aged 65 and above. The total number of elderly households in Indonesia is 16,08 million, accounting for 24.5% of the overall population. The growing older population has significant implications for the elevated old-age dependency ratio. In 2015, there were 74 old dependents for every 100 working-age individuals, with the working-age population supporting the aging population. The elderly dependency ratio is 12.71, with a primary focus on family members or caregivers (BPS, 2021; United Nations, 2015). Based on the data, we can conclude that family caregivers must look after older adults, especially in the Indonesian context.

Elderly caregivers experience significant negative effects on their psychosocial well-being, particularly in terms of the burden placed on their family. Informal caregivers encounter varying levels of burden influenced by factors such as the characteristics of the person with dementia, the caregiver's gender, and their relationship with the individual affected by dementia. These factors impact daily activities and may contribute to problematic behaviors (Laporte Uribe et al., 2017). Providing informal care for individuals with dementia who reside in their own homes is a complex task, involving several facets: improved psychological well-being, caregiving experiences, decreased supervision requirements, and an enhanced QoL (Quality of Life). Male dementia patients with fewer symptoms also benefit from improved caregiving (Lethin et al., 2017). Family caregivers who experience feelings of loneliness are more inclined to provide care for their parents and have a higher likelihood of experiencing a moderate to severe burden (Bonin-Guillaume et al., 2022).

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Previous research has shown that the environment positively impacts older adults. The link between the environment near neighborhoods and the health of senior individuals, as evaluated within a 500-meter buffer area in Beijing, China, was higher than that observed in other places. This link was mediated by physical exercise and social interaction (Li et al., 2022). Older individuals in walkable areas with higher satisfaction with their neighborhood environment and recreational amenities engage in more prolonged leisure-time physical activity. However, neighborhood accessibility to recreational resources is quite limited. Satisfaction with recreational facilities modifies the relationship between objective accessibility and physical activity (Guo et al., 2021).

Family caregiver QoL has a relationship with family function, family environment, and psychosocial aspects. This study investigates the correlation between family functionality and older individuals' caregivers' QoL, based on four distinct components of QoL assessment (Rodríguez-Sánchez et al., 2011). The presence of chronic disease in an older adult caregiver and the constraint of limited living space were identified as factors that predicted the QoL. Additionally, a correlation was observed between the burden and QoL (Tulek et al., 2020). The QoL of senior diabetic patients may be impacted by the family caregiver's knowledge of diabetes and suitable supportive actions (Thongduang et al., 2022). Non-spouse carers of older adults scored the worst in terms of their sex lives, help from others, and personal relationships under the social relationships category QoL (Bierhals et al., 2019).

The results of previous qualitative exploration found that older adult families with chronic diseases experienced various obstacles during the COVID-19 pandemic, such as difficulties in obtaining health services, adherence to taking drugs, and communicating between elderly and family caregivers related to chronic diseases and COVID-19, and negative emotional responses in elderly family members. Therefore, the purpose of this study is to examine psychosocial problems and the family burden and family environment associated with QoL in family caregivers of older adults with chronic diseases. The urgency of this study was due to the lack of research into the psychosocial and family environment of caregivers who care for older adults with chronic disease issues in Indonesia.

Materials and methods

Research design

The research employed a descriptive quantitative cross-sectional study design. The research protocol received approval from the Health Research Ethics Commission of the Faculty of Medicine, Mulawarman University, with reference number 99/KEPK-FK/VII/2022. The study's objectives and procedures were communicated to participants, who can withdraw from the research process. All participants in the study willingly took part and signed the informed consent.

Setting and participants

The participants consisted of carers of older individuals with chronic conditions residing in Samarinda City, located in the East Kalimantan Province, as well as Makassar City and Gowa Regency, both situated in the South Sulawesi Province. The inclusion criteria for this study encompass the following: (1) Individuals between the ages of 18 and 60; (2) Voluntary participation as a respondent in the study; (3) The respondent is an elderly family member afflicted with a chronic illness; (4) The requirement that elderly family members have experienced chronic sickness for a minimum duration of 3 months. The study's exclusion criteria encompassed those who exhibited psychological conditions, including significant depression, post-traumatic stress disorder, and sleeplessness. The present investigation encompassed a set of eight potential variables: age, gender, education level, employment position, income, diseases experienced by the aged, duration of chronic disease affliction, and relationship status with the old. The sampling approach employed in this investigation was purposive sampling. The data-collecting process was conducted utilizing the consecutive sampling approach. The data-collection process involved examining the roster of old individuals afflicted with chronic illnesses at the public health center and elderly community health posts. The researchers provided information and ascertained whether senior households met the research requirements for selection as research participants. A total of 409 family caregivers (older individuals) participated in the survey, and there were no instances of respondent attrition.

Measurement and data collection

Sociodemographics included age, sex, education level, employment status, income, the disease suffered by the elderly person and its duration, and relationship status. The assessment of family burden used the Zarit Burden Interview (ZBI), which consists of 22 questions. The instrument was on a Likert scale ranging from 0 (never) to 4 (Almost always) (Seng et al., 2010). The family environment assessment used a family environment instrument with 30 questions. The instrument was on a Likert scale ranging from 1 (low suitability) to 7 (high suitability) (Sunarti, 2021). The assessment of QoL used the WHOQOL-BREF questionnaire, which has 26 questions. The respondents rated their experiences on a Likert scale ranging from 1 (very poor) to 5 (very good) and 1 (excessive amount) to 5 (not at all).

Data analysis

The bivariate analysis examined the association between family burden, family environment, and QoL using the Spearman correlation test. This test was used in the bivariate analysis because all of the variables were numeric categories, and all of the data distributions were abnormal. The first step of the multivariate analysis was to asses demographic data and QoL variables using various bivariate statistical tests, including Kruskal–Wallis (comparative numeric and categoric variables with more than two categories, abnormal data distribution), Mann–Whitney (comparative numeric and categoric variables with two categories, abnormal data distribution), and Spearman (correlation numeric variables with abnormal data distribution). The next step of the multivariate analysis used regression hierarchy analysis, which employs multiple linear regression. All assumptions in this study were verified prior to completing the analysis. Then, a hierarchical analysis examined the relationships between demographic factors, family burden, family environment, and QoL across four domains: physical, psychological, social, and environmental. The data underwent analysis using SPSS version 21. The analysis tests employed a two-tailed approach with a significance level of $p < 0.05$.

Results

Respondent characteristic

The characteristics of elderly caregivers with chronic diseases are shown in Table 1:

Table 1. Respondent characteristics data (*n* = 409)

	n (%) or M ± SD
Age	38.24 ± 11.22
Late teens (18–25 years)	57 (13.9)
Early adult (26–35 years)	121 (29.6)
Late adult (36–45 years old)	131 (32.0)
Early elderly (46–55 years)	73 (17.8)
Late elderly (56–65 years old)	22 (5.4)
Seniors (over 65 years old)	5 (1.2)
Sex	1.77 ± 0.42
Male	94 (23.0)
Female	315 (77.0)
Education level	3.59 ± 1.00
Illiterate	16 (3.9)
Elementary school	44 (10.8)
Junior high school	93 (22.7)
Senior high school	198 (48.4)
Bachelor	55 (13.4)
Master	3 (0.7)
Employment status	1.54 ± 0.49
Unemployed	188 (46.0)
Employed	221 (54.0)
Income	1.23 ± 0.42
Below minimum wage	313 (76.5)
Above minimum wage	96 (23.5)
Disease suffered by the elderly individual	2.90 ± 2.28
Hypertension	188 (46.0)
Hyperuricemia	55 (13.4)
Diabetes mellitus	43 (10.5)
Hypercholesterolemia	2 (0.5)
Stroke	36 (8.8)
Other	25 (6.1)
Comorbid	60 (14.7)
Period of time disease has been present	2.53 ± 0.72
6 months	56 (13.7)
7–12 months	82 (20.0)
Over 12 months	271 (66.3)
Relationship status with the elderly person	1.57 ± 1.17
Biological child	198 (74.6)
Daughter-in-law	5 (11.7)
Husband	11 (2.9)
Wife	15 (3.7)
Other	24 (7.1)
Family burden	1.27 ± 0.56
Little/no	199 (78.7)
Mild	42 (16.6)
Medium	10 (4)
Heavy	2 (0.8)
Family environment	3.02 ± 0.29
Bad	1 (0.4)
Low	6 (2.4)
Medium	234 (92.5)
High	12 (4.7)
Physical QoL	3.20 ± 0.57
Bad	19 (7.5)
Low	166 (65.6)
Medium	66 (26.1)
High	2 (0.8)
Psychological QoL	3.33 ± 0.55
Bad	10 (4.0)
Low	150 (59.3)
Medium	92 (36.4)
High	1 (0.4)
Social relationship QoL	3.42 ± 0.56
Medium	157 (62.1)
High	86 (34.0)
Very high	10 (4.0)
Environmental QoL	3.45 ± 0.58
Bad	4 (1.6)
Low	138 (54.5)
Medium	104 (41.1)
High	7 (2.8)

The data in the table indicates a significant variation in the ages of caregivers, with a predominant presence in the age categories of early and late adulthood. The prevailing gender group comprises women who care for individuals afflicted with enduring health conditions in advanced age. The predominant educational attainment among the participants study is senior high school and junior high school. The employment status of carers assisting elderly families with chronic diseases showed a relatively equal distribution between those employed and those not. The study participants' income was below the minimum wage established for the region. Hypertension is the most prevalent ailment among the aged population in this research. It is worth noting that the duration of chronic diseases among the senior population tends to exceed 12 months. Biological children predominantly influence the primary determinant of the relationship status.

Correlation analysis between family burden, family environment, and quality of life

Analysis of the correlation between family burden, family environment, and QoL is shown in Table 2.

The variable correlation coefficient examines the relationship between family burden, family environment, and QoL across various physical, psychological, social, and environmental domains. Family burden was negatively correlated with QoL in the physical, psychological, and social domains, while family burden was positively correlated with QoL in the environmental domain. Family environment was positively correlated with QoL in the physical, psychological, social, and environmental domains.

Multivariate analysis between family burden, family environment, and QoL of elderly families with chronic diseases

Analysis of the multivariate between characteristics, family burden, family environment, and physical domain QoL is shown in Table 3.

The regression analysis hierarchy between characteristics, family burden, family environment, and physical, psychological, social relationship, and environmental domain QoL in older adult family caregivers with chronic diseases is shown in Table 3. The regression model for the QoL physical domain

Table 2. The correlation coefficient of family burden, family environment, and QoL variables (physical, psychological, social, and environmental domains) in older adult family caregivers with chronic illness (*n* = 409)

Variable	QoL physical domain	QoL psychological domain	QoL social domain	QoL environmental domain
	r (p)	*r (p)*	*r (p)*	*r (p)*
Family burden	–0.055 (0.267)	0.050 (0.318)	–0.029 (0.556)	–0.097 (0.050)
Family environment	0.244 (0.000)	0.393 (0.000)	0.301 (0.000)	0.412 (0.000)

Table 3. Regression analysis hierarchy between characteristics, family burden, family environment, and QoL of physical, psychological, social relationship and environmental domain in elderly family caregivers with chronic disease (*n* = 409)

Variables	B	SE	β	*P*-value[a]
QoL physical domain				
Diseases suffered by the elderly person	–0.31	0.20	–0.08	0.12
Long-suffering chronic diseases	0.18	0.64	0.14	0.77
Relationship status	–1.45	0.39	–0.17	0.00
Family burden	–0.06	0.04	–0.07	0.13
Family environment	0.11	0.02	0.21	0.00
		R^2 = 0.086; Adjusted R^2 = 0.081; F = 19.01; p = 0.00		
QoL psychological domain				
Gender	2.51	1.44	0.08	0.08
Education level	1.86	0.59	0.14	0.00
Income level	2.63	1.44	0.08	0.07
Long-term chronic diseases	–1.73	0.82	–0.09	0.03
Relationship status	–0.67	0.50	–0.06	0.18
Family burden	0.05	0.05	0.03	0.39
Family environment	0.21	0.03	0.32	0.00
		R^2 = 0.136; Adjusted R^2 = 0.129; F = 21.19; p = 0.00		
QoL social relationship domain				
Age	0.13	0.06	0.10	0.03
Education level	2.14	0.68	0.15	0.00
Employment status	–0.22	1.48	–0.00	0.87
Income level	2.73	1.64	0.11	0.09
Diseases suffered by elderly	0.42	0.29	0.06	0.15
Long-term chronic diseases	2.88	0.92	0.14	0.00
Relationship status	–0.88	0.56	–0.07	0.11
Family burden	–0.05	0.06	–0.03	0.42
Family environment	0.17	0.03	0.23	0.00
		R^2 = 0.126; Adjusted R^2 = 0.115; F = 11.63; p = 0.00		
QoL environmental domain				
Age	0.04	0.05	0.03	0.43
Gender	3.49	1.28	0.12	0.00
Education level	2.14	0.53	0.18	0.00
Income level	2.61	1.29	0.09	0.04
Relationship status	–0.79	0.45	–0.07	0.08
Family burden	–0.12	0.05	–0.11	0.01
Family environment	0.20	0.02	0.33	0.00
		R^2 = 0.204; Adjusted R^2 = 0.194; F = 20.62; p = 0.00		

Note: [a] Linear regression model.

was the relationship status and family environment. The coefficient of determination (*R* square) shows 0.086, which means the regression model can account for 8.6% of the variation in the dependent variable of QoL of the physical domain. A *p*-value of 0.00 indicates a statistically significant relationship between the variable and the QoL measure in the physical domain. Family environment is the factor that most significantly influences the physical domain's QoL (β = 0.21). The regression models were then obtained in psychological QoL: education level, length of suffering from chronic diseases, and family environment. The coefficient of determination (*R* square) shows 0.136, which means the regression model can explain 13.6% variation in the dependent variable of QoL in the psychological domain. A *p*-value of 0.00 indicates a statistically significant relationship between the predictor variable and the psychological domain QoL variable. The family environment is the variable that most significantly influences the psychological domain's QoL (β = 0.17). The regression model for the social relationship QoL domain was age, education level, suffering from chronic diseases for a long time, family burden, and family resilience. The coefficient of determination (*R* square) shows 0.126, which means the regression model can explain 12.6% variation in the dependent variable of QoL of the social domain. A *p*-value of 0.00 indicates a statistically

significant relationship between the predictor variable and the social domain QoL variable. The family environment is the variable that most significantly influences the QoL in the social domain (β = 0.29). For QoL of the environmental domain, the regression model was sex, education level, relationship status with the elderly, family burden, and family environment. The coefficient of determination (*R* square) shows 0.204, meaning the regression model can account for 20.4% variation in the dependent variable of QoL of the environmental domain. A *p*-value of 0.00 indicates the variable possesses a statistically significant predictive ability for the QoL variable within the environmental domain. The variable that has the most significant influence on the QoL of the environmental domain is the family environment (β = 0.33).

Discussion

Our research result shows a negative correlation between family burden and QoL in the physical, psychological, and social domains. Most of the respondents have little/no burden (78%), which means that Indonesian older adult family caregivers felt unburdened. In addition, they were proud and responsible for looking after and assisting the elderly with chronic diseases. Previous studies have shown that Indonesian elderly family caregivers are the main support system for looking after and assisting the elderly. This caregiving role aligns closely with the cultural values surrounding elderly care in Indonesia (Riasmini et al., 2013). The Indonesian elderly prefer trusted family members as caregivers, including children, grandchildren, and daughters with a respectable income (Gondodiputro et al., 2019). The act of caring for elderly individuals with dementia holds significant cultural meaning for Indonesian family caregivers, such as notions of familial obligation, filial piety, and the anticipation of divine reward and blessings from God (Widyastuti et al., 2023). Family caregivers of elderly individuals with Parkinson's disease express feelings of gratitude and a willingness to care for their parents, viewing their role as a form of reciprocation for the care they received in the past (Dekawaty et al., 2019). In conclusion, family caregivers regard caregiving as a fundamental familial responsibility, which serves to reduce their burden when caring for elderly individuals with chronic diseases.

On the other hand, a positive correlation was found between family burden and QoL in the environmental domain. A favorable correlation was found between family environment and QoL across all domains, including the physical, psychological, social relationship, and environmental aspects. Our results are similar to previous studies, which show that caregivers of older adults face increased burden, poorer QoL, and financial strain (Hellis and Mukaetova-Ladinska, 2023). A significant correlation was found between the burden of care and family functioning score, and it will impact the QoL of caregivers of older adults with heart failure (Ghasemi et al., 2020). Subjective caregiver burden significantly impacts China's physical and mental QoL (Yang et al., 2012). The study found that caregivers of older adults with multiple chronic diseases, along with below-average physical and mental health, should prioritize their well-being. This is crucial as their health-related QoL (HRQOL) was found to be low (Duggleby et al., 2016).

The regression model reveals that relationship status and family environment significantly impact the QoL in the physical domain. Education level, chronic disease duration, and family environment positively impact QoL in the psychological domain. Age, education level, chronic disease, family burden, and resilience significantly impact the social relationship domain QoL. Variables of QoL in the environmental domain were significantly impacted by sex, education level, relationship status, family burden, and family environment. Previous studies found that many factors related to QoL, such as the environment and social ties, were strongly associated with the availability and adequacy of services and the competence of physicians among informal caregivers of individuals with dementia (Koukouli et al., 2022). The QoL among Thai family carers of older individuals with dementia is affected by factors such as high perception of social support and intense experiences of close relationships (Pothiban et al., 2020). Family caregivers' QoL with dementia is influenced by external factors, including the available support, caregiving responsibilities, family and social networks, and the presence of role conflict (Daley et al., 2019). Non-spouse caregivers of older adults and family caregivers of stroke survivors tend to report lower scores in the area of social relationship QoL (Bierhals et al., 2019). Caregivers of older adults with cancer have lower QoL due to poor mental health, social support, and performance status (Hsu et al., 2019). Caregivers perceive a connection between their QoL and the quality of care for loved ones with dementia. As cognitive functioning declines, caregivers may struggle to cope with increasing demands, impacting their long-term health and well-being (Hazzan et al., 2022).

The family environment significantly influences the physical domain QoL (β = 0.21), psychological domain QoL (β = 0.17), social relationship domain QoL (β = 0.29), and environmental QoL (β = 0.33) with a *p*-value of 0.00 indicating a significant impact. Our research results are similar to previous studies, showing that barrier-free home environments for disabled older adults reduce caregiver stress, improve family functions, and enhance QoL (Yang et al., 2022). Engaging dementia patients and caregivers in dyadic intervention through comfortable physical environments is an effective strategy (Cheung et al., 2021). Social support was seen to have a notable and favorable impact on institutional contentment. Moreover, the quality of social care services provided by social organizations partially mediates the connection between social support and anxiety among elderly individuals (Ding et al., 2023). Indonesian elderly with chronic diseases use social interaction coping mechanisms, such as regular interaction with family, peers, and neighbors (Bahtiar et al., 2022). Innovative living arrangements include small-scale living, greenhouse models, shared housing, green care farms, dementia villages, group homes, intergenerational living, and others. These arrangements emphasize autonomy, small-scale living, community involvement, nature, work-task integration, and family involvement (Brouwers et al., 2023). An improved street accessibility is positively associated with leisure-time walking behavior among older adults residing in high-density urban areas, leading to increased physical activity in China (Guo et al., 2021; Han et al., 2022; He et al., 2020; Wu et al., 2019; Yu et al., 2020). Additionally, older adults tend to opt for community home-based care over nursing homes because of the perceived unwelcoming atmosphere in such facilities (Ma et al., 2019).

Limitations

Firstly, our participants were family caregivers of older adults with chronic disease residing in East Kalimantan and South Sulawesi Province, Indonesia, which is focused on the middle region of Indonesia and in urban settings, so our findings may not be generalized to rural settings. Secondly, the respondents are mainly hypertension sufferers; the spread needs to be more

varied and equal when it comes to disease type. Thirdly, the sample size must be larger to be strong enough to generalize the results.

Conclusion

We found a positive correlation between family burden and the QoL of caregivers in aspects of the environmental domain. Family environment correlates with all domains of QoL. The family environment was a variable that affected the physical, psychological, social relationship, and environmental domains of the caregiver's QoL. The family environment needs special attention from health workers when providing and designing interventions for elderly families. Our recommendations include in-depth research on detailed aspects of the family environment that impact the QoL of caregivers and older adults with chronic diseases. Further research should also assess the effects of the family environment on the quality of care for older adults living in the community, especially in rural settings. When developing programs for family caregivers of older adults, community health nurses should consider the family environment.

Authors' contribution

BB, RR: Conceptualization, design of research, data collection, and data analysis. *BB, NF:* Analysis of results and drafting the manuscript. *BB, RR, NF:* Final checking and submission of the article.

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Ethical aspects and conflict of interest

The authors declare that there has been no conflict of interest during the research, authorship, and publication process.

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