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Caregivers of Elderly with Moderate to Total Dependence in Activities of Daily Living in Yogyakarta Indonesia: Correlation of Burden and Quality of Life

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Abstract

Background: Aging is accompanied by a functional decline leading to the loss of independence in conducting activities of daily living. The dependence of the elderly can cause burden that affects the quality of life of caregivers. This study aimed to assess the correlation between the burden and quality of life of caregivers looking after moderately to totally dependent elderly.

Methods: This research is a cross-sectional study that used Zarit Burden Interview to assess caregiver burden and World Health Organization Quality of Life to measure the quality of life of people caring for elderly with moderate to total dependence based on the scores in Activities of Daily Living and Instrumental Activities of Daily Living questionnaires. The data were analyzed using Spearman's rank correlation test.

Results: A total of 30 caregivers participated in this study. Significant negative correlations were observed between the burden and quality of life of caregivers of elderly with moderate to total dependence in all four domains: physical ($p = 0.001$), psychological ($p < 0.001$), social relationships ($p = 0.028$), and environmental ($p < 0.001$).

Conclusions: The findings imply that the burden of caring for the elderly with moderate to total dependence may affect the caregivers' burden and quality of life in all domains.

Keywords: burden, caregiver, elderly, quality of life

INTRODUCTION

Aging is accompanied by many organ and system changes associated with functional decline. These changes vary individually. Some elderly exhibit a slow decline and remain independent until the end of life, and others experience a more advanced decline that leads to the loss of independence in daily activities. The latter ones will be dependent on caregivers.¹⁻³ Indonesia has societal norms that require family members to take care of the elderly.⁴ In addition, the lack of alternatives due to inadequate health services prompts families to assume the main responsibility of elderly care.⁴

Caregiver is a general term referring to anyone who provides care for a dependent person to help their daily life activities.⁵ As the elderly age, their dependence increases, causing an increase in the caregivers' burden. Caregiver burden is defined as a multidimensional negative response observed whilst undertaking the role

of primary caregiver.⁶ It affects the caregivers' quality of life.⁷⁻¹⁰

A number of research have been conducted on the correlation between the burden and quality of life of caregivers taking care of elderly.¹¹⁻¹⁴ However, the number of studies on the burden and quality of life of caregivers of elderly with moderate to total dependence is still limited.¹⁵ The study aimed to analyze the correlation between the burden and quality of life of caregivers who care for the elderly with moderate to total dependence in Yogyakarta, Indonesia. The research on the relationship between family caregivers' burden and quality of life was previously conducted in India in 2016.¹² Samples in the study were obtained by purposive sampling by selecting caregivers who care for the elderly diagnosed with Alzheimer's dementia; the caregiver specifically must have cared for and lived with the elderly for more than 1 year and must not have suffered from a chronic disease in the last 1 year.¹²

Naing *et al.* conducted similar research on caregiver burden from caring for the dependent elderly in Myanmar; the participants involved were caregivers aged 18–59 years old and who cared for dependent elderly in the least 6 months.¹⁵ Meanwhile, in this research, the caregivers were not required to be <60 years. Thus, old

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caregivers were not excluded. This study aimed to assess the correlation between the burden and quality of life of caregivers looking after moderately to totally dependent elderly. Data were collected from the caregivers of elderly living in Yogyakarta Special Province because this location has the highest percentage of elderly population (14.5%) in Indonesia compared with other provinces.¹⁶ The growing population of elderly will increase the demand for caregivers, especially family as informal caregivers. This condition may lead to the increased burden borne by productive people.¹⁶ Observing the data, the caregivers' quality of life must be considered as an important issue in Indonesia. A part of the result of this study was presented at the International Conference on Public Health in 2020.¹⁷ This study will provide data for policy makers to develop programs to support caregivers.

METHODS

Ethical approval

This research was approved by the Research Ethics Committee of the Faculty of Medicine, Duta Wacana Christian University.

Study design

This cross-sectional research was an analytic observational study and conducted from December 2019 to January 2020. Data were collected by home visits to the respondents. The study participants were informal caregivers of elderly with moderate to total dependence based on the Activities of Daily Living (ADL) score for more than six months. No age limit was applied for the caregivers. However, caregivers aged 60 years or over were screened for unimpaired cognitive function as indicated by their Mini-Mental State Exam (MMSE) score (>23). The interview of the caregivers was conducted in private to avoid bias if the elderly they took care of was present during the data collection.

Study procedure

Data were collected in two phases. In the first phase, a screening was conducted to identify elderly (aged \geq 60 years old) with moderate to total dependence. The data of elderly were collected from health volunteers in Kampung Pakuncen, Yogyakarta Municipality, who also provided information of the elderly whom they considered as dependent. The researchers paid home visits to the elderly to assess their level of independence, which was measured using Instrumental Activities of Daily Living (IADL) and ADL questionnaires. ADL assesses the independence in daily activities, including personal hygiene or dressing, toileting, grooming, eating or transferring, and ambulating. The ADL scores range from 0 to 20. A score of 0–4 is classified as total dependency, 5–8 as severe dependency, 9–11 as moderate dependency, 12–19 as mild dependency, and 20 as independent. The inclusion criterion for this study was a score < 12. The

independence in more complex activities in daily life was measured using the IADL.¹⁸ IADL covers eight domains, namely, the capability to use the telephone, do housework, wash clothes, shop, prepare food, use transportation, manage finances, and prepare and take medication. The IADL score ranges from 0 to 16. A score of 9–16 is considered as independent, 1–8 as dependent, and 0 as totally dependent. The inclusion criterion for this study was a score < 9. The IADL is more sensitive to assessing the presence of early cognitive decline, and the ADL is more sensitive to determining a person's physical function.¹⁹

In the second phase, data were collected from the caregivers of the elderly identified in the first phase. In this phase, the caregivers had to meet the inclusion criteria, such as being able to communicate well. If the caregiver(s) were aged \geq 60 years old, they had to undergo MMSE assessment as a cognitive screening tool. The Zarit Burden Interview (ZBI) was used to measure the caregiver burden in caring for the elderly. It is a 22-item questionnaire using a 5-point Likert scale, where 0 means "never," and 4 means "almost always."²⁰ ZBI measures the impact of care on the social, physical, emotional, and financial well-being of individuals.²⁰ The items are added up with a total score ranging from 0 to 88, and a high score implies a high burden experienced by a caregiver. The validity and reliability tests of the Indonesian version of ZBI were implemented by Rahmat LAE in 2009, resulting in 75.7% sensibility and 83.6% spesifity.²¹

The World Health Organization Quality of Life (WHOQOL-BREF) was used to assess the caregivers' quality of life; it consists of 26 items and has 4 domains consisting of physical health, psychological, social relationships, and environmental domains.²² This Indonesian version instrument has good discriminant, content, and retest validity.²² The domain scores were scaled in the positive direction (high scores indicate high quality of life). The scores were transformed on a scale from 0 to 100.²²

Sampling method

Participants were selected by consecutive sampling. Based on previous research, the percentage of the elderly in Yogyakarta City with moderate to severe dependence is 2.4%.²³ Calculating 2.4% from the 1,332 total elderly in Kampung Pakuncen, Yogyakarta Municipality, 32 samples were generated; however, in the end, only 30 people were selected due to the inclusion and exclusion criteria of the study.²⁴

Data analysis

The correlation between caregiver burden (ZBI) and quality of life (WHOQOL-BREF) was analyzed using Spearman's rank correlation test. Confounding factors were included in the test and comprised the age of dependent elderly, age of caregivers, education of caregivers (two groups: no schooling to primary school,

high school, and university), marital status of caregivers (two groups: married and not married), relationship between elderly and caregivers (four groups: spouse/siblings, children or children-in-law, grandchildren, and neighbor), duration of caregiving, and the number of hours of caregiving per day. The results were significant if $p < 0.05$.²⁵

RESULTS

Initially, 45 elderlies were referred by the health volunteers. After the assessment, 30 elderlies met the inclusion criteria of having moderate to total dependence. The elderlies were aged between 60–90 years old, with ADL scores in the range of 0–11 and IADL scores of 0–8. Then, the data of caregivers of the 30 elderlies were collected. Table 1 shows the demographic data of the caregivers. Table 2 shows the age, the correlation analysis between the burden, which was measured using ZBI, and the quality of life of the caregivers, which was assessed using WHOQOL-BREF, in this study was carried out with the Spearman's rank correlation test. Table 3 presents the results of the statistical analysis.

All seven confounding factors (age of dependent elderly, age of caregivers, education of caregivers with two groups (no schooling to primary school, high school, and university), marital status of caregivers (married and not married), relationship between elderly and caregivers (spouse/siblings, children or children-in-law, grandchildren, and neighbors), duration of caregiving, and the number of hours of caregiving per day) were included in the statistical analysis and showed significant correlations between the caregivers' burden and all four domains of the quality of life: physical ($p = 0.001$), psychological ($p < 0.001$), social relationships ($p = 0.028$), and environmental ($p < 0.001$).

DISCUSSION

Thirty caregivers of elderly with moderate to total dependence were assessed for their burden and quality of life. Studies have reported varied ZBI scores, implying the wide range of caregiver burden. The burden of the caregivers in this study was lower or higher than those in reported other research.^{11,12,26,27} These variations may be related to the caregivers' age, education, financial situation, and relation to the person being cared for.²⁸

The quality of life of caregivers also varies. The mean quality of life of caregivers of elderly with moderate to total dependence in this study was higher in one or some domains and lower in other domains compared with the values reported by other researchers.^{2,5,27,29} The quality of life is affected by many factors, including culture.^{30–32} A study that investigated the quality of life of 1,056 Indonesians aged 17–75 years using WHOQOL-BREF reported values that were higher in all four domains than

TABLE 1. Demographic data of caregivers (N = 30)

Variable	N (%)
Gender	
Female	24 (80.0)
Male	6 (20.0)
Educational status	
Uneducated	2 (6.7)
Primary school	4 (13.3)
Senior high school	19 (63.3)
Diploma (Associate degree)	1 (3.3)
University (Bachelor's degree)	4 (13.3)
Occupational status	
Unemployed	13 (43.3)
Entrepreneur	10 (33.3)
Private employee	2 (6.7)
Laborer	1 (3.3)
Other occupations	4 (13.3)
Marital status	
Married	21 (60.0)
Not married (single/widowed/divorced)	9 (40.0)
Relation to care recipient	
First generation (wife/husband/sibling)	10 (33.3)
Second generation (children/adopted children/son in law/daughter in law)	16 (53.3)
Third generation (granddaughter/grandson)	2 (6.7)
Neighbor	2 (6.7)
Duration of Caregiving	
6 months to 3 years	11 (36.7)
4–6 years	13 (43.3)
7–9 years	3 (10.0)
10–12 years	2 (6.7)
16–18 years	1 (3.3)
Time frequency of caregiving	
≤ 6 hours	4 (13.3)
7–12 hours	3 (10.0)
13–18 hours	1 (3.3)
19–24 hours	22 (73.3)

TABLE 2. Age, burden, and quality of life of caregivers

Variable	Mean ± SD
Age	49.00 ± 12.28
ZBI Scores	34.27 ± 18.94
WHOQOL-BREF	
Physical Health Domain	63.30 ± 12.83
Psychological Domain	58.17 ± 12.31
Social Relationships Domain	59.77 ± 9.03
Environmental Domain	51.90 ± 9.99

TABLE 3. Correlation between the ZBI and WHOQOL-BREF Caregiver

WHOQOL-BREF	r	p
Physical	-0.659	0.001**
Psychological	-0.730	<0.001**
Social relationships	-0.459	0.028*
Environmental	-0.680	<0.001**

*indicates $p < 0.05$; ** indicates $p < 0.01$

those found in this study.³³ Thus, the quality of life of the caregivers of elderly with moderate to total dependence was lower than that of average Indonesians in all four domains: physical, psychological, social, and environmental. This study revealed a negative correlation between the burden and all four domains of the quality of life of moderately to totally dependent elderly caregivers. The higher the burden of caregivers, the lower the quality of life, and vice versa. The caregiver burden has subjective and objective dimensions. Caregivers experience stress and anxiety as a result of their own situation and the feeling of being manipulated by the care recipient. On the other hand, objective distress refers to the interference and changes in the caregiver's life habits and household caused by care work.³⁴

A significant correlation was observed between the burden and physical domain of caregivers. The burden experienced by caregivers triggers stress.³⁵ When the body experiences stress, the body activates the hypothalamic-pituitary-adrenal axis and the sympathetic adrenergic nervous system. The exposure to stressful stimuli stimulates the pituitary gland to release adrenocorticotropic hormone (ACTH). ACTH triggers the adrenal cortex to release glucocorticoids (cortisol). The simultaneous release of epinephrine (adrenaline) from the adrenal medulla and norepinephrine from the sympathetic nerves activates the sympathetic nervous system. The release of molecules during a stress response affects profoundly the function of most cells and organs throughout the body, including the brain, respiratory system, heart, liver, digestive tract, muscles, skin, and immune system, which deteriorates the caregiver's physical condition.²⁹ The caregiver burden with physical tension while caring for a dependent individual (low ADL score), such as bathing, nursing, and other personal care activities, will increase the occurrence risk of physical health problems. Caregiver burden leads to the increased search for health care.³⁵

A strong correlation was also observed between the caregivers' burden and the quality of life psychological domain. Caregivers are prone to developing depression and anxiety.^{36,37} A study revealed the positive correlation of care burden with anxiety and depression.³⁷ This study revealed a significant correlation between burden and social relationship in the quality of life of caregivers. A total of 22 caregivers spent 19–24 hours per day to care for dependent elderly, leaving very limited time for themselves. The long duration of for caring adversely affects the caregivers' social life, and this change in social interaction aggravates over time.³⁸ Most caregivers in this study were female, which probably explained the lower quality of life in the psychological domain, as reported by Mathias *et al.*, who showed that women typically had greater burden than men in regard to caregiving and consistently described more somatic symptoms linked to caregiving.³⁹ Previous studies

indicated that although both genders are strongly expected to support their elderly parent, task divisions tend to be gender based. Women are more likely to provide direct daily care, as opposed to sons who are more likely to play indirect organizational roles, including monetary support. Nevertheless, changes have been observed in the attitudes of male children, who have started to think that caregiving is also integral to the process of redefinition of gender roles. Similar to breadwinning, they saw that family caregiving should be considered to be a less gendered task. However, this willingness is difficult to change. A study on transnational families reported that men who either migrated or stayed behind in their home country acted as reluctant caregivers, and women remained feeling obliged to undertake care work.⁴⁰

A negative correlation was observed between caregivers' burden and their quality of life in the environmental domain. Caro *et al.* showed that the level of burden can be influenced by factors not related to care due to the burden resulting from the interrelationships between individuals and their environment.⁴¹ Therefore, environmental mental factors may mediate the relationship between caregiver burden and quality of life, indicating the need for future research to identify their role.⁴¹

This study found correlations between the caregiver burden and quality of life in all four domains. Other studies investigating caregivers of elderly with some degree of dependence found a correlation between the burden and quality of life in some domains but not all.^{12,41} The findings of this study indicated that taking care of elderly with more severe level of dependence may have a large impact on the quality of life of caregivers, affecting all domains of their quality of life. A study mentioned that elderly care is family focused, whereby family members are the only persons deserving to provide care for their elderly parents. This cultural habit led to an opinion that involving non-family members in care was perceived as a violation of filial values; it was often considered to be something shameful and to be avoided. This caregiving norm can be found in some cultures, particularly those with a collectivistic orientation as in Indonesia.⁴⁰ This finding was in line with that of the present study, that is, more than 90% of the caregivers were family members (first generation: 33.3%, second generation: 53.3%, and third generation: 6.7%). This factor can be assumed to be a worsening factor of caregiver burden.

The results of this study showed that caregiving for moderately to totally dependent elderly affects the quality of life of caregivers. Support must be provided for caregivers to prevent burnout and risks of abuse of the elderly. The support can be given in several forms. A systematic review has shown that trainings on how to provide care can reduce the burden of caregivers.⁴²

Regular meetings, either offline or online, can be a means to provide peer support to caregivers.⁴³ Not only the support from their peers but also professional help and psychotherapy can be given to strengthen their coping mechanisms, which will ultimately have an impact on the quality of life of caregivers.¹² The utilization of respite care services held by several health facilities in Indonesia can be socialized actively to increase the number of caregivers that use this service when they have other commitments within a certain period. As respite care services are not covered by the national health insurance, their advocacy can be an issue. Support from the central government or local government in the form of caregiver allowance can help solve the financial problems faced by caregivers.⁴⁴

This study encountered some limitations, including the small number of participants and the cross-sectional research method used. This study also did not control for confounding variables, such as chronic illness that the caregiver experienced, which can directly or indirectly affect their quality of life. Therefore, further research should focus on the in-depth exploration of the correlation between the burden and quality of life of caregivers who care for the dependent elderly in Indonesia by controlling these confounding factors.

CONCLUSIONS

Significant negative correlations were observed between the burden and quality of life (physical, psychological, social, and environmental domains) of caregivers of elderly with moderate to total dependence. The higher the burden experienced by the caregivers, the lower their quality of life.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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