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Caregiver's burden and age are related determinants to quality of life in people with dementia

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ABSTRACT Dementia is a degenerative disease with poor prognosis. People with dementia will depend on their caregivers. Care for dementia patients aims to promote or preserve their quality of life. Identification of the factors that affect (determinants) the quality of life of people with dementia is required, and caregiver determinants are proven to play a role. The caregiver's role could affect the frequency and variety of therapy. Long-term cognitive and physical disability in people with dementia further develops the caregiver's burden. This study aimed to assess the determinants of caregivers which have a relation with the quality of life in people with dementia. This cross-sectional study involved subjects who are dementia patients at the Memory Clinic of Dr. Sardjito Hospital, Yogyakarta, Indonesia and fulfilled the inclusion criteria and did not meet the exclusion criteria. Subjects and caregivers were interviewed and helped to complete several questionnaires, including the DEMQOL, ZBI, and GDS. Analysis within variables was performed using Pearson, Mann-Whitney, and T-tests, followed by a multivariate linear regression analysis. As many as 76 people with dementia were included, with the majority having the diagnosis of vascular dementia (53.9%), and the average DEMQOL Career score was 80.58 + 17.62 and 81.82 + 20.80 for DEMQOL Proxy. Bivariate correlation analysis showed a significant correlation between the caregiver's age, gender, family relation, burden (ZBI), and depression (GDS) with the quality of life people with dementia (p <0.05). In the multivariate analysis, caregiver's age was related to the quality of life of people with dementia based on DEMQOL Career (B =0.270; p =0.001) and DEMQOL Proxy (B =0.271; p =0.001) and the caregiver burden was related to the quality of life of people with dementia based on DEMQOL Career (B =-0.629; p =0.000) and DEMQOL Proxy (B =-0.661; p =0.000). In conclusion, the determinants of caregiver that are significantly related to quality of life in people with dementia are caregiver's burden and age.

1. Introduction

Dementia is a chronic degenerative disease. People with dementia need long-term care because of their physical and cognitive limitations.[1] People with dementia have a poor prognosis because they will experience progression in memory loss, loss of orientation, decreased ability to learn new ideas, limitations in daily activities and social relationships. Symptomatic behavior and psychological disorders will appear in later stages. As a result, the people with dementia will be highly dependent on their caregiver.[2]

The progressiveness of dementia could decrease their quality of their life.[1] Quality of life is acknowledged as an indicator of effective psychosocial and pharmacological interventions in people with dementia.[3] To enhance dementia patients' quality of life, identification of the factors that influence (determinant) on their quality of life is required.[4]

Until this study was conducted there has been no consensus on the determinants of dementia patients' quality of life,[5] and previous studies only engaged in discussion and debate regarding the validity and utility of certain measurements.[6] One study by Raggi et al.[7] stated that there are three quality of life determinants for patients with dementia: the conditions of the people with dementia, the caregiver,

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and the professional medical services.

Caregivers have a vital role in the care of people with dementia.[2] The majority of people with dementia remain in their homes and are cared for by informal caregivers.[8,9] Thus, the caregivers could influence important changes in the lives of people with dementia, and affect the frequency and variety of therapy they will require.[2] Dementia caregivers face unique difficulties in providing care because of the disability in the cognitive function and physical disability experienced by people with dementia. Long-term care duration is also a challenge.[10] Helping people with dementia in their daily activities is a burdensome responsibility to caregivers.[8] As far as the author's knowledge, there have been multiple studies that investigated the determinants of quality of life of people with dementia, but until this study was conducted there has been no research on the determinants of caregivers, which might lead to the improvements in the outcome of dementia. This study aimed to assess the determinants of caregivers related to the quality of life in people with dementia.

2. Method

This research was an observational analytic study using a cross-sectional design to assess caregiver determinants related to the quality of life in people with dementia. The independent variables were caregiver characteristics: age, gender, income level, education level, family relationship, training, burden, and depression. Meanwhile, the dependent variable was the quality of life of people with dementia.

Study subjects are people with dementia who underwent outpatient care at the Memory Clinic of Dr. Sardjito Hospital Yogyakarta, Indonesia who fulfilled the inclusion criteria: patient with a diagnosis of dementia, Mini Mental State Examination (MMSE) score > 10, there were caregivers who performed daily care when collecting data, and willing to be respondents. Exclusion criteria were: people with dementia who received psychotropic therapy in the previous month, severe communication disorders, and people with dementia who were not in routine control in the last 3 months. This study was conducted from August to November 2018.

Subjects who fit the criteria were then interviewed to collect the data concerning the patients and caregivers and record the data of diagnosis, gender, level of income, level of education, family relationship, and caregiver training. Additionally, they completed the burden assessment using the Zarit Caregiver Burden Interview (ZBI), and depression assessment using Geriatric Depression Scale (GDS), followed by measuring the quality of life of people with dementia using the DEMQOL career and DEMQOL proxy tests. The examination was done at the Memory Clinic of Dr. Sardjito Hospital.

Criteria for the assessed caregiver were: the person who spent the most time together, provide physical and mental support, most help with basic daily activity, as well as those who best understand the current condition of people with dementia.[11] Burden of caregiver was measured using the ZBI Scale in the Indonesian language which has high internal consistency and good reliability.[12] Consisting of 22 question items, the ZBI values vary from 0 to 88 with higher scores indicating a more severe burden.[12] Depression in caregivers was measured using a short version of the Indonesian GDS, with higher values indicating higher levels of depression.[13] This scale has been tested for validity and reliability with a sensitivity value of 84% and specificity of 95% and reliability value of 0.817 which shows good value.[14]

Dementia quality of life was measured using a DEMQOL instrument consisting of 2 questionnaires, the DEMQOL career, in which patients assess their own quality of life, and the DEMQOL proxy, in which caregivers assess the quality of life of people with dementia. Higher DEMQOL scores indicate a better quality of life.[15] The English version of DEMQOL shows high reliability (internal consistency and test-retest) and has moderate validity in patients with mild or moderate dementia. DEMQOL proxy show good acceptance and internal consistency and moderate validity in mild, moderate, and severe dementia patients.[15] The Indonesian version of DEMQOL has been tested for reliability which confirms good results for assessing the quality of life of people with dementia in clinical practice settings.[16]

Data analysis and statistical calculations were conducted using the relevant computer programs. Data on age, burden, and depression variables are numerical, while gender, level of income, level of education, family relationship, and training are nominal data. Bivariate analysis used Pearson correlation, Mann-Whitney and T-tests with standard deviation (SD) and a confidence interval (CI) of 95%. These results were followed by multivariate linear regression analysis to determine the correlation of several independent variables to the dependent variable.

This research received approval from the Medical and Health Research Ethics Committee for Human Research, Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada with number Ref: KE/FK/0780/EC/2018.

3. Result

Eighty-four people with dementia met the inclusion criteria. Eight were excluded because they had communication disorders (5) and/or used psychotropic drugs (3). The total of 76 people with dementia were the subjects of this study. None of the caregivers refused to do the interview. In the dementia subjects' characteristics (Table 1), it was found that 27.6% of subjects had a diagnosis of Alzheimer's dementia, 53.9% were vascular dementia, 11.8% were mixed type dementia, and 6.6% were diagnosed as other types of dementia. The median score of the MMSE was 21 (10-30). The average DEMQOL Career value in this study was 80.58 ± 17.62 and the DEMQOL Proxy was 81.82 ± 20.80.

Characteristics of caregivers (Table 2) based on the median age were 60, 81.6% had no economic difficulties, 64.8% had an education level more than high school, the majority (64.5%) were married (husband/wife) and 81.6% of the caregivers had never attended caregiver training. Median score of the caregiver burden was 18 and depression was 1.

The results of bivariate analysis (Table 3) revealed that quality of life was related to the age of caregiver based on DEMQOL career score ($r = 0.408$; $p = 0.000$) and DEMQOL proxy ($r = 0.416$; $p = 0.000$), with positive direction correlations indicating the higher the caregiver age, the higher quality of life assessed by DEMQOL career ($R^2 = 0.167$) and DEMQOL proxy ($R^2 = 0.173$). Further analysis of age was conducted by analyzing the average DEMQOL scores based on decades of caregiver age groups. Then, a post hoc analysis showed that there was a statistically significant difference ($p < 0.05$) in the quality of life scores between the age groups 60-69 years compared to the younger age group. The data demonstrated that all of the caregivers in this age group are dementia spouses and there was only one male caregiver. It implies that there is still the probability of moderation of the role variable: spouse and gender variables with correlations between age and QOL. So, it can be concluded that the best caregiver to improve the quality of life for people with dementia is a spouse aged 60-69 years.

Table 1. Dementia subjects' characteristics

Variable	Total	Percentage (%)	Median (Minimum – Maximum)	Mean (SD)
Diagnosis				
Alzheimer Dementia	21	27.6		
Vascular Dementia	41	53.9		
Mixed type Dementia	9	11.8		
Others type Dementia	5	6.6		
Gender				
Female	30	39.5		
Male	46	60.5		
Level of Education				
> High School	46	60.5		
< High School	24	31.6		
Age			65.5 (34-85)	
MMSE			21 (10-30)	
Quality of Life				
DEMQOL Career				80.58 + 17.62
DEMQOL Proxy				81.82 + 20.80

Table 2. Caregiver subjects' characteristics

Variable	Total	Percentage (%)	Median (Minimum – Maximum)	Mean (SD)
Gender				
Female	51	67.1		
Male	25	32.9		
Level of Income				
No economic difficulties	62	81.6		
Economic difficulties	14	18.4		
Level of Education				
> High School	52	68.4		
< High School	24	31.6		
Family Relations				
Spouse	49	64.5		
Children	20	26.3		
others family	3	3.9		
Non-family	4	5.3		
Training				
Ever	14	18.4		
Never	62	81.6		
Age			60 (21-83)	
Burden (ZBI)			18 (0-89)	
Depression (GDS)			1 (0-12)	

Table 3. Bivariate analysis of the correlation of numerical caregiver variables on the quality of life of dementia patients

Variable	DEMQOL career		DEMQOL proxy	
	r	p	r	p
Age	0.408	0.000*	0.416	0.000*
Burden (ZBI)	-0.688	0.000*	-0.720	0.000*
Depression (GDS)	-0.435	0.000*	-0.387	0.001*

* statistically significant (*p* <0.05)

Table 4. Comparative bivariate analysis of nominal caregiver variables on the quality of life of dementia patients

Variable	DEMQOL career		DEMQOL proxy	
	Mean	*p* (95% CI)	Mean	*p* (95% CI)
Gender				
Male	75.00	0.031*	75.96	0.086
Female	83.31		84.69	(-18.71 -1.26)
Level of income				
No economic difficulties	81.74	0.228	83.74	0,089
Economic difficulties	75.42	(-4.04 – 16.67)	73.29	(-1.65 – 22.56)
Level of education				
> High school	80.69	0.935	81.92	0.948
≤ High school	80.33	(-8.36 – 9.09)	81.58	(-9.96 – 10.64)
Family relations				
Spouse	84.29	0.101	86.76	0.041*
Children	73.95		71.90	
Others family	75.67		78.67	
Non-family	72.00		81.82	
Training				
Ever	86.71	0.095	88.79	0.167
Never	79.19		80.24	(-3.64 – 20.73)

* statistically significant (*p* <0.05)

Table 5. Multivariate analysis of caregiver determinants on the quality of life of dementia patients

Variable	DEMQOL Career		DEMQOL Proxy	
	Beta	***p***	**Beta**	***p***
Age	0.270	0.001*	0.271	0.001*
Gender	0.087	0.312	0.048	0.557
Family relations			-0.139	0.190
Level of income	0.054	0.543	0.000	0.998
Level of education	-0.037	0.662	-0.025	0.726
Burden (ZBI)	-0.629	0.000*	-0.661	0.000*
Depression (GDS)	-0.095	0.332	0.022	0.816

* statistically significant (*p* <0.05)

There was a statistically significant relationship between caregiver burden (ZBI) and dementia's quality of life assessed using the DEMQOL career (r =-0.688; *p* =0.000) and DEMQOL proxy (r =-0.720; *p* =0.000) (Table 2), with negative direction correlation, which shows that lower the score of ZBI for the caregiver, the higher the quality of life based on DEMQOL career score (R^2 =0.473) and DEMQOL proxy (R^2 =0.518). Depression in caregivers who were assessed using GDS also had a statistically significant relationship with quality of life based on the DEMQOL career (r = -0.435; *p* = 0.000) and DEMQOL proxy (r =-0,387; p =0.001) (Table 2), with the direction of the correlation is negative, which indicates the lower the depression, the higher the quality of life of people with dementia based on the DEMQOL career score (R^2 =0.189) and DEMQOL proxy (R^2 =0.150).

There were significant differences in the quality of life based on the DEMQOL career score with the caregiver gender (*p* =0.031) and family relations with the quality of life based on DEMQOL proxy (*p* =0.041) (Table 4).

From multivariate analysis, there were two variables significantly related to quality of life, which is caregiver burden (B =-0.629; *p* =0.000 for DEMQOL career and B =0.166; *p* =0.000 for DEMQOL proxy), and age (B =0.270; *p* =0.001 for DEMQOL career and B =0.271; *p* =0.001 for DEMQOL proxy) (Table 5).

4. Discussion

Multivariate analysis results demonstrate that there is a significant relationship between burden of caregivers and the quality of life of people with dementia, with the direction of a negative correlation, which indicates that the higher the burden perceived is related to the lower quality of life for people with dementia. This finding supports the hypothesis that dementia can cause a burden to the caregiver.[12] Secondary effects of dementia can include the caregiver burden and poor health outcomes among informal caregivers.[17] Dementia caregivers frequently feel they are overwhelmed by care responsibilities and this affects their own quality of life.[2] This is in accord with a previous study by Andrieu et al.,[1] which revealed that caregiver's burden was independently related to the lower quality of life of people with dementia. Several prior studies have shown results that are consistent with the results of this study. Some studies have even researched about interventions and training for caregivers to regulate the level of burden and stress they experienced.[13] It is expected that the ability to overcome the level of burden on the caregiver, will improve both caregiver and dementia patients' quality of life.[1]

The caregiver's age is also significantly related to the quality of life of people with dementia. Based on this study, people aged 60-69 are the best caregivers. Nonetheless, the data demonstrated that all of the caregivers in this age group are dementia spouses and there was only one male caregiver. It implies that there is still a probability of moderation of the role variable: spouse and gender variables related to the correlation between age and QOL. Older age is considered to have better adaptability to deal with dementia because they have more experience to manage the condition of people with dementia. Younger caregivers are considered to have a bigger burden when managing people with dementia.[18] Older age caregivers are also acknowledged to have lower demands than other adults, and older age is admitted to be more beneficial to be caregivers.[19] Levels of stress can also be reduced with increasing age and lower risk of experiencing anxiety compared to a younger age. Also, younger age caregivers are estimated to have a bigger burden than old age.[20] This is following previous research by Chappel[20] which stated that there is a significant relationship between older age caregivers and the better quality of life for people with dementia.

Results of bivariate analysis in this study indicate a significant relationship between caregiver gender and the assessment of the quality of life by people with dementia but not in the multivariate analysis. This is estimated because of the limited time possessed by male caregivers to interact with people with dementia, because of their responsibility to work and provide income.[21] Compared to men, female caregivers allocated 50% more time to provide care to people with dementia.[22] This reason also can explain how gender was only significantly related to the quality of life assessed by the patient (career) but not significant to the assessment based on the caregiver (proxy). In addition, women also generally take more responsibility in providing care to families in accordance with the cultural views accepted by the community, where women are considered more suitable as caregivers than men.[23] The relationship between caregiver gender and the quality of life of people with dementia was also found in a previous study by Srivastava et al.,[21] which stated that male caregivers feel more burden in terms of social relations, feelings of incompetence and dependency.

Socio-economic factors such as level of income and level of education in this study did not prove to be significantly related to the quality of life of people with dementia. This is different from previous research by Chen et al.,[24] which stated that socio-economic factors such as level of income and level of education are significantly related to the quality of life of people with dementia. This difference is possibly because of the population differences used in this study compared to the research conducted by Chen et al.[24] which used a community-based population, while this study used a hospital-based population that is considered more homogeneous in terms of socio-economic level. The majority of dementia caregivers who did not bring their dementia family members to treatment in hospitals have lower income levels, lower education levels, lower employment classes, and live in rural areas.[24]

Family relations in this study were significantly related to the quality of life of patients with dementia based on the assessment by caregivers but not related based on the assessment by people with dementia themselves. The hypothesis to describe this difference is that the assessment quality of life taken by others than the patients themselves will have some inherent bias. Whether or not a patient's quality of life is ruled by personal perspectives or objective interpretations through observations is exceedingly affected by the relationship between the assessor and the assessed.[25,26] Caregivers tend to consider factors such as family relations, marriage, and residence (whether family members live in the same house), and these aspects are admitted to have a better impact on other family members including those suffering from dementia.[27]

Caregiver training in this study did not prove to be significantly related to the quality of life of people with dementia. This is caused by several factors, including the fact that psychosocial interventions, in general, present a major obstacle, the content and implementation of psychosocial interventions must be subjective and multi interpretations, with varying duration and intensity among various training programs, and the absence of consensus on the theoretical framework regarding training for family care workers.[28] This study’s findings are consistent with the meta-analysis study conducted by Schoenmakers et al.,[28] which stated that there is weak evidence that interventions and support in the form of training to caregivers provide benefits for improving the quality of life for people with dementia.

The characteristics of dementia diagnosis in this study are dissimilar from previous studies. This difference is due to disparities in exposure to cerebrovascular risk factors such as hypertension, smoking, obesity, and diabetes mellitus. These risk factors will make patients go to the hospital.[29] Because of these disparities, hospital-based studies such as in this study tend toward a predominance of the vascular dementia diagnosis more than Alzheimer's dementia. This study differs from a study conducted by Aguirre et al.,[30] which stated that the majority of dementia are diagnosed as Alzheimer's (34.2%), followed by Vascular dementia (25%), and 8.5% other types of dementia. The majority of studies present a similar prevalence of dementia, with the proportion of Alzheimer's dementia reaching 50-60% and 25-30% vascular dementia.[31] In contrast, a study in Japan by Suzuki et al.[32] reported a prevalence similar to this study, but with a more vascular dementia prevalence than Alzheimer's.

There are several limitations to this study: (1) this research method was cross-sectional, which cannot determine a causal relationship, (2) this population was limited to mild-moderate dementia in the hospital, so it cannot be a representation of the general population with dementia, and (3) analysis of quality of life based on the type of dementia was not performed.

5. Conclusion

Caregiver's burden and age are significantly related determinants to the quality of life of people with dementia. This study provides evidence-based educational material for people with dementia and the relation. Selection of the best eligible caregiver criteria has an impact on better outcomes in people with dementia. This study is also useful for the caregiver community, providing evidence that increasing the burden on caregivers will reduce the quality of life of people with dementia. Some recommendations can be addressed following the results of this study: (1) it is advisable to decrease the caregiver's burden and preference is for a spouse caregiver within the ages 60-69 years for people with dementia, and (2) additional research with community-based populations is required to overcome the limitations of the homogeneity in this study, and it is recommended to use larger populations based on each type of dementia.

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Conflict of interests

The authors have no conflict of interest.

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