

Caregiver Burden, Quality of Life and Vulnerability Towards Psychopathology in Caregivers of Patients with Dementia/Alzheimer's Disease

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ABSTRACT

Objective: To identify caregivers' burden, evaluate quality of life in them; and predict anxiety and depression in caregivers of patients with Alzheimer's disease (AD).

Study Design: Cross-sectional study.

Place and Duration of Study: Neurology and Psychiatry Department of Lahore General Hospital (LGH), from January to December, 2013.

Methodology: A purposive sample of 60 caregivers, who had been taking care of patients with AD for more than one year, were recruited from the study centre. The Zarit Burden Interview was used to assess caregiver burden. The brief version of World Health Organization Quality of Life Scale to assess quality of life and anxiety and depression subscales of symptom checklist-revised were administered to assess caregivers' vulnerability towards psychopathology.

Results: There were 6 males and 54 females caregivers with mean age of 37.60 ± 14.87 years. The burden of caregiving had negative relationship (-0.57; -0.50; -0.48; and -0.50, respectively) with physical, psychological, social, and environmental domains of quality of life. Neither caregiver burden nor quality of life predicted for anxiety and depression in the caregivers.

Conclusion: Caregiver burden may impair quality of life of caregivers but results imply the need to identify the interpersonal and intrapersonal characteristics of caregivers that buffered the adverse effects of caregiver burden and impaired the quality of life on psychological wellbeing of the patients with AD.

Key Words: Alzheimer's disease. Quality of life. Caregiver burden. Anxiety. Depression.

INTRODUCTION

Dementia is a clinical syndrome characterized by deterioration in cognitive, behavioural, and functional abilities of the patient. The prevalence of dementia is below 1% in 60 - 64 years of individuals and increases up to 24 - 33% in people aged 85 years and above in the West; whereas, 60% of demented population resides in developing countries.¹

Cognitive impairment is the hallmark feature of dementia; but it also expresses itself through behavioural and psychological symptoms of dementia which include hallucination, delusion, apathy, depression, anxiety, and a range of other maladaptive behaviours. Behavioural and psychological symptoms of dementia seem to be challenging behaviours for the caregivers. It may become a source of caregiver's burden as well as lead to secondary discomfort and distress for the person with dementia or Alzheimer's disease.²

In India, 53% of the sample diagnosed with AD had delusion and paranoid ideations, 33% had hallucinations, 65% had activity disturbances, 75% had aggressive symptoms, and 55% diurnal disturbances. However, affective and anxiety symptoms were found in 37% and 43% of the patients, respectively.³ On the other hand, BPSD contribute to the major burden of the disease not only for the patients but for the caregivers as well. The caregivers' distress occurs in majority of the caregivers and they often perceive caring for person with AD as burdensome and experience psychological, physical, social, emotional, or financial problems.⁴ In another study, it was found that caring for a person with AD is associated with having symptoms of depression and higher levels of burden among caregivers.⁵

In literature, two terms have been used to explain the caregivers burden. Practical problems linked with provision of caregiving such as financial cost, continuous nursing care, etc. are classified as objective burden of caregiving; whereas, emotional reactions in result of caregiving such as anxiety, depression, reduced socialization are taken as subjective burden of caregiving or caregiving strain.⁶

The assessment, identification, and management of AD are of particular interest not from patients' point of view but also from caregivers' perspective because AD as a progressive condition can affect one's quality of life and

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psychological wellbeing. Risk factors that obstruct caregivers' psychological wellbeing may include financial expenditures to provide formal and informal care, AD patient's early institutionalization in case of need, and his/her limited capacity to function in everyday activities.⁷

The present research was conducted to determine caregiver burden and to evaluate quality of life and vulnerability towards psychopathology in caregivers of patients diagnosed with AD.

METHODOLOGY

The cross-sectional study was implemented on a purposive sample of 60 caregivers of patients diagnosed with AD, coming to Psychiatry and Neurology Units of Lahore General Hospital (LGH). The sample size was calculated through G*Power analysis. The researcher approached those patients with AD who were diagnosed by neurologists, and then their primary caregivers were contacted. The duration of caregiving by the caregivers was at least one year.

Demographic form was devised by the researcher to assess the demographic details of the caregivers such as age, gender, education, occupation, etc. Zarit Burden Interview⁸ was used to measure intensity of the burden in terms of functional and behavioural impairments experienced by caregivers of older people diagnosed with dementia. It includes 12 items which are to be rated on 0-5 Likert type scale (0=never and 5=nearly always). World Health Organization Quality of Life Questionnaire (WHOQOL-BREF)⁹ was administered to assess the quality of life of primary caregivers. Urdu version of this tool was used in the present study. It has 26 items, out of which the first item is about general quality of life; the second item is about general physical health; and remaining 24 items measure four domains of life including: physical health (7 items); psychological health (6 items); social relationships (3 items), and environment (8 items). Higher scores indicate higher quality of life. The Symptom Checklist-Revised (SCL-R)¹⁰ was used to assess the degree of anxiety and depression in caregivers. SCL-R has 148 items with six subscales: depression; somatoform; anxiety; obsessive compulsive disorder; level of frustration tolerance; and schizophrenia. For the purpose of the present study, subscales of depression (24 items) and anxiety (29 items) were used. The items were rated on a Likert type scale on 0 to 3 on each item (not at all=0, rarely=1, moderately=2, and very much=3).

Research Project Evaluation Committee of the Punjab University, Lahore, approved this research project. The researcher administered questionnaires on those caregivers who were primarily caretakers of the patients who were diagnosed with AD by neurologists and were coming to either Psychiatry or Neurology Departments of LGH for follow-ups. Caregivers were briefed about the

purpose of research. The research questionnaires were administered individually. All information was kept confidential and written consent was taken from the caregivers.

Statistical Package for Social Sciences (version 21) was used to analyse the data. Descriptive statistics were used to analyse demographic data. Pearson product moment correlation coefficient was performed to analyse the relationship among caregiver burden, quality of life, and psychiatric symptoms in AD's caregivers. Hierarchical multiple regression analyses were performed to identify the predictors of psychiatric symptoms in caregivers.

RESULTS

There were a total of 60 caregivers including 6 males and 54 females with mean age of 37.60 ± 14.87 years. Table I shows demographic characteristics of caregivers of patients with AD. Table II shows that caregiver burden did not have significant relationship with psychiatric symptoms of anxiety or depression. However, the more burden and distress were experienced by caregivers, the less they reported better quality of life within the domains of physical, psychological, social, and environment. On the other hand, none of the domains of quality of life had significant relationship with either anxiety or depression.

Two separate hierarchical multiple regression analyses were performed to predict anxiety and depression in caregivers by putting gender and occupation as covariate in Block 1 and caregiver burden and four domains of quality of life in Block 2. The assumptions of independent errors and no perfect multicollinearity were met in both analyses (Table III).

Table I: Demographic characteristics of caregivers of patients with AD (N = 60) .

Variables	f(%)	M (SD)
Age	-	37.60 (14.87)
Gender		
Men	6 (10)	
Women	54 (90)	
Relationship with patient having AD		
Spouse	30 (50.00)	
Sibling	2 (3.33)	
Children	26 (43.33)	
Daughter-in-law	1 (1.7)	
Niece	1 (1.7)	
Education		
Illiterate	5 (8.3)	
Less than matriculation	16 (26.67)	
Matriculation	13 (21.7)	
Intermediate	8 (13.3)	
Bachelors	13 (21.7)	
Masters	5 (8.3)	
Occupation		
Employed	13 (21.7)	
Unemployed	47 (78.3)	

Table II: Intercorrelations among caregiver burden, quality of life, and psychopathology (N).

Scales	1	2	3	4	5	6	7
Caregiver burden	-	-	-	-	-	-	-
Physical QOL	-.57***	-	-	-	-	-	-
Psychological QOL	-.50***	.88***	-	-	-	-	-
Social QOL	-.48***	.75***	.78***	-	-	-	-
Environmental QOL	-.50***	.87***	.88***	.68***	-	-	-
Anxiety	.17	-.07	.04	.05	-.02	-	-
Depression	.05	.03	.06	-.04	.05	.02	-
M	29.07	12.62	11.86	14.60	12.68	16.17	16.55
SD	8.65	3.09	2.70	3.16	2.87	6.10	6.11

Note: N = 60; QOL = quality of life; ***p < .001

Table III: Hierarchical linear regression analyses predicting psychiatric symptoms in terms of anxiety and depression from caregiver burden and quality of life (N).

Variables	Anxiety		Depression	
	ΔR^2	β	ΔR^2	β
Block 1	.01	-	.05	-
Control variables ^a				
Block 2	.11		.01	-
Caregiver burden	-	.27	-	.02
Quality of life				
Physical	-	-.34	-	-.02
Psychological	-	.55	-	.13
Social	-	.09	-	-.16
Environment	-	-.15	-	.07
Total R ²	.12		.06	

Note: N = 60; control variables included gender and occupation; *p < .05

In case of anxiety, model 1 ($R^2=0.01$, $F(2, 57) = 0.36$, $p=0.70$) was not significant, indicating that gender and occupation did not have an effect on anxiety of caregivers. Model 2 ($R^2=0.12$, $F(7, 52) = 1.03$, $p=0.42$) was also not significant suggesting that there was no overall significant effect of covariates and predictors such as caregiving burden and quality of life on anxiety of caregivers. Similarly, after controlling for gender and occupation, caregiving burden and quality of life did not significantly predict for anxiety in caregivers $F(5, 52) = 1.29$, $p=0.28$.

In case of depression, covariates (gender and occupation) in Block 1, $F(2, 57) = 1.47$, $p=0.24$ and overall effect of covariates and predictors (caregiving burden and quality of life) in Block 2, $F(7, 52) = 0.50$, $p=0.83$ were unable to significantly predict for depression in caregivers. Similarly, subtracting the effect of covariates from Block 2 and retaining predictors could not make the model significant, $F(5, 52) = 0.15$, $p=0.98$.

DISCUSSION

The present research identified the nature of relationship among caregiver burden, quality of life, and psychiatric symptoms in terms of anxiety and depression. Moreover, it established the predictive role of caregiver burden and quality of life for psychopathology in caregivers of patients diagnosed with AD.

According to results, caregiver burden significantly related with impaired quality of life in domains of physical, social, psychological, and environment. Previous studies also validate present finding that quality of life is significantly compromised in caregivers of patients with AD.¹¹⁻¹³ Since patients with AD not only experience cognitive decline but also have psychological and behavioural problems. On the other hand, there is an increase in the responsibilities of caregivers with a decline in their quality of life. In addition, if caregivers tend to have deep long-lasting relationship with patients then it is more likely to negatively affect quality of life of the caregivers.¹⁴ It may be argued that caregivers of the patients with AD feel themselves burdened because caregiving requires prolonged time and effort as well as the experience is emotionally charging, too.

In the present study, caregiver burden and quality of life did not have significant relationship with or predicted for psychiatric symptoms of depression or anxiety. This surprising finding can be explained by number of reasons. First, researchers found that caregivers may have intact psychological wellbeing depending upon their perception of caregiving experience; management strategies they adopt; or nature of therapy being provided to patients with AD.^{15,16} Thus, it might be possible that caregivers in the present study did not manifest vulnerability towards psychopathology because they did not have maladaptive cognitive appraisal regarding caregiving experience; used satisfactory management strategies in response to functioning level of AD patients; and were satisfied with the treatment plan of patients with AD. Second, caregivers were recruited from a government teaching hospital of Lahore city leaving out sample that did not have access to treatment in Pakistan for their patients with AD. Third, all the patients with AD in present study were non-institutionalised, suggesting that their caregivers might have family support which could have resulted in the bearable amount of caregiver burden due to which caregivers did not show signs of psychopathology. Previous studies have also depicted the role of family support in delaying institutionalisation of patients with AD on behalf of the caregivers.^{17,18}

The present study had several limitations. First, demographic variables such as duration of caregiving and kind of treatment provided to AD patients as well as caregivers' interpersonal (family support) and intrapersonal factors (personality traits; cognitive appraisal) were not taken into account that could make a difference in explaining why caregivers in present study did not show vulnerability towards psychopathology. Secondly, caregivers' vulnerability towards psychopathology might differ according to severity level of AD, endorsed by patients, which was not determined in present study.

CONCLUSION

In the end, although caregivers did not exhibit signs of depression or anxiety but their impaired quality of life within the domains of physical, psychological, social, and environment due to caregiver burden was an alarming sign that their psychological wellbeing might deteriorate in near future. Therefore, this population might need intervention programmes and counselling regarding adequate management strategies that may decrease patient problem behaviours and increase caregiver competence.

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