Original Article

The Impact of Psychosocial factors on Quality of life among the Caregivers of Person's with Dementia

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Abstract

Objective: To assess caregiver burden, social support, and quality of life among caregivers of people with dementia, as well as the link between caregiver burden and quality of life.

Place and duration of study: The study was conducted in various health care units of Rawalpindi and Islamabad for 6 months from September 2020 to Febraury 2021.

Material and Methods: There were (N=50) informal caregivers among the participants. The study included participation from both men (n = 18, 36%) and women (n = 32, 64%). Purposive sampling was used to gather data from hospitals' departments of neurology and psychiatry. The research design used for the study was a correlational survey. The Statistical Package for the Social Sciences (SPSS) was used to examine the study's findings. The association between quality of life and psychosocial factors was evaluated using bivariate Pearson's correlation analysis. To determine if psychosocial factors are predictive of quality of life, hierarchical multiple regression was utilized.

Results: The results of the study showed a strong positive correlation between social support and quality of life. Additionally, it was found that caregiver burden and quality of life were significantly correlated negatively. The results of the hierarchical multiple regression analysis showed that while caregiver burden had a negative effect on quality of life, social support positively predicted quality of life.

Conclusion: The quality of life of caregivers is a crucial topic in the current era, particularly in a nation like Pakistan where caregivers tend to their elderly family members for the majority of the time. The negative experience of caregivers can influence the individuals with dementia continuity of care, compliance with treatment and social support. Then, it becomes a vicious cycle

Keywords: : Informal Caregivers, Persons with Dementia, Quality of Life, Caregiver Burden, Social Support.

1. Introduction

"Caregiving typically entails substantial expenditures of time, energy, and money over potentially extended periods. It entails tasks that may be unpleasant and inconvenient, as well as psychologically stressful and physically exhausting".(1) Family caregivers are deemed as the foundation of healthcare unit in Pakistani society. Caregivers perform daily tasks including household chores, family finances, drug administration, and medical care. As a result, caregivers report poor physical health compared to non-caregivers. People who look after people with dementia can be classified as formal and informal caregivers. Formal caregivers are defined as health care professionals such as nurses, social workers, rehabilitation professionals and doctors who receive financial compensation for their care. (2) When care can no longer take place at home, then systematic formal caregivers begin to function more fully. This could be a living together, assisted living, a persistent retirement care Centre or a nursing home. Care for extended period of time significantly impacts the finances of a caregiver, as well as a healthy partner living at home. (3) Increasingly, systematic caregivers and their families lack social support and are unable to cope with work pressures and other emotional problems. (4) Informal caregivers are untrained Individuals who provide residential care for another

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person like family member or a friend. They also provide care or people with any other physical , psychological problems. (5) In order to cater the basic necessities of individuals with dementia, these caregivers play an essential part in providing assistance, attention and support they require. (6) Informal caregivers frequently lack the technical expertise and inadequate training required to address the requirements of individuals with dementia, who are likely to experience an immense burden of care and symptoms of depression.(7)

The primary caregiver (PC) is an individual who is expected to provide the dementia patient with support, sense of belongingness and everyday care; the person in the patient`s company most often. Usually, the primary caregiver is a spouse, woman, older child or daughter-in-law connected with the patient in need of treatment. (8) The secondary or supporting caregiver (SC) is an individual who assists or replaces the primary caregiver whenever required; thus, looking after the person with dementia. There may be a relative, friend or neighbor of the secondary caregiver.(9) Older people are regarded with honor, dignity and esteem in our society in the context of traditional family and cultural norms. It is expected that assistance, caring and compassion for the elderly would come from family members.(10) For long periods, ranging from months to years, they are bound to provide psychological, physical, emotional and social benefits to the patients of dementia. Such a huge responsibility would in turn impact the wellbeing of these caregivers. (11) Studies have identified that caregivers with greater caregiving burdens have poorer quality of life. (12)

Dementia harms not only the individual but also the caregivers. However, Dementia is more than an occasional memory loss. Dementia is the most common disorder triggered by impairment in memory due to malfunctioning of numerous brain cells. It also damages thought pattern, actions and individuals' capacity to manage day-to-day activities. It is considered as chronic and progressive disease. (13)

According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), dementia is a general term for a number of neurological conditions. The predominating sign of such problems was the loss of brain control because of changes in brain's physiology. That's why it is considered discrete and was distinguished from all other psychological disorders (American Psychiatric Association. (14) Dementia is labelled as Neurocognitive Disorder (NCD) by the American Psychological Association (APA, 2013). This group of Neurocognitive Disorder is subdivided into major neurocognitive disorder and minor neurocognitive disorder. Dementia usually causes impairment in memory, planning, attention, language, learning, visuospatial and social skills or in other essential cognitive functions.

2. Materials & Methods

In the current study, correlational design was used to assess the relationship between quality of life, caregiver burden and social support. The impact of caregiver burden and social support on quality of life was also assessed. Data was collected purposively using quantitative tools. Sample size was calculated through *Raosoft* sample size calculator for the current study. Total 50 informal caregivers were enrolled in the study with 18 males and 32 females. The age range of the respondents was 18 to 60 years. Data was collected using purposive sampling technique from various health care units of Rawalpindi and Islamabad. Primary caregivers who have been offering care to individuals with dementia for at least 6 months have been included.

The consent form comprised of objective of the study. Initially, participants were informed regarding purpose and requirements of the research. They were also briefed about their voluntary participation and right to withdraw from study at any time. Participants were also assured about the confidentiality of their personal information and responses to the questionnaire. After taking verbal consent, written consent of the participants was needed to proceed further in the study.

The demographic sheet contained information about the participants. It includes caregivers` age, gender, socio economic status, education, caregiver relationship with patient, number of caregivers', duration of care provided by caregiver. Socioeconomic status was measured on the basis of family monthly income of participants. The information about the persons with dementia includes age, gender, types of dementia, severity level of dementia and relevant medical and psychiatric history of the persons with dementia.

The WHOQOL Group and Orley et al. (1994) developed the scale, and Khalid and Kausar (2006) translated it into Urdu. (15,16) The quality of life of dementia caregivers was evaluated using the scale. This illustrates a subjective response by assessing the preceding two weeks. The abbreviation for WHOQOL-100 is WHOQOL-BREF. There were four subdomains and 26 items on the scale. There are 7 items related to physical health, 6 related to psychological health, 3 related to social relationships, and 8 related to the environment. A 5-point Likert-type scale was used to rate the items. The measure was self-reported. For each domain high score indicated better quality of life. There were 3 reverse coded items; item 3, item 4 and item 26 which were recoded into same variables before computed the total score. Cronbach`s alpha reliability values in the original English version of WHOQOL-BREF for each domain reliability values ranged from .66 to .84, indicating good internal consistency (World Health Organization, 1998). Moreover, alpha reliability in the Urdu translated version was reported as .78, .71, .73 for physical, psychological, environment and social relationship respectively. Social relationship had alpha reliability of .56 which showed not so good internal consistency due to the minimum number of items. (17)

The scale was designed by Zarit et al. (1980) and Urdu-translated by Butt and Bashir (2014). The original English version had 29 items and 22 item version (ZBI-22) was substituted in 1985. The subjective burden challenged by primary caregivers was assessed with it. It was a questionnaire that was self-administered or could be administered by an interviewer. There are five subscales of ZBI questions: 6 items in interpersonal burden, 7 items in mental well-being, 4 items in family and social life, 1 item in finances, and 4 items in lack of control over one's life. A 5-point Likert-type response structure is used to rate the items, with *0 = Never, 1 = Rarely, 2 = Sometimes, 3 = Quite Frequently, 4 = Nearly Always*. Total scores on the overall scale ranged from 0 to 88, with a greater degree of burden suggested by higher scores. Reliability coefficients in the original English version for responses to the full-scale ranged from α =.88 to α =.94 (O'Rourke & Wenaus, 1998). Moreover, reliability coefficient in the Urdu translated version were reported as .89.

The scale was developed by Zimet et al. (1988) and Urdu-translated version by Tonsing et al. (2012). MSPSS was deigned to determine the perceived acceptability of social support from three systems: family, friend and significant other. It was a self-administered questionnaire. The consisted of 12 items and 3 subscales including family, friend and significant other. Each subscale consisted of four items. Items were scored on a 7-point Likert scale, with answer categories of *Very Strongly Disagree* = 1, *Strongly Disagree* = 2, *Mildly Disagree* = 3, *Neutral* = 4, *Mildly Agree* = 5, *Strongly Agree* = 6, and *Very Strongly Agree* = 7. Overall, ratings varied from 12 to 84. The MSPSS original English version exhibited strong internal reliability coefficients of.87,.85, and.91 for the family, friend, and significant other subscales, respectively (Zimet et al., 1988). Furthermore, alpha reliability in the Urdu translated version was revealed to be.93,.91, and.90 for family, friend, and significant other, respectively.(18) Permission was obtained from the relevant authors of scales by email. The University's Institute Review Board (IRB) provided formal and ethical permission. The researcher got an authority letter from the Department of Clinical Psychology, confirming their institutional relationship with the department. A list of targeted hospitals was developed. The concerned authorities at Benazir Bhutto Hospital in Rawalpindi and the Pakistan Institute of Medical Sciences in Islamabad were called. A signed approval for data collection was received from the Head of Department of these hospitals via an authority letter. The researcher individually approached the subjects to collect data. Data was gathered from individual participants. The research included 50 informal caregivers (M = 18, F = 32).

Participants were informed about the nature, aim, and objectives of the study prior to data collection. The study's aims were discussed with consenting participants. It was explicitly stated that the gathered information will be kept secret and utilized strictly for research purposes. The participants were then requested to sign the written consent form in order to take part in the study. The assessment measures were divided into two parts: demographics and scales. First, a demographic sheet was presented, followed by measures to assess quality of life, caregiver burden, and social support. The researcher gave clear instructions concerning the scales. There was enough time to fill the scales. Finally, the participants were praised for their participation and cooperation. All the ethical considerations were followed in this study. Ethical approval was taken from (IRB) Institute Review Board. Ethical permission was taken from the authors of the scales before using them. Then data was collected from the participants. Participants were briefed about the objectives and implication of the study. No deception was done about the objective of the study. The confidentiality of information and anonymity of participants was respected. Then written consent was taken from the caregivers. Research population was caregivers, so empathetic relationship developed with the respondents.

3. Results

The current study investigated the influence of psychosocial variables on quality of life among informal caregivers of individuals with dementia. The WHOQOL-BREF, Zarit Burden Interview, and Multidimensional Scale of Perceived Social Support were employed. The Alpha reliability coefficient for the scales was calculated. *Descriptive analysis* was performed to determine frequency and percentages among respondents. *Bivariate Pearson's correlation analysis* and *hierarchical multiple regression* were used to estimate the quality of life of caregivers based on social support and caregiver burden. Results are given in the following tables

Table 1
Demographic Characteristics of Caregiver

Characteristics	*n*	%
Gender		
Men	18	36
Women	32	64
Age		
18-40	36	72
41-60	14	28
Education		
Below Matric	11	22
Matric	10	20
Intermediate	8	16
Bachelor	6	12
Graduation	12	24
Post-Graduation	3	6
Socioeconomic Status		
Lower	16	32
Middle	34	68
Caregiver Relationship with patient		
Spouse	6	12
Children	36	72
Siblings	2	4
Grandchildren	6	12
Number of Caregivers		
1	10	20
2	30	60
3	5	10
4	5	10
Duration of Care Provided		
6 months-1 year	16	32
2 years-4 years	11	22
5 years-7 years	13	26
8 years-10 years	10	20

Table 1 revealed that majority of women caregivers (*n* = 32, 64%) participated in the study as compared to men caregivers (*n* = 18, 36%). Higher number of caregivers aged 18-40 (*n* = 36, 72%) participated in the study as compared to age 41-60 (*n* = 14, 28%). Majority caregivers were graduates (*n* = 12, 24%) while others were below matric (*n*=11, 22%), matric (*n*=10, 20%) intermediate (*n*=8, 16%) bachelor (*n*=6, 12%) and postgraduate (*n*=3, 6%). Regarding socioeconomic status, majority of them belonged to middle class (*n* = 34, 68%) as compared to lower class (*n*=16, 32%). Most caregivers were the patient`s children (*n*=36, 72%), (*n*=6, 12%) were spouse and grandchildren; and (*n*=2, 4%) were siblings. The greater number of caregivers for persons with dementia were 2 (*n*=30, 60%) compared to 1 (*n*=10, 20%), 3 and 4 (*n*=5, 10%) respectively. Mostly caregivers were provided care from the duration of 6 months-1 year (*n*=16, 32%).

Table 2

Characteristics	*n*	%
Gender		
Men	26	52
Women	24	48
Age		
50-70	25	50
71-90	22	44
91-105	3	6
Severity Level of Dementia		
Mild	9	18
Moderate	25	50
Severe	16	32
Types of Dementia		
Alzheimer`s disease	37	74
Vascular dementia	7	14
Lewy body dementia	3	6
Frontotemporal dementia	3	6
Comorbidities		
Absent	27	54
Physical Illness	23	46

Demographic Characteristics of Persons with Dementia

Table 2 shows demographic characteristics of persons with dementia. Among patients, there was a slight gender difference between men (n=26, 52%) and women (n=24, 48%). Majority of patients were 50-70 (*n*=25, 50%) while others were 71-90 years of age (*n*=22, 44%) and only few of them were 91-105 years of age (*n*=3, 6%). Greater number of patients had moderate level (*n*= 25, 50%) of dementia. Higher number of patients had Alzheimer`s disease (*n*= 37, 74%) in comparison to Vascular dementia (*n*=7, 14%), had Lewy body dementia and Frontotemporal dementia (*n*=3, 6%) respectively. Majority of the patients had no comorbidities (*n*=27, 54%) along with dementia as compared to patient with physical illness (*n*=23, 46%).

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Table 3

Descriptive Statistics and Correlations for Study Variables

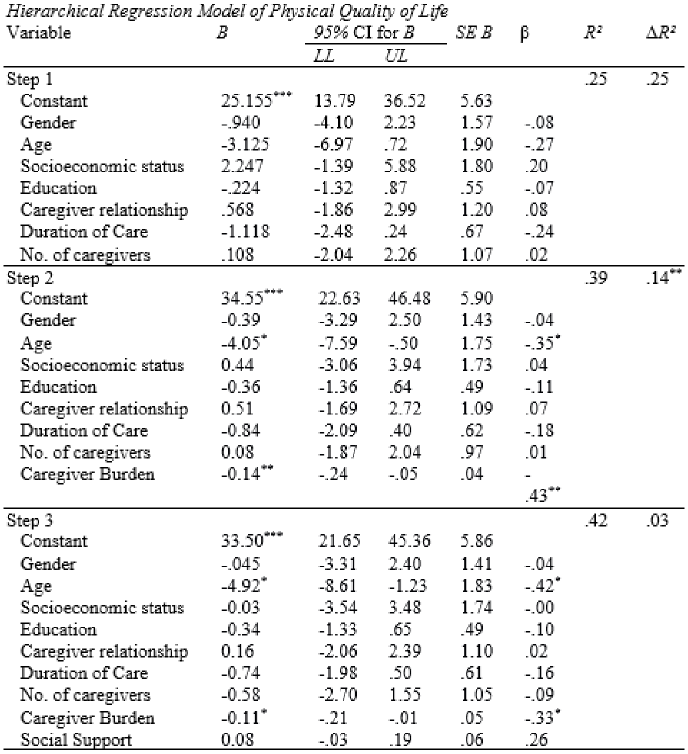
Variables	*n*	*M*	*SD*	1	2	3
1. QOL	50	79.04	17.88	_		
2. MSPSS	50	42.22	16.45	.59**	_	
3. ZBI	50	42.40	15.71	-.61**	-.49**	_

Note. Quality of Life Scale = (QOL); Multidimensional Perceived Social Support = (MSPSS); Zarit Burden Interview = (ZBI). $^{**}p<.01$

Table 4 revealed that quality of life had significant positive relationship with social support (r = .59, p<.01). A statistically negative correlation was observed between quality of life and caregiver burden (r = -.61, p <.01). There was highly significant negative correlation was existed between social support and caregiver burden (r = -.49, p <.01)

Table 4

Hierarchical Regression Model of Physical Quality of Life



Hierarchical Regression Model of Physical Quality of Life

Variable	*B*	95% CI for *B*		*SE B*	β	R^2	ΔR^2
		LL	*UL*				
Step 1						.25	.25
Constant	25.155***	13.79	36.52	5.63			
Gender	-.940	-4.10	2.23	1.57	-.08		
Age	-3.125	-6.97	.72	1.90	-.27		
Socioeconomic status	2.247	-1.39	5.88	1.80	.20		
Education	-.224	-1.32	.87	.55	-.07		
Caregiver relationship	.568	-1.86	2.99	1.20	.08		
Duration of Care	-1.118	-2.48	.24	.67	-.24		
No. of caregivers	.108	-2.04	2.26	1.07	.02		
Step 2						.39	.14**
Constant	34.55***	22.63	46.48	5.90			
Gender	-0.39	-3.29	2.50	1.43	-.04		
Age	-4.05*	-7.59	-.50	1.75	-.35*		
Socioeconomic status	0.44	-3.06	3.94	1.73	.04		
Education	-0.36	-1.36	.64	.49	-.11		
Caregiver relationship	0.51	-1.69	2.72	1.09	.07		
Duration of Care	-0.84	-2.09	.40	.62	-.18		
No. of caregivers	0.08	-1.87	2.04	.97	.01		
Caregiver Burden	-0.14**	-.24	-.05	.04	-.43**		
Step 3						.42	.03
Constant	33.50***	21.65	45.36	5.86			
Gender	-.045	-3.31	2.40	1.41	-.04		
Age	-4.92*	-8.61	-1.23	1.83	-.42*		
Socioeconomic status	-0.03	-3.54	3.48	1.74	-.00		
Education	-0.34	-1.33	.65	.49	-.10		
Caregiver relationship	0.16	-2.06	2.39	1.10	.02		
Duration of Care	-0.74	-1.98	.50	.61	-.16		
No. of caregivers	-0.58	-2.70	1.55	1.05	-.09		
Caregiver Burden	-0.11*	-.21	-.01	.05	-.33*		
Social Support	0.08	-.03	.19	.06	.26		

Note. CI = confidence interval; *LL* = lower limit; *UL* = upper limit.

$^{*}p < .05$; $^{**}p < .01$; $^{***}p < .001$

Table 4 showed the impact of demographic variables, caregiver burden and social support on physical quality of life in caregivers of persons with dementia. In Step 1, the R^2 value of .25 revealed that the demographic variables explained 25% variance in the physical quality of life with F (7, 42) = 1.98, p > .05. In Step 2, the R^2 value of .39 revealed that the demographic variables and caregiver burden explained 39% variance in the physical quality of life with F (8, 41) = 3.37, p < .01. The findings revealed that age (β = -.35, p < .05) and caregiver burden inversely predicted physical quality of life (β = -.43, p < .01). In Step 3, the R^2 value of .42 explained that the 42% variance in the physical quality of life was predicted by demographic variables, caregiver burden and social support with F (9, 40) = 3.32, p < .01. Age (β = -.42, p < .05) and caregiver burden (β = -.33, p < .05) negatively and significantly predicted physical quality of life. The ΔR^2 value of .14 revealed 14% chance in the variance of model 1 and model 2 with ΔF (1, 41) = 10.04, p < .01. The ΔR^2 value of .03 revealed 3% chance in the variance of model 2 and model 3 with ΔF (1, 40) = 2.18, p > .05.

4. Discussion

The purpose of current study was to identify the impact of psychosocial factors on quality of life among the caregivers of persons with dementia.

Descriptive analysis for the caregivers (See Table 1) showed that females were higher than males in the sample population. Gender differences showed that more women than men provide the care to the persons with dementia. Results of this finding covary with the previous researches as it seems to indicate that the detrimental aspects of caregiving cause women to suffer more . Usually women have assumed the role of caregivers and women provide more family care than men.(21) Female caregivers tend to experience more distress in general and use more community resources than males. In addition, it has been proposed that women are more likely to be subjected to caregiving stressors and also experience and cope differently than men with these stressors. (19)

The age range of the respondents was from 18-60 years. Majority of the caregivers were form the age range of 18-40 years. The findings showed that most of the caregivers were young as compared to older caregivers. This might be due to the fact that young people have more energy and understanding while older people are fragile and disabilities which increasing with age. Older caregivers face more difficulties in coping with their caregiving duties. It was easy for younger caregivers to provide care to persons with dementia than older caregivers. (19)

Descriptive analysis for the persons with dementia (See Table 2) showed that there was a slight gender differences between men and women. Life expectancy for women is higher than However, many previous studies have quoted non-significant differences between men and But few studies have suggested that the risk of dementia is higher in women as compared to men. The results can vary across different countries and over time (Alzheimer's Association, 2017). Individuals with dementia above the age of 50 were included in the study. Higher number of persons with dementia was from the age range of 50-90 years. The reason for this might be due to the fact that age is the strongest risk factor for dementia. So, Alzheimer's disease mostly develops in the age of 65 or older. Younger people may have Alzheimer's disease but they are less likely to develop the disease than older people . (20)

The major aim of the study was to examine link between the burden of caregivers and their quality of life. The findings of the study support the alternative hypothesis that there is a negative relationship exists between the caregiver burden and the quality of life. This indicates (See Table 3) that an increase in the caregiver burden will decrease the quality of life of dementia caretakers. The findings are covary with other studies reported by Srivastava et al., (2016) that a negative association between burden and quality of life suggests that the caregivers` quality of life affected due to the burden of caregiving for dementia (21)

The link between social support and quality of life is also found through this research, the findings show that there is a major relationship between these two variables. This indicates (See Table 3) that an increase in social support of caregivers would also increase the quality of life. Previous studies further validate current findings that the quality of life in caregivers is higher if they have maximum amount of social support available The most possible way through which social support contributes to increase the quality of life for caregivers is to be able to discuss the problems of caregiving with others, along with increased emotional support. (20)

The demographic variables of the present study were a) age, b) duration of care provided, c) socioeconomic status duration of care provided and d) caregiver relationship. These variables have significant effect on the domains of quality of life. While other variables such as gender, education and number of caregivers was the non-significant predictors of quality of life. Hierarchical regression model showed that out of all the demographic variables, age was found to be significant negative predictor of physical quality of life. One explanation for this would be that with increasing age, family members lose their physical abilities to take care of elderly. One model of caring was indicated in a study that more attention should be paid to include more family members and motivate young members in the caring process, and teach them the basics for providing such care too. (16)

Another hypothesis of the study was that the burden of caregivers and social support would possibly predict the quality of life. Study findings indicated the quality of life among caregivers predicted by both burden of the caregiver and social support. A possible explanation for the strong correlation between these variables showed that caregivers expected to have a higher degree of family support would in turn be correlated with low burden and a higher quality of life in caregiving In this study, hierarchical regression showed a significant negative effect of caregiver burden on all four domains of quality of life: physical health, psychological health, social relationship and environment. A possible reason might be that the higher level of caregiver burden reduces the quality of life, because caregiving is a continuing process and by the time, the caregivers get exhausted and their quality of life got affected badly. As studies suggested that the quality of life is significantly influenced in caregivers with dementia patients. (22)

Conclusion:

The current study examined the impact of psychosocial factors on quality of life among the caregivers of people with dementia. In the modern era, it is important to focus on the quality of life of caregivers, especially in a country like Pakistan where caregivers provide most of the care to their older family member. The negative experience of caregivers can influence the individuals with dementia continuity of care, compliance with treatment and social support. Then, it becomes a vicious cycle. Therefore, individuals with dementia should be treated as a group together with their families, and treatment should focus not on the patients, but also on their caregivers as well. In addition, physicians and clinicians should make efforts to enable caregivers to engage in more religious and spiritual activities and to inspire caregivers with hope and optimism. Improving the quality of life of caregivers will also not only assist them, but will also have a positive effect on the result of the condition of an individual with dementia. However, quality of life linked negatively with the burden of caregiver and positively with social support.

Disclosure /Conflict of interest:

Authors declare no conflict of interest.

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