

Quality of Life and Functional Disability in Caregivers of Patients with Dementia

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Abstract

Introduction: Dementia is a common cause of cognitive impairment in the elderly population. Family carers of people with dementia are the most important support that causes profound impairment in social functioning and quality of life.

Aim: The present study was conducted to study the quality of life and disability between dementia caregivers and normal control.

Methods: A total of 40 dementia caregivers and 40 normal control were enrolled in this cross-sectional study. Caregivers were assessed using semi-structured demographic proforma, WHO Quality of Life-BREF and Sheehan Disability Scale. Data were analyzed using the Statistical Package for Social Sciences (SPSS-20).

Results: Poor quality of life in physical, psychological, social and environment domains, as well as the overall quality of life was found in dementia caregivers as compared to the normal control group. The dementia caregivers group was significantly more disabled compared to normal control group in work, social and environment.

Keywords: Caregivers; Quality of Life; Functional Disability

Introduction

Dementia is characterized by a significant decline in cognitive and physical functioning and is a leading cause of disability in later life [1]. Symptoms include forgetfulness, limited social skills and thinking abilities impairment, which interferes with daily functioning. Caring for someone with dementia is a huge task and many people feel strained [2]. Identifying the functional needs of dementia patients could be helpful to clinicians and primary caregivers to reduce caregiver burden.

Many older adults with dementia are cared for at home, primarily by spouses and adult children. Providing care for patients with dementia can have significant consequences on caregivers, including poorer physical health, increased rates of emotional distress and depression, and a higher risk of mortality than non-caregiving individuals [3].

Dementia caregivers are at risk for cardiovascular diseases, especially hypertension, which is mediated by a chronic inflammatory response and sympathetic over activation [4-6]. Another meta-analysis found overall prevalence rates of 34 and 44%, respectively, of elevated depressive and anxiety symptoms [7].

Through the studying of the bibliography, it is understood that providing for a family member with dementia is a stressful process with negative effects on both physical and mental health of the caregiver affecting the quality of their life. The increased burden of care leads mainly to degradation in QoL of both the caregivers and their patients. It has been confirmed that poor QoL of the caregiver as a result of poor mental and physical health, is a predictor of increased use of health care services by the same, as well as the institutionalization of the patient [8].

Different approaches have been made to find an appropriate definition and measure for the concept of Quality of Life (QoL) in the context of informal caregiving, but due to the multidimensional nature of this concept, no consensus has yet been reached. Some attempts have been made to establish determinants of Caregiver's QoL, finding that lower QoL levels in informal Caregivers seem to be associated with e.g. greater severity of the patient's behavioral problems, higher levels of Caregiver burden and greater levels of depressiveness [9-12].

In their systematic review, Farina and colleagues [13] tried to identify factors predicting QoL in Caregivers of people with dementia and found that Caregiver's better physical health, mental and emotional well-being (i.e. lower levels of depression, anxiety and perceived burden), greater Caregiver independence, self-efficacy and coping skills were related to Caregiver's QoL.

Caregivers of patients with both functional and cognitive impairment experienced higher burden and poorer QoL than those who take care of patients with only one impairment-symptom in 276 female-spouse caregivers, aged 78 - 83 years old, to the study of Tooth, *et al.* (2008) [14]. In a study of Rosness, *et al.* (2011), for QoL and depression of caregivers of patients with early onset dementia, it appeared that the QoL was associated positively with increased age of caregivers but also awareness by patients of their condition [15].

Purpose of the Study

The purpose of this study was to explore the dimensions of Quality of Life in a sample of dementia caregivers experiencing high levels of distress due to their caregiving role and to examine different predictors of these dimensions of caregiver burden. We sought to explore the relationships between the various aspects of caregiver burden and demographic variables, caregiver depression, and patients' behavioral symptoms and cognitive and functional status.

Materials and Methods

The study aimed to assess the quality of life and disability between caregivers of dementia patients and a normal control group. It was a cross-sectional hospital-based study carried out at Jawaharlal Nehru Medical College, Aligarh Muslim University, Uttar Pradesh India during the period of the year 2017 - 2018. The sample size consisted of 40 cases of dementia caregivers and 40 healthy matched controls, enrolled for the study after obtaining ethics committee approval. The caregivers who meet the inclusion criteria were matched with healthy controls age 18 - 45 of both sexes willing to participate in the study and who gave their consent. Purposive sampling technique was used and a semi-structured Socio-demographic Performa specially designed for the study along with the scales was administered.

Tools used

Sheehan disability scale (SDS)

David Sheehan gave it in the year 1983 (Sheehan, 1996). The SDS is a 3-item self-report questionnaire that assesses the level of impairment experienced due to illness in social, occupational, and family life. The impairment scores for each domain (possible scores range

from 0 to 10) and the total score is calculated summing scores on each of three domains (possible scores range from 0 to 30). Higher scores indicate higher impairment [16].

Whoqol-Bref

Contains the 26 items divided into four domains that are physical health, psychological, social relationships and environmental. The scale is clinically rated 5-point rating scale ranging from 1 (not present) to 5 (severe). The test-retest reliability coefficients ranged from 0.41 to 0.79 at item/facet level and 0.76 to 0.80 at domain level (all $p < 0.01$) [17].

Statistical analysis

In this study, the data was evaluated using the Statistical Package for the Social Sciences (SPSS Inc. version 17.0). The Statistical techniques used for analyzing data were frequencies, percentages and correlations. The statistical significance value was set at $p < 0.05$.

Results

In the present study, the mean age of dementia caregivers group was 28.5 ± 7.7 years. Majority of caregivers were females, married, self-employed, Hindu coming from a rural background and belonging to the nuclear family. The analysis of socio-demographic profile revealed that both group’s caregivers and healthy controls were similar in respect to age, education, income, and gender, marital status, employment, religion, residence and type of family.

Table 1 shows a comparison of Quality of life in Caregiver group (N = 40) and Control group (N = 40) using WHO-QOL BREF scores on various domains, i.e. physical, psychological, social and the environment as well as on total score for quality of life; applying independent t-test. Results showed statistically significant differences in quality of life in all domains as well as on the overall quality of life in both groups. It showed poor quality of life in physical, psychological, social and environment domains as well as on total score for quality of life in dementia caregivers as compared to the control group.

Variables	Caregivers Group (N = 40)	Normal Control Group (N = 40)	t (df = 78)	p
	(Mean ± SD)	(Mean ± SD)		
Physical QOL	23.88 ± 2.18	25.88 ± 1.18	-4.21	<.001***
Psychological QOL	13.11 ± 1.99	25.08 ± 1.47	-30.89	<.001***
Social QOL	11.10 ± 1.37	12.78 ± 0.67	-5.90	<.001***
Environment QOL	18.99 ± 2.91	33.10 ± 1.89	-23.26	<.001***
QOL (Total score)	66.94 ± 5.13	95.63 ± 2.96	-30.15	<.001***

Table 1: Comparison of quality of Life in caregivers of patients with dementia and normal control group.

Table 2 shows a comparison of Disability in dementia caregivers group (N = 40) and normal Control group (N = 40) using an independent t-test on the Sheehan Disability Scale (SDS) scores on various domains. Results showed statistically significant differences in disability in all domains, i.e., Work, Social, Family Life, as well as total disability scores in both the groups. The caregivers were significantly more disabled compared to the control group.

Discussion

Caregivers of dementia patients are often called invisible second patients as they face a variety of challenges that change their life completely. Several studies have found that caregivers are at higher risk of negatively affecting both their physical and mental health as

Variables	Caregivers Group (N = 40)	Normal Control Group (N = 40)	t (df = 78)	p
	(Mean ± SD)	(Mean ± SD)		
Work	5.98 ± 0.83	1.31 ± 0.79	30.59	<.001***
Social	5.98 ± 0.86	2.30 ± 0.97	18.89	<.001***
Family Life	5.76 ± 0.90	0.73 ± 0.90	21.80	<.001***
Disability (Total)	18.03 ± 1.78	4.20 ± 2.18	32.95	<.001***

Table 2: Comparison of disability in caregivers of dementia patients and normal control group.

compared to non-caregiving subjects of the same age and population [18,19]. Pinquart and Sörensen [19] found significantly higher levels of perceived stress in caregivers compared to non-caregivers, which is associated with greater physical health problems and a higher risk of developing psychological and psychiatric illnesses, as well as higher mortality rates [20-22].

The present study has examined the quality of life and functional disability of dementia caregivers in comparison to the normal control group. Results demonstrated significant differences between the two groups on quality of life and disability. Caregivers of dementia patients showed the poorer quality of life as well as a functional disability when compared to the normal control group. Statistically significant differences in quality of life in all domains as well as on the overall quality of life in both the groups were found. Results showed poor quality of life in physical, psychological, social and environment domains as well as on total score for quality of life in dementia caregivers as compared to the control group. Results also revealed statistically significant differences in disability in all domains, i.e. Work, Social, Family Life, as well as total disability scores in both the groups. The caregivers were significantly more disabled compared to the control group.

In line with previous literature, the results of the present study also showed a poorer overall quality of life and functional disability among the caregivers of dementia patients as compared to the normal control group.

Conclusion

The study reveals a significant amount of disability and decreased quality of life as compared to healthy controls. Additional research is needed to assess which aspects of QOL and psychosocial functioning can be helped by therapies so that that specific treatment approaches can be planned.

Limitations of the Study

The patients selected from only one medical college, and hence the results cannot be generalized. Studies with community sample or even taking different medical colleges from all parts of India are needed more so with a longitudinal study design.

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