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Determinants of quality of life among the caregivers of persons suffering from dementia

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ABSTRACT

Aim: Dementia is a chronic and progressive neurodegenerative disorder resulting in impairment of cognition and behaviour. Caring for person with dementia results in significant stress and this study aims to assess the quality of life of caregivers of patients suffering from dementia and the factors associated with it in the semi urban South Indian population

Methodology: This study was conducted in the outpatient of the department of Psychiatry at a tertiary care hospital in south India. Persons over the age of sixty years meeting the diagnosis of dementia according to ICD 10 criteria along with the carers who were staying with them for at least a year were included in the study. Quality of life of the care givers which is the primary outcome measure of this study was assessed using the WHOQOL BREF version.

Results: Half of the caregivers included in the study had poor quality of life. Some of the factors that predict poor quality of life among the caregivers are being unmarried or widowed, having comorbid physical illness, presence of behavioural and psychological symptoms in patients with dementia.

Discussion: The results emphasize the importance of caring the caregivers and the management should be considered as a unit and treatment should not only focus on the patients but also on their caregivers.

Conclusion: The findings of our study suggest that the caregivers of the persons suffering from dementia have poor quality of life. Female caregivers, elderly caregivers and with history of comorbid illness, the caregivers of dementia patients with behavioural and psychological symptoms have poor quality of life.

Key Words: Dementia, Caregiver, Quality of life, WHOQOL- BREF

INTRODUCTION

Dementia is a syndrome due to disease of brain, usually of a chronic or progressive nature in which there is disturbance of multiple cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied and occasionally preceded by deterioration in emotional control, social behaviour or motivation.¹

This growth in the number of elderly is inevitably accompanied by an increase in the number of people with age related diseases especially Dementia.² It is critically important to recognize that dementia strikes a family unit and is not

limited to the effects on the individual manifesting the cognitive impairment. Dementia progresses from a mild syndrome to increasingly severe impairment where the individual needs help with every activities of daily living.³ Most studies have found that depressive and anxiety symptoms in caregivers of people with dementia are strongly associated with care recipients behavioural and psychological symptoms particularly depression.⁴

Caregivers are often faced with the loss of friends, privacy and leisure opportunities. The combination of these factors increases the risk that caregivers become isolated in their situations which in turn can lead to increased depression, social deprivation and poorer quality of the caregiving. As

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dementia progresses caregivers give up most of their activities to provide more time for care giving leading to enormous stress and related problems.^{5,6}

There are many factors found to worsen caregiver quality of life including strained finances, poor family functioning, difficulty patient behaviour, financial burden and the amount of time caregivers spend caring for dementia patient.^{7,8} There are lot of studies for the western world about caregiving aspects, factors that increase the carer burden and affecting their quality of life. We know that there are significant differences in our culture compared to the western world. In our society most of the care giving is done by family members also called informal carers in contrast to the developed countries where formal care arrangements are readily available. In this study, we try to assess the quality of life of caregivers of patients suffering from dementia and the factors associated with it in the semi urban South Indian population.

METHODOLOGY

This study was conducted in the outpatient of the department of Psychiatry at a tertiary care hospital in south India. The multi-speciality teaching hospital provides care to patients with a wide variety of disorders. The study subjects include 41 elderly persons suffering from Dementia along with their caregivers.

Persons over the age of sixty years meeting the diagnosis of dementia according to ICD 10 criteria along with the carers who were staying with them for at least a year were included in the study. Persons having comorbid severe mental illness, substance abuse except tobacco and other degenerative disorders were excluded from the study. Informed consent was obtained from the study subjects and their carers. Ethical approval was obtained from the institutional ethics committee.

Demographic details of the patient and the caregivers were obtained using a semi structured proforma specifically designed to capture the relevant factors that will impact on the quality of life of the caregivers as known from the previous studies. Study subjects were screened for cognitive impairment using the Mini Mental State Examination (MMSE).⁹

Quality of life of the care givers which is the primary outcome measure of this study was assessed using the WHOQOL BREF instrument which is a shorter version of the original instrument. It covers 4 domains 1) Physical health (item no 3, 4, 10, 15-18), 2) Psychological health (item no 5-7, 11, 19, 26), 3) Social relationships (item no: 20-22) and 4) Environment (item no 8, 9, 12-14, 23-25). In addition two items on general wellbeing (item no 1 and 2).¹⁰ Each item is scored between 1 and 5 except for item 3, 4 and 26 which are scored in a reverse manner. Domains were derived via a polytomous

scoring algorithm which is adjusted for relative order of the items and converted onto a 0-100 scale.¹¹ The psychometric property of the brief version is comparable to the full version WHOQOL group 1998. A high correlation of domain score (0.89) between the four domains of the two scales has been established. The scale has established discriminate validity, content validity, test and retest reliability and internal consistency. Final scoring and calculation for analysis is done by using formula as per SPSS syntax editor.

RESULTS

The age of the persons suffering from dementia ranged from 63 to 83 and the mean was 69.88 (sd 5.08). Of the total sample 68.3% were women and 31.7% were men. 65.9% came directly to the psychiatry while 34.1% were referred from other departments. Hindus constituted 65.9%, of the sample, Christians and Muslims were 17.1% each, 39% belong to nuclear family type and 59% joint family type. Of the total sample 58% were married and 39% were widowed. 75.6% had completed high school and 24.4% did not complete high school. 9.8% depend on pensions for their source of income, 36% from Savings, 22% income from other sources, 24% depend on children and 7.3% Dependence on others. (Table 1)

The age of the caregivers ranged from 42 to 76. The mean age of the caregiver is 59.12 (sd 10.35). Of the caregiver sample, 46.3% were women and 53.7% were men. 48.8% of the caregivers were spouses, while 19.5% were daughters, 22% were sons and 9.8% are daughters in law. The mean age of spouse is 69.22 (sd 5.3). Of the caregivers 2.4% were illiterate, 9.8% had completed primary education, 17.1% had completed middle school education, 24.4% had completed high school, 19.5% had completed intermediate or post high school diploma, 17.1% had graduated and 9.8% are post-graduates. 58.5% of the caregiver study sample has time for religious activities. (Table 1)

Table 1: Demographic variables of persons suffering from dementia and their caregivers

Demographic variables	Persons with dementia (41)	Caregivers (41)
Age in years	Mean age - 69.88	Mean age -
<70	49%	59.12
>70	51%	43%
		57%
Sex		
Women	68.3%	53.7%
Men	31.7%	46.3%
Education		
>high school	75.6%	29.3%
<high school	24.4%	70.7%

Occupation		
Home maker	36%	39%
Professional		12.2%
Semi-skilled		48.8%
worker	74%	
Retired		
Income		
<15000	65%	78%
>15000	35%	22%
Marital Status		
Married	58.5%	82.9%
Unmarried	2.5%	2.4%
Widowed	39%	14.6%
Family h/o depression		
Yes	17%	13%
No	83%	87%
Relationship with the patient		48.8%
Spouse		19.5%
Daughter		22%
Son		9.8%
Daughter in law		
Time spent with the patient		
Full time		75.6%
Part time		24.4%
Religious activities		
Yes		58.5%
No		41.5%

Mean duration of illness of dementia is 2.21 years (sd 1.33). The mean duration of treatment for dementia is 1.70 years (sd 1.11). Of the subtypes of dementia in study sample, 63.4% had Alzheimer s dementia, 22% vascular Dementia, 12.2% Parkinson disease dementia and 2.4% others (post head injury Dementia). 63.4% have history of behavioural and psychological symptoms of Dementia. On screening with Mini Mental Status Examination, scores ranged from 5 to 24 with meanof 15.9 (sd 4.9). In patients suffering from dementia, 37.5% have comorbid diabetes Mellitus, 34.1% hypertension, 40% have osteoarthritis, 4% have respiratory Distress, 10% sustained fractures in the past, 7% history of cerebrovascular accident in the past. 17% of the total sample has family history of depression.

20% of the caregivers have a past history of depression. On studying history of comorbid physical illness among the caregivers 43.9% have comorbid diabetes mellitus, 26% have hypertension and 24.3% have osteoarthritis (Table 2).

Table 2: Clinical variables of persons with dementia and their caregivers

Clinical variables	Persons with dementia	Caregivers
Past h/o physical illness		
Diabetes	37.5%	43.9%
Hypertension	34.1%	26%
Osteoarthritis	40%	24.3%
Respiratory distress	4%	
Cerebrovascular accident	7%	
Fractures	10%	
Past h/o depression		
Yes		20%
No		80%
Type of dementia		
Alzheimer’s type	63.4%	
Vascular dementia	22%	
Parkinson’s type	12.2%	
Dementia followed by head injury	2.4%	
BPSD		
Yes	63.4%	
No	36.6%	

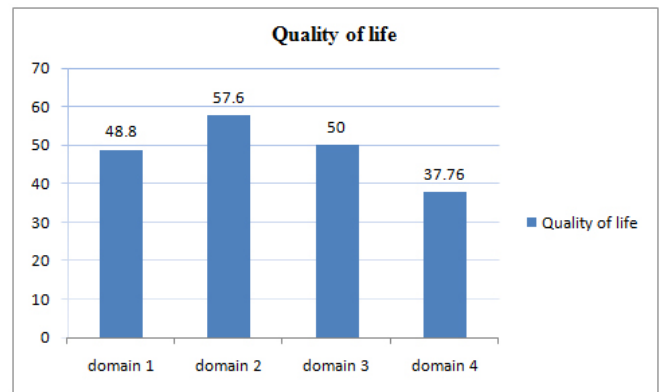


Figure 1: Mean quality of life among the caregivers

The quality of life of the caregiver was assessed by WHO Quality of life scale BREF which has 26 items with 4 domains. The first domain denotes the physical health, the scores ranged from 13 to 81, the mean being 48.8 (sd 20.25). The second domain denotes the psychological health, the scores ranged from 13 to 88, the mean of 57.66 (sd 19.56). The third domain denotes the social relationships and the scores ranged from 19 to 75, the mean being 50.02 (sd 22.65). The fourth domain denotes the environmental, with scores ranging from 13 to 69 with mean of 37.76 (sd 18.6).

In this study, a score of 50 was taken as overall mean score of quality of life across all domains and scores above the mean was taken as having good quality of life. Correlation statistics was obtained to find any demographic or clinical factors among the patient or their caregiver would affect the perceived quality of life in the carer. Percentage of people who scored less than 50 in each domain suggesting poor

quality of life indicating positive correlation is given below (Table 3 – 5).

Table 3: Correlation between caregiver marital status and quality of life

Marital status	Domain 1	Domain 2	Domain 3	Domain 4
Single	0%	100%	100%	100%
Married	41.2%	50%	35.3%	32.4%
Widowed	100%	100%	100%	0%
Pearson chi square	0.01	0.05	0.05	0.08

Table 4: Correlation between caregiver comorbid physical illness and quality of life

Physical illness	Domain 1	Domain 2	Domain 3	Domain 4
No	11.8%	47.1%	17.6%	17.6%
Yes	48.8%	58.5%	46.3%	29.3%
Pearson Chi Square	0.05	0.07	0.02	0.06

Table 5: Correlation between presence of behavioural and psychological problems in patients with dementia and the caregiver quality of life.

BPSD	Domain 1	Domain 2	Domain 3	Domain 4
Yes	65.4%	88.5%	61.5%	46.2%
No	20%	6.7%	20%	0%
Chi square	0.005	0.00	0.10	0.02

From table 3 – 5, it is evident the caregivers who are either unmarried or widowed, who have comorbid physical illness, presence of behavioural and psychological symptoms in patients with dementia are found to have poor quality of life across all domains. According to this study there is no correlation between the duration of the illness and duration of stay of the caregiver with the patient.

DISCUSSION

There has not been many studies conducted in developing world where there is major demographic shift is ongoing with lot of aging population and associated health care problems. This study helps us to understand the impact of a degenerative illness among the caregiver. As evident from previous studies patients suffering from dementia with as-

sociated behavioural and psychological symptoms have significant stress and poor quality of life. The results from this study confirm the findings from earlier studies that significant percent of carers have poor quality of life. The higher the age of the patient, poorer quality of life of the caregiver as the cognition worsens with age and patients becoming more dependent on the carer.¹¹⁻¹³

Caregivers who are single or widowed have poor quality of life as they themselves are in need emotional and social support. Caregivers who are spouses and daughters have poor quality of life as they have close relationship with the patient prior to the onset of the illness compared to others seeing the gradual decline in functioning. There is a positive correlation between quality of life of the caregiver and the comorbid physical illness as it limits their ability to provide the required level of care and some carers develop sense of guilt feelings leading to poor quality of life.^{15, 16}

The positive correlation between quality of life of the caregiver of persons suffering from dementia with behavioural and psychological problems has been noted in several studies and it includes agitation, aggressive behaviour, wandering behaviour, perception abnormalities, thought content mood or behaviour, hoarding and disinhibited behaviour. These symptoms have a significant impact on the quality of life of the caregiver.¹⁷⁻²⁰

The poor quality of life of the caregivers would affect the care given by them to the persons suffering from dementia. This will further increase the cognitive as well as behavioural problems of the patient thus becoming a vicious cycle. Hence persons suffering from dementia along with their relatives have to be considered as a unit and treatment should not only focus on the patients but also on their caregivers.

The limitations of the study are its low sample size, being a hospital based sample, the results are not truly representative of the community and a comparative group would have strengthened the findings of this study.

CONCLUSION

The findings of our study suggest that the caregivers of the persons suffering from dementia have poor quality of life. Female caregivers, elderly caregivers and with history of comorbid illness, the caregivers of dementia patients with behavioural and psychological symptoms have poor quality of life. The need for good psychosocial support to the caregivers of the dementia persons is needed. Application of recent advances in medical therapies and treatment of behavioural problems along with support to the caregivers would go a long way in reducing the stress.

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