



## QUALITY OF LIFE AMONG CAREGIVERS OF PERSONS WITH DEMENTIA

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### ABSTRACT

Dementia is a multifactorial syndrome that requires high levels of care, which are provided by informal structures, mainly the family. However, support from the family caregiver comes at a cost, with high levels of burden, psychological morbidity, poor physical health, social isolation and financial difficulties. The objective of the study was to assess the quality of life among caregivers of persons with dementia. The sample comprised of 50 Caregivers of persons with dementia. The data collected from NIMHANS Geriatric Clinic. The patients who fulfilled the inclusion and exclusion criteria were identified based on information from the patient undergoing treatment at geriatric clinic in NIMHANS were selected using simple random sampling. The following tools were used for the current study: Socio-demographic data sheet was used to study the socio demographic details of the caregivers of persons with dementia and to measure Quality of life WHO QOL was used. The result found that caregivers of patients with dementia experienced poor quality of life in all the domains of quality of life. And also it shows that caregivers of patients with dementia who come from joint family experienced better quality of life and who come from urban background has better quality of life.

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### INTRODUCTION

The international working group for the harmonization of dementia guidelines has recommended that quality of life be included as an outcome measure in dementia trials. Despite the growing consensus about the need to measure quality of life in dementia trials, there is a lack of agreement about how to define and measure quality of life in keeping with the World Health Organization's definition of health, health-related quality of life is generally considered to be a multidimensional construct that includes physical health, mental health, social function and general well-being. Numerous different quality of life measures have been developed, which can be categorized into disease specific or generic measures. Studies of caregiver outcomes have tended to focus more on constructs such as burden, affect and physical health than on quality of life. Caregiving for patients with dementia has detrimental effects on caregiver quality of life.

The term "family caregiver" is attributed to people from the close or distant family environment, who care for patients which are unable to cope with daily requirements. Family care differs from the formal (the employed) to the fact that is unpaid, based on ties of affinity and emotional connection of

the caregiver and of the care recipient, the time limits are not defined, and the services that are offered are varied in order to serve the specific needs of the patient(Mace, 1999).

### MATERIALS AND METHODS

The sample comprised of 50 Caregivers of persons with dementia. The data collected from NIMHANS Geriatric Clinic. The patients who fulfilled the inclusion and exclusion criteria were identified based on information from the patient undergoing treatment at geriatric clinic in NIMHANS were selected using simple random sampling. The following tools were used for the current study: Socio-demographic data sheet was used to study the socio demographic details of the caregivers of persons with dementia and to measure Quality of life WHO QOL was used.

### RESULTS

The results show the different age categories of caregivers of dementia such as 42% of caregiver between the age group of 25-35 years, 20% between 36-45 years, 18% between 46-55 years, 12% between 55-65 years and similarly 8% of caregivers of dementia 66-75 years. In terms of family type, the study revealed that 72% of the caregivers belonged to

nuclear family and 28% belonged to Joint family.

**Table-1** Socio demographic variables

Variables	Frequency	Percentage
<b>Caregiver age classification</b>		
25-35	21	42 %
36-45	10	20 %
46-55	9	18 %
56-65	6	12 %
66-75	4	8 %
<b>Family type</b>		
Joined	14	28 %
Nuclear	36	72 %
<b>Religion</b>		
Hindu	45	90 %
Muslim	3	6 %
Christian	2	4 %
<b>Domicile</b>		
Rural	22	44 %
Urban	28	56 %
<b>Educational Qualification</b>		
Illiteracy	4	8.0%
Primary	10	20.0%
High school	8	16.0%
PUC	15	30.0%
Graduate and above	13	26.0%
<b>Occupation</b>		
Business	5	10 %
Farmer	7	14 %
Government	7	14 %
Retired government servant	4	8 %
Private	9	18 %
Home maker	15	30 %
Unemployed	12	4 %
Daily wage labourer	1	2 %

In terms of religion the study sample shows that 90% of the caregivers were belonging to Hindu religion, 6% were Muslim and remaining 4% were belonging to Christian. The result suggests that the majority of caregivers 56% were from urban background and 44% of the caregivers from rural background. The result shows that majority of i.e 30% of the caregiver were homemaker, 18 % were private job holder, 14 % were farmers, 14% were Govt servants, 10% were business, 8% were RetdGovt servants, 6% were private job, 2% were daily wage labourer and 4% were unemployed. The result also shows that majority of the caregiver studied up to PUC 30%,

The above table shows the mean value of the quality of life for the caregivers. And it was found that in the physical health domain the mean value 66.10 (SD=9.02), psychological quality of life for the caregivers found to be 53.25 (SD=10.42), social quality of life for the caregivers found to be 65.50 (SD=12.02) and Environmental quality of life for the caregivers found to be 56.50 (SD=9.38).

The above table shows that there is a significance difference was seen with respect to the Quality of Life among the caregivers based on the family type of the caregiver ( $t=2.327$  &  $p .005$ ) between Joint and Nuclear type of the family. The mean score of between joint and nuclear type of family (72.0238) was found the family type which is joint family is having much physical health than Nuclear family.

The above table explains that there is a high significance difference was seen with respect to the Psychological Health Quality of Life among the caregivers based on their residence ( $t=2.327$ ,  $p .05$ ). Rests of the dimensions of quality of life were not found to be significantly differing.

**DISCUSSION**

The results show that majority the caregivers age groups between 25-35 years (42%), studied up to PUC (30%) and mostly were home Maker (38%), belonging to Hindu religion 45(90%), staying in urban area is 28 (56%) , nearly three fourth 36 (72%) of the caregivers belonged to nuclear family type. This study results match with previous study done by Rosdinom (2001) and the author found that most of the caregivers were in the middle age group (mean age of 49.23 years), (66.2%) were female, (55.4%) were Malays, majority were married (81.5%), mostly were patients’ own daughters (40%), still employed (55.4%), and enjoyed shared caregiving with other family members (58.5%). Most of them had educational level up to secondary school level (43.1%) and reported no financial difficulties (81.5%).

**Quality of life of the caregivers**

Caregivers of patients with dementia experienced poor quality of life in all the domains.

**Table No-2** Level of quality of life of the Caregivers

Quality of Life	N	Range	Min.	Max.	Mean	SD
Physical health	50	42.86	42.86	85.71	66.1071	9.02996
Psychological health	50	58.33	29.17	87.50	53.2500	10.42228
Social Relationship	50	66.67	33.33	100.00	65.5000	12.02440
Environment	50	46.88	40.63	87.50	56.5000	9.38223

**Table No-3** Differences of Quality of life among caregivers based on the Family type

Quality of Life	Family type	N	Mean	SD	t	p
Physical health	Joint	14	67.0918	10.77625	.427	.674
	Nuclear	36	65.7242	8.39551		
Psychological health	Joint	14	54.7619	13.94981	.524	.607
	Nuclear	36	52.6620	8.86141		
Social Relationship	Joint	14	72.0238	12.91290	2.327	.030*
	Nuclear	36	62.9630	10.80940		
Environmental	Joint	14	58.0357	9.55078	.713	.483
	Joint	14	58.0357	9.55078		
	Nuclear	36	55.9028	9.38326		

complexity of the treatment, the continuous commitment of the person who cares, the inadequacy of social services, consequent effects from emotional and interpersonal relations, direct and indirect costs of care, have a significant effect on the social, psychological and physical integrity of the caregiver. Care is considered to be very demanding, especially in emotional involvement while the continuous commitment to it leads to physical and mental health problems, burden and degradation of Quality of life.

away from caregiving) likely affect outcomes relevant to patients such as time to institutionalization. Our first step was to assess what kinds of caregiver measures were available in the literature. The current study result on Differences of Quality of life among caregivers on the basis of Residence shows that there was a high significance differences was seen with respect to the Psychological Health among the caregivers based on their residence ( $t=2.327$ ,  $p .05$ ).

**Table No-4** Differences of Quality of life among caregivers on the basis of Residence

Caregiver Quality of Life	Residence	N	Mean	SD	t	p
Physical health	Rural	22	65.0974	9.60416	.688	.495
	Urban	28	66.9005	8.64609		
Psychological health	Rural	22	49.6212	8.90027	2.327	.024*
	Urban	28	56.1012	10.78707		
Social relationship	Rural	22	66.2879	15.31790	.383	.704
	Urban	28	64.8810	8.88806		
Environment	Rural	22	54.6875	8.98235	1.227	.226
	Urban	28	57.9241	9.60302		

(Riedijk, 2006. Kurz, 2003, Serrano-Aguilar, 2006 & Markowitz, 2003). Extensive review of primary research studies reveal that individuals who provide care to persons with AD may be at risk for more emotional and physical problems due to their caregiving responsibilities (Schulz & Beach, 1999). Alzheimer's disease is known for placing great burden and stress on caregivers from emotional, social, psychological, physical, and economic or financial perspectives. A noted study found that family caregivers for persons with Alzheimer's disease suffer from increased levels of depression (Given, Given, Stommel, & Azzouz, 1999).

#### ***QOL based on socio-demographic variables.***

The current study result on Differences of Quality of life among caregivers based on the Family type indicates that caregivers hailing from nuclear family seem to be less quality of life in terms of social quality of life. The caregivers hailing from joint family seem to be high level of social quality of life. This phenomenon could be because the urban people have less social quality of life because of less availabilities of time. Similarly the quality of life of the caregivers in terms of psychological quality of life is high level in the urban areas. This phenomenon could be because the urban people have high level of accessibility of health services. Providing care for individuals with a progressive, debilitating condition such as dementia can adversely impact the quality of life (QOL) of caregivers in many ways. Studies to assess the impact of new treatments or new ways of delivering care for people with dementia should incorporate instruments that very broadly address not only domains of health-related quality of life, but also non health-related quality of life, because these dimensions (for example perceptions of family involvement in caregiving, caregiver's perceptions of having personal time

## **CONCLUSION**

The results found that caregivers of patients with dementia experienced poor quality of life in all the domains of quality of life. And also it shows that caregivers of patients with dementia who come from joint family and from urban background has better quality of life.

#### **Conflict of Interest**

The Authors declares that there is no conflict of interest.

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