

Quality of life in caregivers of persons with mental retardation and chronic schizophrenia: A comparative study

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Abstract

Introduction: The caregivers of persons with chronic psychiatric disability experience considerable amount of burden leading to a poor quality of life (QoL). **Aim:** The aim of the present study was to assess the QoL of caregivers of persons with mental retardation and compare them with caregivers of persons with chronic schizophrenia. **Method:** The sample comprised of 30 caregivers of patients with mental retardation and 35 caregivers of chronic schizophrenia patients. After informed consent, the caregivers were assessed on a semi structured socio-demographic proforma and Hindi version of WHOQoL - Bref (World Health Organization Quality of Life – Bref). The patients were assessed using SOFAS (Social and Occupational Functioning Assessment Scale). **Results:** The scores of caregivers of persons with mental retardation were not significantly different from caregivers of chronic schizophrenia. Female gender and lower socio-economic status was associated with poor quality of life among schizophrenia caregivers. **Conclusion:** The findings should be considered while planning intervention services for the caregivers of the persons with schizophrenia and intellectual disability.

Key words: Quality of life, Caregivers, Schizophrenia, Mental retardation

Introduction

The families of persons with chronic mental disorders and mental retardation undergo considerable caregiving stress on a regular basis. Patients' illness affects the QoL of relatives⁷. Caregivers are the directly affected population on whom people with chronic psychiatric conditions such as schizophrenia and mental retardation depend for lifelong support. The prevalence of psychological ill health in families of schizophrenia patients has been reported to be upto 75%⁸ and psychological distress in caregivers of schizophrenia is around twice that expected in general population.⁹

Quality of life (QoL) measurement is an important parameter which draws attention to an individual's perception of positive and negative dimensions of life.⁶ Quality of life has been construed as subjective perception of life satisfaction, happiness, social relationships, physical health and feeling of well being. It is a uniquely personal perception denoting the way individuals feel about their health status and nonmedical aspects of their lives. However, some researchers have emphasized on objective assessment of quality of life by measuring income, type of housing, occupation and physical health.

In families caring for children and persons with mental retardation, social restrictions and impact on psychological, physical and financial well being has been reported.¹⁰ As family's perception of stress increases, their quality of life decreases.^{11,12} This is more relevant in Indian setting where there are strong and close emotional bonds among the family members. Hence, if one member falls ill, it affects the whole family's functioning by producing emotional turmoil. Quality of life of caregivers is also important because it affects the outcome of a disorder.

The main aim of this study was to assess QoL of caregivers of persons with mental retardation and compare with QoL of caregivers of chronic schizophrenia patients. A subsidiary aim was to determine the relationship of level of performance in persons with mental retardation and chronic schizophrenia with the QoL of their caregivers. The caregivers of persons with schizophrenia have been taken as a comparison group because schizophrenia like mental retardation is a chronic psychiatric disorder needing regular care, supervision and assistance by the caregivers.

Materials and method

The data collection was carried out in the outpatient department of Psychiatry at Govt. Medical College and Hospital (GMCH), Chandigarh and at Govt. Institute for Mentally Retarded Children (GIMRC), Chandigarh.

The study group comprised of adult caregivers of persons with mental retardation (IQ between 20-69, aged 8-18 years, attending special school for last at least one year and having no significant comorbid illness). The control group comprised of adult caregivers of chronic schizophrenia patients (diagnosed according to ICD-10,¹³ who had the illness at least for two years, were stable for at least last

three months and having no significant comorbid illness).

Caregivers in both the groups were included if they fulfilled the following criteria: (a) first degree relative or spouse staying with the subject (b) age between 20-59 years (c) staying in same household and taking care of patient for a minimum period of last one year (d) no comorbid psychiatric or major chronic physical illness (e) no other family member having major psychiatric illness, mental retardation or chronic physical illness to care for and (f) willing to participate.

After obtaining consent and assuring confidentiality, the caregivers were assessed on a semi structured socio-demographic proforma and Hindi version of WHOQOL - Bref (World Health Organization Quality of Life - Bref).¹⁴ The patients of mental retardation and schizophrenia were assessed on SOFAS (Social and Occupational Functioning Assessment Scale)¹⁵ to have a group with score not less than 20.

Results

A total of 30 caregivers of patients with mental retardation and 35 caregivers of persons with schizophrenia participated in this study. The sociodemographic characteristics are shown in Table 1.

The SOFAS score showed no significant difference between the caregivers of schizophrenia patients (Mean = 50.8, s.d. = 7.7) and caregivers of persons with mental retardation (Mean = 47.3, s.d. = 7.5). Quality of Life (QoL) scores on the four domains of care providers of the two groups showed no significant difference except domain 2. On domain 2 assessing psychological health, the QoL score of caregivers for mental retardation significantly correlated with SOFAS score (Table 2). There was no significant correlation between QoL

Table 1: Socio-demographic variables of caregivers

Variables	Caregivers		t / ζ (p)
	Mental retardation group (n = 30)	Schizophrenia group(n=35)	
Age (in yrs)	45.7 \pm 9.2	43.4 \pm 11.1	0.910 (p > 0.05)
Gender			
Male	15	17	0.013
Female	15	18	(p > 0.05)
Marital status			
Single	—	04	4.66
Married	29	28	(p>0.05)
Others	01	03	
Family type			
Nuclear	19	22	0.085
Extended	04	04	(p>0.05)
Joint	07	09	
Religion			
Hindu	20	26	1.406
Sikh	09	09	(p>0.05)
Others	01	—	
Income (in Rs/month)			
0-3500	06	16	10.78
3501-7000	10	15	(p<0.05)
7001 & above	14	04	
Education			
Illiterate	02	07	10.85
Primary	02	05	(p<0.05)
Middle	01	03	
Matriculate	03	07	
Diploma/Inter	03	04	
Graduate	09	06	
Postgraduate	10	03	
Occupation			
Skilled/semi-skilled	11	09	14.33
Teaching/semi-prof	06	01	(p<0.05)
Agriculture/business	—	05	
Administrative etc	—	01	
Housewife	06	15	
Retired	07	04	
Locality			
Urban	25	26	2.573
Rural	04	09	(p>0.05)

domains of caregivers and IQ of mentally challenged persons.

Only female caregivers of schizophrenia patients reported significantly low (p<0.05) QoL score on domain 1 assessing physical health (Mean = 11.78, s.d. = 2.02) compared to males (Mean = 13.35, s.d. = 2.47). There was no

significant gender difference in care givers for mental retardation.

The caregivers of schizophrenia patients with monthly income less than Rs.7001/- had significant correlation with QOL in domain 4 assessing environmental health, while domain 1,2,4 on QoL scale assessing Physical,

Table 2: Relationship between QoL and SOFAS scores

QoL domain	SOFAS	
	Mental retardation group	Schizophrenia group
Domain 1 (Physical)	0.186	0.095
Domain 2 (Psychological)	0.353*	0.163
Domain 3 (Social)	-0.059	0.112
Domain 4 (Environmental)	0.288	0.310

*P<0.05

Psychological and Environmental health in caregivers of mental retardation were significantly affected in income group less than Rs. 3501/- per month (Table 3a & 3b).

Discussion

The QoL of the caregivers in both the groups was comparable. This indicates that both schizophrenia and mental retardation are

Table 3a: Relationship of QoL to Income of mental retardation caregivers

Domain	(0-3500) (i)	(3501-7000) (ii)	(7001& above) (iii)	t (between)	p
1. Physical	12.1 ± 2.5	12.4 ± 2.1	14.5 ± 1.9	-0.2 (i-ii) -1.7 (i-iii) -1.7 (ii-iii)	p > 0.05
2. Psychological	11.8 ± 2.4	12.3 ± 1.7	12.5 ± 1.7	-0.6 (i-ii) -0.5 (i-iii) -0.1 (ii-iii)	p > 0.05
3. Social	10.9 ± 2.4	11.6 ± 1.9	12.7 ± 1.7	-0.8 (i-ii) -1.3 (i-iii) -1.0 (ii-iii)	p > 0.05
4. Environmental	11.3 ± 2.1	11.8 ± 1.3	13.5 ± 0.5	-0.8 (i-ii) -1.9 (i-iii) -2.4 (ii-iii)	p > 0.05 (i-ii) p < 0.05 (i-iii) p < 0.05 (ii-iii)

Table 3b: Relationship of QoL to Income of schizophrenia caregivers

Domain	(0-3500) (i)	(3501-7000) (ii)	(7001&above) (iii)	t (between)	p
1. Physical	11.0 ± 2.3	13.2 ± 1.6	14.0 ± 2.1	-2.1 (i-ii) -2.7 (i-iii) -0.9 (ii-iii)	p < 0.05 (i-ii) p < 0.05 (i-iii) p > 0.05 (ii-iii)
2. Psychological	10.5 ± 1.2	13.6 ± 1	13.3 ± 2.2	-5.3 (i-ii) -2.8 (i-iii) -0.3 (ii-iii)	p < 0.05 (i-ii) p < 0.05 (i-iii) p > 0.05 (ii-iii)
3. Social	10.8 ± 2.9	12.5 ± 2.0	12.2 ± 1.9	-1.3 (i-ii) -1.3 (i-iii) -0.2 (ii-iii)	p > 0.05
4. Environmental	9.3 ± 1.8	13.0 ± 1.1	13.8 ± 2.0	-4.9 (i-ii) -4.6 (i-iii) -1.1 (ii-iii)	p<0.05(i-ii) p<0.05(i-iii) p > 0.05 (ii-iii)

comparable in terms of their effect on the caregivers. However SOFAS score of mentally challenged persons significantly correlated with psychological health of caregivers on QOL. This would signify that more the degree of dysfunction in the mentally challenged persons, more will be the psychological distress in the caregivers. An earlier study has also reported higher mental stress in parents of children with intellectual disability.¹⁶ The caregivers of mentally challenged persons with mild to moderate degree of mental retardation may not be affected to the same degree as the caregivers of persons with severe and profound retardation. In an earlier study, the parents of children with Down's syndrome reported significantly different scores in mental health domain.¹⁷

On the physical domain of QoL scale, female caregivers of schizophrenia patients reported a lower score, implying that they have poorer physical functioning compared to their counterparts in mental retardation group. Though mental retardation is a disabling condition, but it begins early and with passage of time, the caregivers might learn to live with it and thus, at the time of study, they might have recovered from the early impact of the condition. In a similar study,¹⁸ elderly black mothers who cared for their adult children with schizophrenia were reported to be vulnerable to chronic physical health conditions though having emotional resilience. The female caregivers of dementia patients had also reported lower QoL on physical domain¹⁹. In another study, 64- 72% of elder female caregivers reported depressive symptoms.²⁰ The strongest predictor of psychological morbidity in the form of clinical depression and anxiety in parents of children with intellectual disabilities was the feelings of guilt.²¹ It is possible that the females who look after the house are also expected to take care of the person who has significant dysfunction, thus

putting extra burden on the female caregivers. The help seeking for medical problems may also be low among females.

Income less than Rs. 3501/- per month showed significant effect on physical, psychological and environmental domains of QoL in care givers of persons with mental retardation. Only environmental domain was significantly affected in care providers of schizophrenia patients having income less than Rs. 7001/- per month. Considering these findings together, the results show that caregivers from lower income group experience significantly more impact on their physical and mental health. An earlier study²² has also reported that individuals from lower household income groups are disadvantaged with regard to indicators of ill health, internal and external satisfaction.

The study had several limitations. The sample size was small and the population studied was restricted to an outpatient clinic and a special school. Also, related variables like coping mechanisms, family burden and social support have not been studied. Other studies have mentioned importance of same.^{23,24}

In conclusion, the study suggests that QoL scores of caregivers of the mentally challenged and chronic mental disorder (schizophrenia) is comparable. The female caregivers of persons having schizophrenia had significantly poor physical health. The caregivers from lower income group showed poor quality of life. These findings need to be taken into account while planning intervention services for the caregivers of the persons with schizophrenia and mental retardation.

References

1. Pai S, Kapur RL. The burden on the family of a psychiatric patient. Development of an interview schedule. *Br J Psychiatry* 1981;

- 138 : 332-35.
2. Greenberg JS, Greenley JR, McKee D, Brown R, Griffin-Francell C. Mothers caring for an adult child with schizophrenia: the effects of subjective burden on maternal health. *Family Relations* 1993; 42 : 205-11.
 3. Tsang HW, Tam PK, Chan F, Cheung W. Source of burdens on families of individuals with mental illness. *Int J Rehab Res* 2003; 26 : 123-30
 4. Jenkins JH, Schumacher JG. Family burden of schizophrenia and depressive illness. *Br J Psychiatry* 1999; 174 : 31-8.
 5. Gopinath PS, Chaturvedi SK. Distressing behaviour of schizophrenics at home. *Acta Psychiatr Scand* 1992; 86 : 185-8.
 6. The WHOQOL Group. The World Health Organization Quality of Life assessment (WHOQOL): Position paper from The World Health Organization. *Soc Sci Med* 1995; 41 : 1403-9.
 7. Ali RM, Bhatti RS. Social support system and family burden due to chronic schizophrenia in rural and urban background. *Indian J Psychiatry* 1988; 30 : 349-53.
 8. The Scottish First Episode Schizophrenia Study. IV. Scottish Schizophrenia Research Group. Psychiatric and social impact on relatives. *Br J Psychiatry* 1987; 150 : 340-4.
 9. Oldridge ML, Hughes IC. Psychological well-being in families with a member suffering from schizophrenia : An investigation into long standing problems. *Br J Psychiatry* 1992; 161 : 249-51.
 10. Roos P. Burden among parents of mentally retarded people. *Int J Ment Health* 1977; 6 : 96-119.
 11. Browne G, Bramston P. Stress and the QOL in the parents of young people with intellectual disabilities. *J Psychiatr Ment Health Nurs* 1998; 5 : 415-21.
 12. Peshawaria R, Menon D, Ganguly R, et al. Parents : Impact. In : *Understanding Indian families having persons with mental retardation*. Secunderabad. National Institute for the Mentally Handicapped 1995; 17-39.
 13. ICD - 10. Classification of mental and behavioral disorders: Clinical description and diagnostic guidelines. World Health Organisation, Geneva. Oxford University Press : New Delhi 1992.
 14. Saxena S, Chandiramani K, Bhargava R. WHOQOL – Hindi : a questionnaire for assessing quality of life in health care settings in India. *World Health Organization Quality of Life. Natl Med J India* 1998; 11 : 160 – 165.
 15. Goldman HH, Skodol AE, Lave TR. Revising Axis V for DSM – I V : A review of measures of social functioning. *Am J Psychiatry* 1992; 149 : 1148-56.
 16. Gupta R, Kaur H. Stress among parents of children with intellectual disability. *Asia Pacific Disability Rehabilitation Journal* 2010; 21 : 118-26.
 17. Hedov G, Anneren G, Wikblad K. Self perceived health in Swedish parents of children with Down's syndrome. *Qual Life Res* 2000; 9 : 415-22.
 18. Magana SM, Greenberg JS, Seltzer MM. The health and well being of black mothers who care for their adult children with schizophrenia. *Psychiatr Serv* 2004; 55 : 711-13.
 19. Golimbet V, Trubnikov V. Evaluation of the dementia carers situation in Russia. *Int J Geriatr Psychiatry* 2001; 16 : 94-99.
 20. Chou YC, Pu CY, Fu LY, Kröger T. Depressive symptoms in older female carers of adults with intellectual disabilities *Intellect Disabil Res*. 2010 Dec; 54 : 1031-

44. doi: 10.1111/j.1365-2788.2010.01332.x. Epub 2010 Oct 26.
21. Gallagher S, Phillips AC, Oliver C, Carroll D. Predictors of psychological morbidity in parents of children with intellectual disabilities *J Pediatr Psychol*. 2008 Nov-Dec; 33 : 1129-36. Epub 2008 Apr 22.
22. Freidl W, Strongegger WJ, Rasky E, Neuhold C. Associations of income with self reported ill health and health resources in a rural community sample of Austria. *Soz Praventivmed* 2001; 46 : 106-14.
23. Urizar AC, Maldonado JG, Castillo CM. Quality of life in caregivers of patients with schizophrenia : A literature review. *Health and Quality of Life Outcomes* 2009; 7 : 84.
24. Pariante CM, Carpiniello B. Family burden in relatives of schizophrenics and of people with mental retardation: a comparative study. *Eur Psychiatry* 1996; 11 : 381-

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