



A STUDY OF CARE GIVER QUALITY OF LIFE IN SPOUSES OF PATIENTS WITH SCHIZOPHRENIA

Mental Health

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ABSTRACT

Background : Schizophrenia is a severe mental illness, resulting in impairing and debilitating worldwide. The primary care giver is expected to meet all the deficiencies of the sick relative leading to reduction in their QOL. So the present study aims to study QOL and factors influencing them, so as to facilitate better prognosis and to improve their QOL.

Aim : To study the caregiver quality of life in the spouses of patients with schizophrenia.

Objectives:

1. To study the quality of life in the spouses of patients with schizophrenia.
2. To study the factors influencing the caregiver quality of life.

Methodology : A consecutive sample of spouses of 100 patients with schizophrenia were taken at IMH, Hyderabad. A semi structured questionnaire was administered to collect the socio demographic details. Followed by IDEAS for measuring and quantifying the mental illness, WHO –QOL BREF to assess the quality of the life respectively. Statistical analysis was done using SPSS.

Results : Mean quality of life in four different domains are : 44.9±15.9 in physical health, 36.2±15.0 in psychological health domain, 37.9±16.8 in social health domain and 37.3±14.4 in environmental health domain . Better QOL is seen in younger age group, post graduates, male gender, urban, extended family, homemakers, who are financially not dependent on the patient, with monthly income > 10,000, who are having no mental illness, no substance abuse and no physical abuse by the patient. Of which age appears to be statistically significant in physical and social domains. The factors like type of schizophrenia and severity of illness strongly associated QOL.

Conclusions: Better QOL is seen in physical health domain and in socio demographic details younger age is found to be significantly associated with better QOL than other details. Psycho-therapeutic techniques like psycho education, family and couple therapy may help in better coping of spouses of mentally ill persons. Group therapy can help spouses in sharing their views and understanding various coping methods employed by others.

KEYWORDS

schizophrenia, spouses, quality of life

INTRODUCTION:

Schizophrenia is a severe mental illness, resulting in impairing and debilitating worldwide. The Global Burden of Diseases Report(1) revealed that schizophrenia mainly contributed to the disability around the world. This disability of the patients has disturbed the capabilities of people with mental illness and in turn could have an effect on their families. In today's world, psychiatric patients receive relatively short inpatient care and early discharge from the hospital, which adds to the important role of a caregiver. In India, where rehabilitation services are almost nonexistent, and there is no social security system, the role of the family becomes more important(2). And also, as system of joint families still exists, the primary care giver is expected to meet all the deficiencies of the sick relative, he may have to confront the stigma associated with it. It may take a toll on his daily routine and on his physical and mental health.

A caregiver has been defined as a family member who has been living with the patient and has been closely involved in his/her activities of daily living, health care, and social interaction for more than a year(3). WHO defines QOL as individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns(4).

It is a wide concept implying many aspects and many interpretations have come from it. QOL concept comprises different dimensions: individual's physical and emotional health, psychological and social well-being, fulfillment of personal expectations and goals, economic assurance, and finally functional capacity to develop daily routines normally (5). Because of the chronicity of the illness, family caregivers have to provide long term care for their loved-one, and this situation in turn could affect to their quality of life as the impact of caregiving.

Caregivers may experience reduced productivity at home and in the workplace thus losing wages (6). This combined with the health care costs for the patients diagnosed with severe mental illness affect the caregivers' financial situation thus creating or worsening poverty(6). Caregivers are also prone to experiencing social consequences including; disrupted social networks, stigma and discrimination, which exposes them to high levels of depression, stress and anxiety(6). These social, economic and psychological changes may greatly impact

on the caregivers' Quality of Life (QoL)(7). several previous studies found that factors influencing QoL of the caregivers consisted of characteristics of caregivers, caregiver burden, perceived control of symptoms, and perceived social support (8).

In the health field, QOL is one of the most important components associated with delivering an integral service to an ill person and their family. In this context, one of the main objectives is the development of supporting activities rather than reducing symptoms and preventing relapses only. Until recently, due to the inclusion of new drugs, research on QOL has been focused on schizophrenia patients rather than their caregivers. Currently, informal and formal caregivers are being considered as a valuable component of an integral treatment for patients, thus their QOL is being evaluated(9).

Therefore it is important to understand their QoL, which may give baseline information on their way of life and guide health workers and policy makers on the development of appropriate interventions to support the caregivers in their role. So the present study aims to study the quality of life and factors influencing the QOL in the spouses of patients with schizophrenia , so as to facilitate better prognosis and to improve the quality of life.

AIM :

To study the caregiver quality of life in the spouses of patients with schizophrenia.

OBJECTIVES:

1. To study the quality of life in the spouses of patients with schizophrenia.
2. To study the factors influencing the caregiver quality of life.

MATERIAL AND METHODS :

study design : A cross sectional study conducted at Institute of mental health, Hyderabad. This is a tertiary psychiatric center ,which is 800 bedded psychiatric hospital. A consecutive sample of spouses of 100 patients with schizophrenia (according to ICD – 10 criteria) , who are both inpatients and outpatients in the family wards were selected. Inclusion and exclusion criteria were assessed. Informed consent in writing was obtained before patients were included in the study. On

first contact with the study subjects, a semi structured questionnaire was administered to both patient and his/her spouse to collect the socio demographic details. This was followed by a detailed physical examination to assess the presence of coexisting physical complications. Positive findings and deficits were recorded. IDEAS (Indian disability and evaluation scale) was administered to the patient for measuring and quantifying the mental illness, followed by administering WHO –QOL BREF to the spouse of the patient to assess the quality of the life, factors influencing the quality of the life respectively.

INCLUSION CRITERIA:

1. Spouses of schizophrenia patients, who were diagnosed as per ICD-10.
2. Who has given written informed consent.
3. 18-60 years of age, either gender.
4. Patients with schizophrenia more than 2 years.
5. Spouses who are living with the patient over a period of 2 years.

EXCLUSION CRITERIA:

1. Patients with mental retardation, organic brain disease ,major medical illness like HTN, DM, etc.
2. Who did not give the consent.
3. Spouses who had mental retardation, major medical illness like HTN, DM, etc.

STATISTICAL ANALYSIS:

Statistical analysis was done using statistical package for the social sciences (spss) for windows version 19. Quantitative data is analyzed using percentages and bar graphs; Qualitative data is analyzed using chi-squared test .p value <0.05 was considered significant.

RESULTS AND DISCUSSION:

SOCIO DEMOGRAPHIC CHARACTERISTICS OF THE SPOUSES:

Out of 100 spouses, 65 % are females and 35 % are males, 13 % are illiterates, 35% have studied up to elementary, 35 % upto high school standard, where as graduate and post graduate are only 3 % each.

In employment status, we found that 9 % are employed for full time, 21% are employed for part time, 29 % are self employed, 19 % are unemployed and only 8 % are homemakers. Majority of them are self employed in the current study in order to meet the expenses. Most of the spouses are making monthly income in between Rs 2500 - Rs 5000 (37%) followed by 33 %, with a monthly income > Rs 10,000 and 26% of them have a monthly income between Rs 5000 - Rs 10,000. Only 4 % of them are earning below Rs 2500 per month. Financial dependence

on patients is seen in 45 % of the spouses. Remaining 55 % are making their own ways to earn monthly income. In the above study 85 % of the spouses are not having any mental illness. 84% of the spouses are having no history of substance abuse. Abuse in the spouses is not seen in 95 % , where as 5 % of the suffered with abuse by patients with schizophrenia.

QUALITY OF LIFE :

Table 1 : Quality of life in spouses

Domains	Mean	Median	Minimum	maximum	Standard deviation
Physical health	44.9	50	11	69	15.9
Psychological health	36.2	38	0	56	15
Social health	37.9	44	0	75	16.8
Environmental health	37.3	38	13	63	14.4

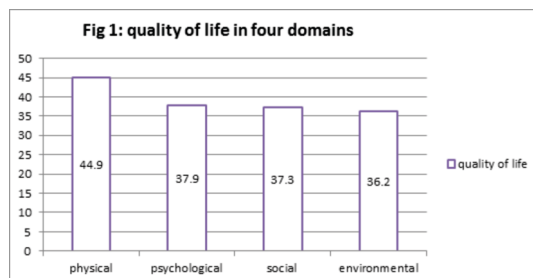


Table 1 and Fig 1 showing mean scores quality of life in spouses of schizophrenia patients in four different domains. Better quality of life is seen in physical health domain (44.9) followed by social health domain (37.9), environmental health domain (37.3) and psychological health (36.2).

Similar results were found in the study done by Sabreen Basheer, Kera Anurag et al (10), found that the caregivers experienced lower QOL levels, where the most affected was psychological domain and the least was physical domain. Physical domain implied that our study population had good activities of daily living, adequate energy and mobility, less pain and discomfort, sufficient sleep and rest, and good work capacity. A low psychological domain score in our study reflected negative attitude toward life and reduced self-esteem. This might be due to the social stigma associated with the mental health disorders.

Table 2 : Comparison of socio demographic details of spouse with quality of life

	Quality of life			
	Physical (44.9)	Psychological (36.2)	Social (37.9)	Environmental (37.3)
1) Age of spouse				
15-30 years	52.75	37.79	45.00	39.70
30-45 years	40.37	37.20	33.68	37.44
>45 years	45.64	33.51	38.70	35.41
P value	0.005*	0.279	0.015*	0.281
r value	-0.141	-0.110	-0.118	-0.109
2) education of the spouse				
Illiterate	30.00	32.69	31.69	35.69
Elementary	40.82	36.31	38.00	37.77
High school	45.69	40.05	39.60	37.60
Pre university	47.09	28.54	39.72	37.09
Graduate	48.85	35.33	50.00	43.66
Post graduate	52.33	34.00	27.00	31.66
P value	0.099	0.211	0.361	0.944
r = value	-0.330	-0.13	0.83	0.008
3) sex of the spouse				
Male	47.11	33.88	34.40	34.62
Female	43.83	37.44	39.87	38.83
P value	0.330	0.261	0.121	0.168
4) Domicile				
Urban	47.10	35.82	36.17	38.41
Rural	44.11	36.35	38.69	36.92
P value	0.399	0.875	0.500	0.644

5) family type				
Nuclear	43.39	37.7	37.8	37.6
Extended	48.86	32.4	38.2	36.7
P value	0.121	0.108	0.905	0.781
6) Employment status of the spouse				
Employed full time	53.77	41.66	39.55	31.33
Employed part time	43.76	34.57	38.61	36.38
Self employed	41.06	36.68	38.55	38.89
Unemployed	42.52	34.52	34.78	33.84
Retired	47.35	33.42	35.28	42.00
Home maker	54.12	41.37	44.50	41.37
P value	0.102	0.560	0.678	0.156
7) Financial dependence on the patient				
Yes	41.64	36.06	40.53	38.17
No	47.70	36.30	35.85	36.69
P value	0.059	0.937	0.167	0.612
8) monthly income of the spouse				
<Rs1000	33.66	50.00	56.00	44.00
Rs 1000-2500	42.51	27.00	25.00	39.66
Rs 2500-5000	42.42	34.75	37.45	34.59
Rs 5000-10,000	50.24	38.73	37.00	38.26
> Rs 10,000	63.00	36.24	39.90	39.23
P value	0.063	0.432	0.392	0.336
r value	0.120	0.048	0.067	0.098
9) mental illness in the spouse				
Yes	36.14	39.86	37.13	32.86
No	36.53	45.88	38.10	38.15
P value	0.180	0.926	0.838	0.194
10) H/O substance abuse in the spouse				
Yes	41.17	35.21	37.38	36.78
No	43.93	41.37	41.00	40.37
P value	0.778	0.134	0.433	0.367
11) H/O abuse in the spouse				
Yes	37.66	36.05	37.85	31.33
No	45.44	38.50	39.66	37.74
P value	0.250	0.720	0.799	0.296

Table 2, showing the comparison of quality of life with the details of the spouse including socio demographic profile, financial dependence on the patient, any history of mental illness, history of substance abuse and history of abuse in the spouse. Of which significant finding is seen in age of the spouse in physical (0.005*) and social (0.015*) health domain.

On comparison of mean quality of life with age of the spouse, as the age is increasing, quality of life across all domains is reducing with a negative correlation. In both physical and social health domain it is found to be significant with $p = 0.005^*$ and $p = 0.015^*$ respectively. In a study done by Sabreen B et al, It was found that caregiver's age was inversely proportional to QOL, which might be attributed to their own age related morbidities and financial dependence. At the expense of their health and other co-morbidities, older caregivers have to provide emotional support, assist them with daily living, and advocate for various services. The results are similar to several studies that found older caregivers having a higher care burden hence poorer QOL(10).

It has shown that, males are having better QOL in physical health domain, where as in other three domains like psychological, social and environmental female are found to have better quality of life than males. Similar results were found in the study done by Pratima Kaushik et al, that female spouses experienced below average quality of life (11).

It is observed that higher the education level, better is the quality of life in the current study. Similar results are seen in study done by Cynthia et al on quality of life of caregivers of patients diagnosed with severe mental illness at national referral hospitals in Uganda, found that, the education level of the caregiver was positively correlated with QoL (12). Highly educated caregivers tend to have more knowledgeable and develop more effective skills, better paying jobs or sources of income and are able to adequately use their financial and social resources available in their communities to deal with the caregiving burden resulting in better QoL.

In physical and psychological health domain better QOL is seen in

those who are employed full time, where as on social and environmental health domains, better QOL is seen in home makers and retired spouses respectively, which is found to be not statistically significant in this study.

The finding was consistent with a study reported by Zamzam et al. who suggested that family caregivers who were unemployed were more likely to report higher in physical and psychological domain of the quality of life. The possible reason to explain the consistency is the unemployed family caregivers are more likely to have more time to manage the difficulties in caregiving task and have less adjustment between the working life and the caregiving activities, which could influence to the better perception regarding the quality of life(13).

As the monthly income of the spouses is more the QOL across all domains is getting better with a positive correlation. Similar results were observed in a study done by Anli Leng et al. on Quality of life in caregivers of a family member with serious mental illness: Caregivers of lower social-economic status and income might experience higher rates of family conflicts and disharmony than more affluent and higher socio-economic status families. Therefore, financial support for caregivers that lessens their financial difficulties would attenuate the perceived caregivers' burden and facilitate a better QOL(14).

QOL in the spouses who are having mental illness is better compared to those who are not having mental illness across all domains. Similar results were seen in a study done in Uganda by Cynthia N et al. The caregivers who were dissatisfied with their health were more likely to have a poor QoL. Caregivers sacrifice themselves to care for their patients, resulting in strain on their physical and mental health (12). This dissatisfaction in health is influenced by the inadequate time the caregiver spends on their health concerns since most of their time is invested in their role. As caregivers adjust their social lives to the needs of patients diagnosed with mental illness, they usually have concerns about their own health but neglect them therefore their health deteriorates which eventually impacts on their perception of their overall QoL. It was suggested that people with good health status may have a better QoL since they are usually satisfied with the state of their health.

Table 3 : Comparison of patient details with quality of life

	Quality of life			
	Physical (44.9)	Psychological (36.2)	Social (37.9)	Environmental (37.3)
1) Diagnosis				
Paranoid	50.75	56.00	36.37	50.00
Undifferentiated	42.81	34.09	39.81	38.63
Hebephrenic	22.00	38.41	34.50	34.58
Not otherwise specified	39.33	30.25	40.58	40.66
ATPD	44.00	38.00	31.00	17.46
P value	0.001*	0.013*	0.504	0.101
2) Duration of illness				
< 2 years	50.14	35.71	43.71	42.14
2-5 years	45.52	37.23	37.82	36.47
5-10 years	42.47	36.09	36.57	35.57
> 10 years	46.4	33.80	36.20	41.20
P value	0.279	0.727	0.238	0.262
r value	-0.110	-0.036	-0.122	-0.053
3) Severity of illness				
No disability	48.00	37.53	41.66	45.23
Mild	46.59	37.63	39.38	41.83
Moderate	43.53	33.33	38.54	35.44
Severe	41.11	32.66	32.00	32.27
Profound	0	0	0	0
P value	0.154	0.402	0.155	0.001*
r value	-0.145	-0.042	-0.144	-0.062

Table 32 shows comparison of quality of life with diagnosis, duration of illness and severity of illness. In which significant finding is seen in diagnosis of patient in physical ($p = 0.001^*$) and psychological health domain ($p = 0.013^*$) and in severity of illness in environmental health domain ($p = 0.001^*$).

On comparing diagnosis of the patient with the mean QOL across all domains, it has shown that in physical health domain, better QOL is seen in patients with diagnosis of paranoid schizophrenia followed by acute and transient psychotic disorders, which is found to be statistically significant with a $p = 0.001^*$. In psychological health domain, better QOL is seen with the diagnosis of paranoid schizophrenia, in social health domain, it is with schizophrenia not otherwise specified and in environmental health domain also spouses of paranoid schizophrenia patients are having better QOL, which is found not to be statistically significant.

Duration of illness in the patient, is compared with the mean QOL in the spouses in the current study and it has shown that, QOL is better with the shorter duration of illness and in it is inversely related with the duration of illness i.e longer the duration of schizophrenia, lesser is the QOL. Though it is negatively correlated, it is not found to be statistically significant.

In a Malaysian study by Zam Zam et al in schizophrenic patients found that, the level of care burden generally reflects the QOL in caregivers (15). Duration of illness of less than ten years were significantly associated with higher scores in all domains of the caregivers' QOL. Implies better QOL is seen with shorter duration of illness, which was found to be statistically significant (13).

When mean QOL in the spouses is compared with the severity of the illness in the schizophrenia patients, it has shown that as the severity of the illness is increasing, the QOL in their spouses is reducing across all the domains like physical, psychological, social and environmental health with a negative correlation of -0.145, -0.042, -0.144, -0.062 respectively. It was found to be statistically significant in environmental health domain with $p = 0.001^*$ and not significant in the other three domains.

Sanjibani, Rajendra et al concluded in their study that quality of life is moderately low in caregivers of schizophrenia patients. Quality of life of caregivers is inversely related to severity of illness. This study suggests that taking care of caregivers is quite important to improve their overall quality of life, whose findings are similar to the findings in the current study (16).

The chronic illness of a family member can be a source of stress for the caregiver who can appraise this stressor as one with a high level of demands in relation to caregiving. The results of this study show that there is a significant association between caregivers' QoL and patients'

QoL mediated by psychotic symptoms severity. For the first time, this study shows that caregivers' QoL may have a positive association with psychotic symptoms severity and patients' QoL, confirming the central role of caregivers in the treatment of patients (17).

LIMITATIONS :

1. The current study was conducted at a tertiary care center that may not represent the general population.
2. Study population was mostly from the lower socioeconomic group. So the results cannot be generalized for middle and higher economic groups.
3. This is a hospital based cross sectional study on a small group of patients.
4. Other factors that influence experience and reporting of burden like social support and expressed emotions were not taken into account.
5. This is a cross sectional study and more prospective studies are needed in further understanding of the burden in spouses of mentally ill person

CONCLUSION :

The study aimed to look at the QOL in the spouses of patients with schizophrenia. Better QOL is seen in physical health domain, the factors like type of schizophrenia and severity of illness strongly associated QOL. And in socio demographic details younger age is found to be significantly associated with better QOL than other details. In the above study, it was found that, severity of burden and QOL are inversely related.

Measures to improve the treatment effectiveness may lead to reduction of perceived stress in the spouses and to improve QOL. Psychotherapeutic techniques like psycho education, family and couple therapy may help in better coping of spouses of mentally ill persons. Group therapy can help spouses in sharing their views and understanding various coping methods employed by others.

FUTURE DIRECTIONS:

- In view of perceived burden in the spouses of mentally ill persons, need to develop family intervention programs focusing on psycho education to family members and imparting skills to manage spouses is present.
- Access to better rehabilitation and psycho social services to be ensured to patients.
- Self help groups for spouses should be encouraged where they can seek mutual support, learn from others' experiences and share problems with others to better cope with spouse illness.
- Periodic screening of spouses is required given their vulnerability to develop psychological problems.
- Financial incentives from the government agencies can help in reducing the burden of spouse

CONFLICTS OF INTEREST : There are no conflicts of interest.

REFERENCES:

1. Murray CJ, Ezzati M, Flaxman AD, Lim S, Lozano R, Michaud C, et al. GBD 2010: design, definitions, and metrics. *Lancet*. 2012 Dec; 380(9859): 2063-6.
2. Kate N, Grover S, Kulhara P, Nehra R. Relationship of caregiver burden with coping strategies, social support, psychological morbidity, and quality of life in the caregivers of schizophrenia. *Asian J Psychiatr*. 2013;6:380-8.
3. Glossary of Aging Terms. Department of Health and Human Services. 2005. [Last cited on 2014 Mar 12].
4. World Health Organization: Report of WHOQOL Focus Group Work: WHO(MNH/PSF/93.4)1993.
5. Garre J, Hernández M, Lozano M, Vilalta J, Turón A, Cruz Ma, Camps G, López S: Carga y calidad de vida en cuidadores de pacientes con demencia tipo Alzheimer. *Rev Neurol* 2000, 31:522-527.
6. Dalui A, Guha P, De A, Chakraborty S, Chakraborty I. Assessment of stress & related albuminuria in caregivers of severe mentally ill persons. *Indian J Med Res*. 2014;139(1):174-7.
7. Yikilkan H, Aypak C, Gorpelioglu S. Depression, anxiety and quality of life in caregivers of long-term home care patients. *Arch Psychiatr Nurs*. 2014;28(3): 193-6.
8. Awadalla AW, Ohaeri JU, Salih AA, Tawfiq AM. Subjective quality of life of family caregivers of community living Sudanese psychiatric patients. *Soc Psychiatry Psychiatr Epidemiol*. 2005 Sep; 40(9): 755-63.
9. Barria J: Síndrome de Burnout en Asistentes Sociales del Servicio Nacional de Menores de la Región Metropolitana. *Psyke* 2003, 12:213-226.
10. Sabreen Basheer and Khera Anurag et al, Quality of life of caregivers of mentally ill patients in a tertiary care hospital, *Ind Psychiatry J*. 2015 Jul-Dec; 24(2): 144-149.
11. Kaushik P, Bhatia MS. Burden and quality of life in spouses of patients with schizophrenia and bipolar disorder. *Delhi Psychiatry Journal*. 2013;16:83-9.
12. Cynthia N et al., Quality of life of caregivers of patients diagnosed with severe mental illness at the national referral hospitals in Uganda, *BMC Psychiatry* (2016) 16:400
13. R ZamZam et al, Schizophrenia in Malaysian families: A study on factors associated with quality of life of primary family caregivers, *Int J Ment Health Syst*, 16(5), 2011.
14. Leng, A., Quality of life in caregivers of a family member with serious mental illness: Evidence from China *Archives of Psychiatric Nursing*.
15. Dyck DG et al. predictors of burden and infectious illness in schizophrenia care givers ; *psychosomatic medicine* 1999; 61:411-419.
16. Sanjibani Panigrahi , Rajendra Kumar Acharya et al., Quality of life in caregivers of patients with schizophrenia and its correlation with severity of illness *The International Journal Of Engineering And Science (IJES)* ,3: 6 || Pages ,55-60, 2014.
17. Caqueo-Urizar, A. et al. (2017). Caregiver's quality of life and its positive impact on symptomatology and quality of life of patients with schizophrenia. *Health and Quality of Life Outcomes*, 15, Article ID 76.