

Original Research Article

A comparative study of family burden and quality of life between caregivers of schizophrenia and dementia patients

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ABSTRACT

Background: In chronic mental diseases, as the disease progresses, it carries with tremendous burden both physically and psychologically on the family members, who are usually in the process of caregiving. The quality of life (QOL) of these caregivers is directly related to the subjective and objective burden of the illness. The objective of the study was to assess and compare the level of family burden and QOL between caregivers of Schizophrenia and Dementia patients as well as to find out the relationship between family burden and QOL.

Methods: A total of 128 key caregivers (64 caregivers of each group) fulfilling the inclusion criteria purposely selected from the OPD of MHI, S. C. B. Medical College and Neuropsychiatric Consultation Centre, Cuttack. The impact of family burden on key caregivers of dementia and schizophrenia patients was assessed by using family burden interview schedule and the quality of life of key caregivers was assessed by using WHOQOL BREF scale. Data was analysed by using chi-square, t test and Pearson correlation. Data analysis was performed by SPSS.

Results: Statistical significant differences ($p < 0.05$) were found in the areas of financial burden, disruptions of family routine activities, family leisure and family interaction between dementia and schizophrenia caregivers. Whereas there was no statistical significant difference ($p > 0.05$) found in different domains of quality of life between these two groups of caregivers. There were significant negative correlations found between family burden and psychological, social relationships and environment domains of quality of life.

Conclusions: Caregivers perceived subjective and objective burden ultimately affecting their QOL.

Keywords: Caregiver burden, Dementia, Schizophrenia, Quality of life, Family burden interview schedule

INTRODUCTION

A caregiver is defined as the person who fulfills the need of physical and psychological wellbeing of the diseased individual. Caregiver burden is a multi-dimensional response to the perceived stress and negative appraisal resulting from taking care of an ill individual. A caregiver plays a significant role both physically and mentally by taking care of a chronic mentally ill person.¹ Caregiver burden affects the psychological, physical and emotional

health of the individual who cares for the illness of the chronic mentally ill patient.

A person suffering from schizophrenia is less likely to get a good employment and to marry which produce higher amount of burden on the family of the patient in financial, routine activities, family interaction, physical health and mental health of the family members. Family burden in care giving of chronic mental illness includes financial stress, domestic routine disturbance, disruption of social and leisure activities of the family and less

caring for other family members.² After long years of research on family burden it has been concluded that the degree of burden experienced by the caregivers depends on many contextual factors, care giving related factors and primary stressors including the socio-demographical status of the caregiver and care recipients and perceived stress resulting from caregiving.

Family caregivers in chronic mental illness and in medical illness show their support for caring because of the sense of love or reciprocity, spiritual fulfillment, a sense of duty, guilt, and social responsibility and at times because of social pressure. Family caregivers, who accept caregiving as social and cultural norms, are more likely to suffer from psychological distress than caregivers with more positive motivation towards caregiving.³

In patients with dementia, the most of the caregivers are either spouses or adult members of the family. Many studies have found that caregivers of those with dementia have higher level of burden than other caregivers. This includes personal care like bathing, feeding, assisting with toileting. In a survey in 2003 in USA with dementia caregiver nearly one quarter provided 40 hours of care or more per week (compared with 16% of non-dementia caregivers). Caregivers in developing countries spend a median 3 to 6 hours in a day with the person with dementia and 3 to 9 hours in assisting with activities of daily living.⁴ In the long term course of psychiatric illness like dementia and schizophrenia, course and prognosis of the disease generally depend on the effective caregiving. As the disease progresses, care giving for the activities of daily living (ADL) of the patients, take lots of psychological and physical burden resulting in rigorous activity of caregiving, which has negative impact on physical, psychological and social quality of life. In this process the act of caregiving create a negative impact on the quality of life of the caregiver.^{5,6}

The quality of life (QOL) of caregivers of chronic mental illness is directly related to the subjective and objective burden of the illness. The objective burden is the reflection of physical and psychological dependence of the person with mental illness. The subjective burden is the physical and emotional impact, which also depends on the objective burden. Hence, the continuous burden of caregivers in the domains of finance, family routine activities and family interaction in the course of time lead to poor physical and emotional consequences, which is associated with poor quality of life.⁷⁻⁹ Basing on these facts the association between family burden and quality of life has been assessed in this study.

Objective of the study

- a. To assess and compare the level of family burden between caregivers of Schizophrenia and Dementia patients.
- b. To assess and compare quality of life between caregivers of Schizophrenia and Dementia patients.

- c. To assess the association between family burden and quality of life of caregivers of Schizophrenia and Dementia patients.

METHODS

Settings

The study was conducted at the outpatient department of Mental Health Institute, Cuttack, India and Neuropsychiatric Consultation Centre, Cuttack during the period between October 2015 to October 2016. Data was collected from the key care givers of patients of schizophrenia and dementia.

Procedure

The key caregiver of patients diagnosed with schizophrenia and dementia as per ICD-10, aged more than 18 years, caring and living with the patient for more than 1 year, having no chronic physical or mental illness since last 1 year and providing written informed consent, were included in the study. The procedures of the study were described to them. Socio-demographic data sheet was used to collect socio-demographic details of each patient. Family burden interview schedule was administered on each caregiver in order to assess their level of burden while caring the patients with Dementia and Schizophrenia. WHO Quality of Life Bref scale was administered to assess quality of life of each caregiver.

Sampling

Purposive sampling method was used to collect data. A total of 128 caregivers (64 caregivers from both schizophrenia and dementia group) were selected to collect the data.

Inclusion criteria

Inclusion criteria were key caregivers of patients with schizophrenia and dementia with duration of illness of 2-5 years; key caregivers are the persons who are responsible for providing care to the index case most of the times on the day to day basis. The caregiver could be spouse, children or any other family members who were living with the index case in the same house and shares same kitchen and is taking responsibilities of activities of daily living; age range of caregivers was 20-60 years; those who had given written informed consent to take part in the study; a key caregiver staying with the patient for at least previous 1 year and having no chronic physical and mental illness.

Exclusion criteria

Exclusion criteria were caregivers of patients with comorbid psychiatric or chronic physical illness; those caregivers who are taking care of another family member for either psychiatric or physical illnesses except than the

index patient; caregivers with disturbances in cognitive functioning/ memory.

Tools used

- ICD-10 criteria for diagnosis of schizophrenia and dementia.¹⁰
- Socio-demographic Sheet*: This is used to collect various socio-demographic details of caregivers.
- Mini-Mental State Examination (MMSE)*: This scale has been developed by Folstein et al.¹¹ This scale has 11 items, which was used in this study for screening out cognitive status of the caregivers, to ruled out cognitive disturbances.
- Family burden interview schedule (FBIS)*: This is developed by Pai and Kapur in 1981. This scale is widely used to measure caregiver stress of those who are performing care giving activities of any family member with any chronic illness. It measures both subjective and objective burden of caregivers. This is a semi-structured interview schedule comprising 24 items grouped under six areas viz. financial burden, disruption of routine family activities, family leisure, family interactions, effect on physical and mental health of others. Rating of burden is done on a three-point scale for each item and a standard question to assess the 'subjective' burden is also included in the schedule. The validity and reliability of the scale has been shown to be satisfactory. The inter-rater reliability for all items was reported to be more than 0.78 by the authors of the schedule.¹²
- WHO Quality of Life Bref (WHOQOL Bref) scale*: This scale is developed by World Health Organization. This consists of 26 items that concerns with the four domains (Physical, Psychological, Environmental and Social relations) of quality of life of a person.¹³

Statistical analysis

Data was analyzed by using SPSS, Version 17.0 (SPSS Inc. Illinois, USA). The qualitative variables were compared using Chi-square and the quantitative variables were compared by using t test. The relationship between domains of family burden and quality of life of caregivers

of each group were analyzed by using Pearson correlation.

Ethics

The institutional ethics committee permission was taken before conducting this study.

RESULTS

A total of 128 caregivers (64 in each group—one caring for dementia patients and one for schizophrenia patients) were included in the study. Each care giver (study participant) was assessed for specific domains on two separate scales, i.e. WHOQOL Bref scale and family burden interview schedule. The socio-demographic parameters of the two groups were compared. As shown in Table 1, the differences between the groups were found not to be statistically significant, thereby implying that the study groups were inherently comparable.

Table 1: Socio-demographic details of caregivers of both schizophrenia and dementia patients.

Variables	Dementia (n=64)	Schizophrenia (n=64)	p value
Age	47.66 ±12.8	47.52 ±10.8	0.95*
Duration of illness	4.02 ±1.5	4.28 ±0.863	0.26*
Sex			
Male	37	35	0.72*
Female	27	29	
Religion			
Hindu	61	64	0.08*
Muslim	3	0	
Family Type			
Nuclear	36	34	0.7*
Joint	28	30	
Domicile			
Rural	45	52	0.149*
Urban	19	12	

*p > 0.05 (Statistical Non-significance at 0.05 Level).

Table 2: Comparison of objective family burden scores between caregivers of schizophrenia and dementia patients.

Areas of Family Burden	Dementia (n=64) Mean±SD	Schizophrenia (n=64) Mean±SD	t value	p value
Financial burden	6.15 ± 2.98	5.04 ± 2.84	2.15	0.033*
Disruption of family routine activities	5.34 ± 2.48	3.25 ± 2.37	4.86	0.000*
Disruption of family leisure	3.95 ± 2.01	1.57 ± 1.45	7.65	0.000*
Disruption of family interaction	3.34 ± 2.60	1.76 ± 1.55	4.16	0.000*
Effect on physical health of others	0.64 ± 0.84	0.43 ± 0.73	1.45	0.148
Effect on mental health of others	1.03 ± 0.56	0.79 ± 0.96	1.68	0.095

*p < 0.05 (Statistical significance at 0.05 Level).

Table 2 shows comparison of area wise family burden scores between schizophrenia and dementia care givers.

Statistical significant differences (p < 0.05) were found in the areas of financial burden, disruptions of family

routine activities, family leisure and family interaction. However, there was no statistical significant difference

found in the areas of effect on physical and mental health of others between these two groups of caregivers.

Table 3: Subjective perception of family burden between caregivers of dementia and schizophrenia patients.

Level of subjective perception of family burden			
	Percentages of Dementia caregivers(n=64)	Percentages of Schizophrenia caregivers (n=64)	p value
None	4 (6.3%)	6 (12.5 %)	0.001*
Little	32 (50%)	47 (73.4%)	
Severe	28 (43.7%)	9 (14.1%)	

*p <0.05 (Statistical significance at 0.05 Level)

Table 4: Comparison of WHOQOL Bref scores between caregivers of schizophrenia and dementia patients.

Domains	Dementia (n=64) Mean±SD	Schizophrenia (n=64) Mean±SD	t value	P value
Physical health	54.65 ± 10.04	57.82 ± 14.04	-1.46	.14*
Psychological	55.54 ± 11.40	58.23 ± 16.15	-1.08	.27*
Social relationships	58.64 ± 13.51	59.06 ± 14.94	-.16	.86*
Environment	59.78 ±15.58	59.71 ±16.12	.02	.98*

*p >0.05 (Statistical non-significance at 0.05 Level).

Table 5: Correlations between family burden and domains of quality of life of caregivers of dementia and schizophrenia patients.

	Domains of WHOQOL Bref scale			
	Physical Health	Psychological	Social Relationships	Environment
Family burden of dementia caregivers	-0.20	-0.37**	-0.305*	-0.46**
Family burden of schizophrenia caregivers	-0.16	-0.27*	-0.09	-0.14

** Correlation is significant at 0.01 level, * Correlation is significant at 0.05 level.

Table 3 shows the level of subjective perception of the care givers towards their responsibilities. While half of the care givers of dementia patients felt that the family burden was little, nearly three quarters (73.4%) of those caring for schizophrenia patients had similar perception. Only a small proportion of the caregivers in both the groups had no perception of family burden (i.e., 6.3% and 12.5% for dementia and schizophrenia respectively). Overall the association between the level of subjective perception of family burden and the caregiver type was found to be statistically significant.

Table 4 shows comparison of the scores of different domains of WHO quality of life Bref scale. There was no statistical significant difference (p >0.05) found in different domains of quality of life between these two groups of caregivers.

Table 5 shows the correlations between family burden and domains of quality of life of caregivers of dementia and schizophrenia patients. In case of dementia caregivers, there were significant negative correlations found between family burden and psychological, social relationships and environment domains of quality of life. Whereas in case of schizophrenia caregivers, there was a

significant negative correlation found between family burden and psychological domain of quality of life.

DISCUSSION

The research on burden on the caregivers is always neglected in comparison to the disease burden of the human being. In most of the chronic psychiatric disorders, the caregivers' burden has not been focused till date. Our study has been focused on comparison of caregivers' burden on two chronic psychiatric disorders, i.e., schizophrenia and dementia.

In the present study it was found out that the objective burden of family finance, family routine activities, family leisure and family interactions were particularly affected in dementia caregivers in compared to schizophrenia caregivers. Financial burden is primarily a direct outcome of loss of patient's income and secondarily due to expenditure burden of the treatment. The possible reason for the greater financial burden on caregivers of dementia may be due to the fact that dementia is an age related, continued chronic illness associated with both physical and mental disability, in which a patient is mostly dependent on the family members both for financial and physical factors. This result of the study is consistent with

other Indian studies and Western studies,^{5-9,14} where physical health, psychological health and financial burden are definite domains to be affected. On the other hand, most of the schizophrenic patients after treatment get into paid employment with difficulty but they find difficult in holding the jobs for which caregivers may need to carry a substantial financial burden even at the adult age of the patient, where the patient has to earn at a regular basis. This is because of off and on exacerbation of symptoms of schizophrenia and the disease itself imposes a disproportionately large economic burden due to loss of productivity, treatment and hospitalization.¹⁵ However, in this study this difference was not due to duration of illness of the patient, as they were comparable in both the groups.

Disruption of family routine activities is another area on which caregiver burden was focused in this study. Most of the families ascertained about the patient's inability to work to complete his daily routine activities were most inconvenient and distressing to the caregivers. It was also found out that disruption of family leisure and interactions were more affected in case of dementia caregivers. This revealed that dementia caregivers were engaged at least 3-4 hours every day in fulfilling the daily routine activities of the patients. Thereby, decreasing their family interaction and getting less time for family leisure. A significant number of dementia caregivers reported reduced interactions with friends and relatives because of their emotional burden and continuous stress in the family, whereas schizophrenia caregivers have less family interactions only at the time of exacerbation of symptoms of the patient, but in other times they get sufficient time for family interactions. Caregivers of schizophrenia have specifically complained of restrictions of their social contacts because of stigma, discrimination and guilt feelings persisting within the society.¹⁶⁻¹⁸ Hence, this group of population requires more practical support from social networks where stigma is more prevalent particularly in rural areas. Schene et al reported that caregivers avoid their social and leisure activities to make reciprocity balance in role.¹⁹

The mental and physical health of family members can be affected if an index patient has a chronic psychiatric disorder. There was no significant difference between the study groups with respect to effect of burden on physical and mental health of others. In other words, the burden equally affects physical and mental health of caregivers of dementia and schizophrenia patients.²⁰⁻²²

The study findings revealed that the subjective perception of family burden was more on dementia caregivers than schizophrenia caregivers. More than half of the dementia caregivers reported of little burden because in our Indian cultural pattern, most of the families have accepted the act of care giving of senior family members as part of their activities of life in a cohesive family environment.^{23,24}

In this study the quality of life of the caregivers of both the groups were compared. Although quality of life in physical health, psychological, social relationship and environment were deteriorated in both the groups, but it was not statistically significant in both the groups. As in both the groups, caregivers were exposed to continuous psychological and emotional trauma in the chronic course of both the diseases, so quality of life was deteriorated.²⁵

The most important finding of this study was negative correlation between family burden and quality of life of caregivers in both the groups. In dementia caregiver group, it was observed that with increase in caregivers' family burden resulted in poor functioning of psychological, environmental and social relationship domains of quality of life. In case of caregivers of schizophrenia, the psychological domain of quality of life was affected as the family burden increases, because of stigma, discrimination and variations in the course of the disease.^{25,26}

The key caregivers during their caring for the chronic psychiatric patients have subjective experiences of anger, fear, dependency, incompetency, embarrassment, expectation and uncertainty. This burden affects their quality of life. The findings are consistent with other Indian and Western studies.^{5,6,13}

CONCLUSION

The present study supports the conclusion that the caregivers perceived subjective and objective burden is more in caregivers of dementia group in compared to caregivers of schizophrenia group. As the caregiver burden increases, it resulted in poor functioning of their quality of life, which affects their personal, social and occupational domains.

The future directions emerged from this study is as follows:

1. This study has implications for clinical practice and further research.
2. Professional counseling and supportive psychotherapy can be provided to the caregivers to reduce their psychological burden, improve their coping skills thereby modifying the quality of life.
3. The psychosocial intervention programme has to be planned after assessment of caregivers' coping strategies as well as resources available in the community.
4. The caregiver burden widens the area for rehabilitation of chronic mentally ill patients in the community in future.

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