



Research Article

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Assessment of burden in caregivers of patients with chronic schizophrenia; who attend the tertiary care center

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Abstract

Background: Schizophrenia a chronic, debilitating illness affecting entire family in addition to the sufferer. The family is a major source of support for the mentally ill in India where caregivers assume significant role. The pressure of care giving adds to significant stress in the care giver. Seeking out causes of care giver burden will help plan its alleviation. **Methods:** Eighty-four people with schizophrenia and their primary care givers were part of the study. Schizophrenia was diagnosed using DSM 5 criteria. Positive and negative symptoms were measured by the "Positive and Negative Syndrome Scale for Schizophrenia" (PANSS), Clinical Global Impression (CGI) Scale was used to assess the severity and improvement rate, and Global Assessment of Functioning (GAF) assessed the clinical progress. Care givers were administered Zarit Care Giver Burden scale. **Results:** More caregiver burden was reported with male patients. Educational level of patients did not influence burden score. Severity of burden increased as the severity of illness increased and functioning level of patients declined. Improvement with treatment reduced burden of caregivers. Among factors related to care givers, burden increased linearly with increasing age of the care givers. Care givers who suffered from co morbid medical illnesses reported significantly higher levels of burden. **Conclusion:** Care giver burden is an important issue to be considered in the overall management plan of schizophrenia. Care givers need better support for their own physical and mental well-being, to reduce symptoms and improve functioning level of schizophrenia patients.

Keywords: Schizophrenia, Positive symptoms, Negative symptoms, Care giver.

INTRODUCTION

Schizophrenia is a chronic, debilitating and often lifelong disease, affecting entire family in addition to the sufferer socially as well as financially.

The family is a major source of support for the mentally ill in India [1]. It needs patience, empathy and financial support from the relative who assumes the caregiver role. World Federation of mental Health (WFMH) assessed those giving support to people with chronic illnesses. It reported that care giving demands from the supporter lot of sacrifices, emotional, psychological and financial matters and affects their daily life. There is a chance that these care givers ignore their own health needs in their efforts to help the patient [1]. Schizophrenia leading to care giver stress can be assessed in different dimensions of physical, Psychological and socio-economic terms

Huge pressure on person giving care has been a focus of research since 1950s and the word "Care giver Burden" came in to vogue since 1970s [1]. The seminal work of Grad & Sainsbury provided burden types, subjective and objective. Whereas subjective burden is emotional reaction of the care givers objective refers to physical burden of care providing. Significant family burden was reported in several studies in the past [2].

WFMH reports majority of those supporting people with Schizophrenia are women (80%) in the form of spouse, mother, or daughter of the patient.

These women who care are themselves prone to Psychological problems like anxiety and depression 6 times more than those who have no such responsibility [1]. The factors that influence the caregiver

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burden is affected by gender of the patient, severity of the illness, caregiver age, cultural factors, stigma, duration of the disease [3, 4].

Aim and Objective

To explore the burden experienced by caregivers of people suffering with Schizophrenia in Indian cultural background.

MATERIALS AND METHODS

Study was conducted during November 2017 till January 2018. Eighty-four patients who suffered from Schizophrenia and their primary care givers were included in the study. Caregivers were those family members who assisted the patients in their daily functions and treatment for at least preceding one year.

With 95% confidence level and margin of error of $\pm 10\%$, a sample size of 84 subjects will allow the study to determine the burden among the caregivers of chronic schizophrenia patient with finite population correction.

Inclusion Criteria:

1. People with Schizophrenia aged between 18 and 65 years who have suffered from illness not less than 2 years
2. Those fulfilling the criteria of Schizophrenia by semi structured clinical interview based on DSM-5.
3. Those who are willing to participate in the study

Exclusion Criteria:

1. Patients with organic mental illnesses and intellectual disability,
2. Care givers who performed this work as a professional job
3. Care givers who themselves had suffered from psychiatric illness in the past or who were on psychotropic medication.

Procedure: Participants were included in the study after taking due consent from them.

Institutional ethical committee clearance was obtained Patients and the care giver interviews were conducted separately.

Tools for Assessment:

The tools used in the study are as follows:

Scales Administered to Patients.

1. Semi-structured proforma: It contained questions relating to the patient's age, marital status, education, income status, family history of psychiatric illness and other relevant data.
2. Positive and negative symptoms measured by the Positive and Negative Syndrome Scale for Schizophrenia (PANSS): It is a medical scale having 30-items, used for measuring symptom severity of patients with Schizophrenia [5].
3. Clinical Global Impression (CGI) Scale: To assess the severity, improvement rate, and medication side effects of psychiatric disorders [6].
4. Global Assessment of Functioning (GAF): To monitor the clinical progress of an individual [7].

Scale formats given to Caregivers

1. Care giver details in a structured format.
2. Zarit Care Giver Burden scale [8].

Statistical Analysis

SPSS was used to process the data. Chi-square test and Fisher's exact test were used to analyse categorical values and check the association between two variables.

RESULTS

The study participants were 84 people with Schizophrenic illness and 84 primary care givers of these patients.

Data of Patients

Eighteen patients were below 30 years of age (21.4%) and Sixty-six were above 30 years (78.6). Among the participating patients thirty were male (35.7) and fifty-four female (64.3). Majority of the patients (88.1) had educational level less than class XII. While majority remained married (52.4) eleven patients (13.1) had broken marriages. A large majority (88.3) had no associated physical co morbidity in this study. Interestingly we found 54.8% patients suffering from the illness for more than 10 years. 81% suffered from the illness for a period of 2-5 years before seeking any Psychiatric treatment. Table 1 summarizes the data on patients.

Table 1: General data on Patients

Age	No. of Patients	Percentage %
<30	18	21.4
30-60	63	75.0
>60	03	03.6
Gender		
Male	30	35.7
Female	54	64.3
Education		
Up to PUC	74	88.1
Above PUC	10	11.9
Marital Status		
Unmarried	22	26.2
Married	44	52.4
Widow	07	8.3
Separated	11	13.1
Total Duration of illness(yrs)		
2-5 years	16	19.0
5-10 years	22	26.2
10-15 years	26	31.0
>15 years	20	23.8
Duration of illness (yrs) (Before Treatment)		
2-5 years	68	81.0
5-10 years	15	17.9
10-15years	01	01.1
Co-morbid Physical problem		
Yes	14	16.7
No	70	83.3

General data on caregivers

Among the 84 care givers significant majority were above the age of 40 years.(79.7%).Women were represented much more (61.9%) than men (38.1%).Distribution of care giver families in to Nuclear and Joint were nearly equal,44 and 40% respectively.92.9% care givers had additional responsibilities which varied from working outside as an employee to being a housewife with responsibilities of other family members.69% reported suffering from one or the other medical ailments like diabetes mellitus, hypertension, Ischemic heart disease etc. Care givers who suffered from co morbid medical illnesses reported significantly high levels of Care Giver Burden Scores(CGBS) compared to those who did not have co morbid medical problems.78% more than 40 CGBS compared to 21.4% respectively. Table 2. gives the summary of general data on caregivers.

Table 2: General data on care givers.

Age	No. of Patients	Percentage. (%)
<40	17	20.3
40 - 49	07	8.3
50 - 59	13	15.5
60 - 69	37	44.0
70 - 79	10	11.9
Gender		
Male	32	38.1
Female	52	61.9
Education		
Up to PUC	73	86.9
Above PUC	11	13.1
Family		
Nuclear	44	52.4
Joint	40	47.6
Others responsibility of Caregiver		
Yes	78	92.9
No	06	7.1
Any medical Illness in Caregiver		
Yes	58	69.0
No	26	31.0
Help from other family members		
Yes	47	56.0
No	37	44.0

Presence of positive symptoms and negative symptoms among the patients did not affect the Care Giver Burden Score (CGBS) score. 52% caregivers reported more than 40 CGBS when the patients experienced positive symptoms whereas 50.7% caregivers reported same CGBS when the patients experienced negative symptoms. Reporting of burden increased linearly with increasing age of the care givers.56.6% of care givers in 50-80 age group reported burden score of more than 40. Gender of the patients appeared to influence caregiver burden. While 59.2% care givers reported moderate to severe burden (>40 CGBS) when the patients were males only 33.3% care givers reported moderate to severe burden (>40 CGBS) when the patients were females. Burden was not influenced by the educational levels of the patients, patients with education up to XII class as well as those above XII class their care givers reported similar burden levels (50%).We did not find significant differences between those patients who reported substance use and those who did not. Caregivers reporting of severity

of burden proportionately increased as the functioning level of patients declined. Table 3 summarizes the relationship.

Table 3: Severity of Illness v/s CGBS

Severity of illness	CGBS.SCORE (Binned)					Chi square test
	< 20	21-40	41-60	>60	Total	
Normal, not at all ill	5 33.3%	4 14.8%	1 2.6%	0 0.0%	10 11.9%	P<0.0001*
Borderline mentally ill	1 6.7%	8 29.6%	3 7.9%	0 0.0%	12 14.3%	
Mildly ill	7 46.7%	6 22.2%	3 7.9%	0 0.0%	16 19%	
Moderately ill	1 6.7%	5 18.5%	17 44.7%	0 0.0%	23 24.7%	
Markedly ill	1 6.7%	4 14.8%	13 34.2%	0 0.0%	18 21.4%	
Severely ill	0 0.0%	0 0.0%	1 2.6%	4 100%	5 6.0%	
Total	15 100%	27 100%	38 100%	4 100%	84 100%	

Our study found good statistical significance between the severities of Schizophrenic illness and the severity of burden experienced by the caregivers (Table 4). It shows increasing severity lead to increased burden among the family members of the patients who were in charge. A significant statistical relationship was also noted (chi square=0.0001) between patients improvement with treatment as assessed by Clinical global impression(CGI)scale with reported reduced burden by the family caregivers.

Table 4: CGI Improvement v/s CGBS

Clinical Global Impression	CGBS.SCORE (Binned)					Chi square test
	< 20	21-40	41-60	>60	Total	
Not assessed	0 0.0%	0 0.0%	3 7.9%	0 0.0%	3 3.6%	P<0.0001*
Verymuch improved	12 80.0%	12 44.4%	2 5.3%	0 0.0%	26 31.0%	
Much improved	2 13.3%	6 22.2%	6 15.8%	0 0.0%	14 16.7%	
Minimally improved	0 6.7%	9 33.3%	24 63.2%	0 0.0%	33 39.3%	
No change	1 6.7%	0 0.0%	3 7.9%	3 75.0%	7 8.3%	
Minimally worse	0 0.0%	0 0.0%	0 2.6%	1 25%	1 1.2%	
Total	15 100%	27 100%	38 100%	4 100%	84 100%	

DISCUSSION

We studied causes related to the caregiver burden in family members of patients with schizophrenia. The causes that suggested burden in our study were functioning ability of patient, illness severity and response to treatment. Other points that correlated with caregiver burden were caregiver's age and associated medical problems. The patient's level of functioning was found to be a good predictor for caregiver burden in our study. Patient's social functioning and its correlation with the family's functioning was demonstrated in an earlier study [9]. Similar relationship between patient's level of functioning and prediction of care giver burden was reported in other studies [10, 11].

In our study, it has been shown that most people assuming the role of caregiver are women. This was also found in previous studies on caregiver burden [12]. A study conducted in UK showed 58% of

caregivers were women in the United Kingdom [13]. Asian studies reported nearly 70% of caregivers being women [14]. This point helps us to look in to the needs of female caregivers and plan appropriate support to them.

Our study revealed increasing age of the caregiver was associated with increasing burden. Cultural factors, reduced social support, financial issues and medical problems among the caregivers might explain this phenomenon. This was also borne out by other studies. Increasing caregiver burden with increased age of the caregiver is reported in certain countries of Asia [15]. In the present study we also checked in to how the level of education of those who provide care is related to perception of burden. It has been reported earlier that the education level of the family member is inversely related to caregiver burden. With increasing levels of literacy burden reduces. Our study also corroborated this fact that as the education level of the caregiver increased, caregiver burden decreased. It's possible that educated people perceive fewer burdens when providing care to patients with schizophrenia. We found out in our study that the severity of illness increases the caregiver burden. Similar findings were reported in previous studies too [16].

Correlation between the patients' ages, gender versus caregiver burden was not found to be statistically significant in this study echoing similar finding in an earlier study [17].

Limitations

Small sample size, most patients came from low socio economic background and their cultural practices make it difficult to generalize the findings. Another limitation of the study is that significant percentage of caregivers reported sharing the burden with other family members; we do not know whether those people concurred with the feelings of primary care giver. The current study treated the burden as single dimensional variable; it needs to be analyzed separately for objective and subjective burden.

CONCLUSION

It is important to improve patient treatment, functioning, and rehabilitation programs. Better support and help to the caregivers for their own physical and mental wellbeing need to be developed. Involvement of younger family members in caring the mentally ill can be encouraged.

Highlights:

- Severity of illness increases burden and improvement reduces it.
- All efforts should be focused on patient's functioning and rehabilitation.
- Increasing age and medical problems among care givers are important factors.

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