

Perceived Level of Burden of Care and Its Association with Socio-Demographic Profile of Patients with Schizophrenia and Their Caregivers

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ABSTRACT

Background: Schizophrenia is a clinical syndrome of variable, but profoundly disruptive, psychopathology that involves cognition, emotion, perception and behaviour. Caregiver burden refers to negative response that occurs when the caregiver assumes an unpaid and unanticipated responsibility for the person with disabling mental health problems. The burden varies with socio-demographic parameters of patients and caregivers. **Aims & Objectives:** To study socio-demographic details of schizophrenia patients and caregivers. To assess perceived level of burden in caregivers and its association with socio-demographic profile of patients and caregivers. **Materials & Methods:** Ethics committee approval and informed consent was taken. 100 consecutive patients with their primary caregiver, presenting to psychiatry OPD of general hospital, satisfying inclusion criteria, were included in the study. Socio-demographic details of caregiver were collected using semi-structured proforma. Caregiver's perceived burden was assessed with Burden Assessment Schedule. Data thus obtained, was pooled & analyzed by using SPSS software, descriptive statistics, mean, percentage, Chi-Square test. **Results:** The sample consisted of 52 female & 48 male patients. Prevalence of burden in caregivers was found to be 52%. The perceived burden was found to be high in caregivers of female patients, patients of older age, less educated, single, and unemployed patients. Majority of caregivers were female and of older age. The burden perceived was found to be significantly high in female caregivers, especially mother.

Keywords: Schizophrenia, caregiver burden, socio-demographic variables

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Schizophrenia is a debilitating illness affecting 1% of the world's population. Its treatment is often as varied as its course as well as its symptoms and can pose numerous psychosocial difficulties for patients as well as family members who care for their loved ones. In past 50 years, the deinstitutionalization of psychiatric patients has resulted in transferring the responsibility and day to day care to family members. With the emergence of practice of community psychiatry, families are often integral part of the treatment team.

The role of family has been pivotal in the mental health care programmes in India. In contrast with the emphasis on professionals and institutions in mental health care in the developed countries, the emphasis in India has been on the family as the single most important caregiver of the mentally ill patients.

Evidence suggests that family members experience significant stress in coping with a person with schizophrenia. The caregivers suffer emotional, financial and physical burden while playing the role of carer. Burden of care is influenced by various factors like age, sex, duration of illness, marital status, previous hospitalization, education and family structure, and employment status of the patients and caregivers.

Over the years, the families in India have undergone changes with respect to increasing urbanization, breakdown of the traditional joint families, increasing numbers of nuclear families, increase in the geriatric population, single parent and working parent families. This has led to a decline of resources within the family threatening the support available to patients with chronic mental illness.

Therefore, this study was undertaken to study the perceived level of burden of care and its correlates in caregivers of patients with schizophrenia.

Aims & Objectives

1. To study socio demographic details of schizophrenia patients & caregivers
2. To assess perceived level of burden in caregivers
3. To study association between caregiver burden and socio demographic details of patients and caregivers.

MATERIALS

Semi structured proforma specially designed for the study to obtain various socio demographic characteristics like age, sex, education, occupation, marital status, family type and relationship of caregivers with patients etc.

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Modified Kuppuswamy scale (urban) with 2007 modification: This scale was used to measure the socio economic status of the patient. This scale has been widely used in clinical research and is specially designed for use in urban areas where this study was conducted. This scale assesses the socio-economic status of the patient based on three broad parameters: Education of the head of the household, Occupation of the household and per capita income (in Rs per month). Each parameter is categorized step wise in a descending order and each option is assigned a specific weightage. Five socio-economic classes are defined based on total points as; upper (score- 26-29), upper middle (score- 16-25), lower middle (score- 11-15), upper lower (score- 5-10), lower (score- <5).

Burden Assessment Schedule (BAS): It is a structured instrument with 20 items used to assess perceived burden by the caregiver. Each item is rated on a three point Likert scale where 1=not at all; 2=to some extent and 3=very much. The items of the schedule are categorized under five sub domains: Impact on well being, Impact on marital relationships, Appreciation for caring, Impact on relationship with others and Perceived severity of the disease.

METHODOLOGY

Prior to the study, patients and their caregivers were informed of the research objectives and assured of the confidentiality of their responses. Informed consent was taken. Ethics committee approval was obtained. It was a cross sectional study in which, 100 consecutive patients of age 18-60 years, diagnosed as having chronic schizophrenia according to DSM-IV TR attending out-patient set up of Department of Psychiatry in a general teaching hospital and their caregivers were selected using universal sampling method.

The Pollack and Perlick method was used to identify the primary care giver. Socio-demographic details of patients as well as caregiver were collected using semi-structured proforma. Caregiver's perceived burden was assessed using Burden Assessment Schedule. The data was pooled and subjected to statistical analysis using SPSS 17 package; Chi- square test, frequency, mean calculations etc.

RESULTS

As seen in table 1, 45% of the patients belonged to age group of 18-30 yrs & 31-45 yrs with mean age of 34.25 yrs. In the study sample, majority of the patients were unemployed (36%), housewife (32%), belonging to nuclear family (42%), had secondary education (64%), and married (40%).

Among caregivers, majority was in age group 46-60 yrs, was females (59%), and had secondary education (46%). Mothers comprised of 40% of the caregivers while spouses accounted for 33% of them. 73% of the caregivers were married and 41% of them were housewife.

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Perceived burden of care was observed in 48% of the caregivers as seen in chart 1. Among various domains on BAS, 55% of the caregivers perceived burden on factor 1, i.e. impact on well being of BAS and 51.5% of them perceived burden on factor 2, i.e. marital relationship. Only 33% of the caregivers perceived burden on factor 3 which is appreciation for caring. (Table 2)

As observed in table 3, nearly half of the caregivers of patients belonging to age group of 46-60yrs and of female patients, perceived burden. Caregivers of patients with secondary education perceived maximum burden i.e. 59.6% while 19.2% of caregivers caring for patients with higher education perceived burden.

Cumulative percentage of the caregivers who were caring for single patients (unmarried/ separated/ widowed/ divorced) was high i.e. 57.8% and 42.3% of the caregivers who were taking care of married patients perceived burden. Caregivers of unemployed patients perceived maximum burden i.e. 46.2%.

In patients belonging to upper middle and middle socio economic class, caregivers perceived maximum burden i.e. 40.4% and 42.3% respectively. Among patients and caregivers belonging to nuclear families, 48.1% of them perceived burden.

Caregivers in the age group of 31-45 yrs and 46-60 yrs perceived maximum burden i.e. 46.2% each. Female caregivers perceived more burden than male caregivers. As seen in the table 4, this difference was found to be statistically significant. Mother and spouses in their role of caregiving perceived significantly higher burden as compared to other relation as a carer. Caregivers who were secondary educated (42.3%) and housewife (46.2%) perceived the maximum burden. Most of the married caregivers perceived burden.

DISCUSSION

Schizophrenia is a serious, debilitating psychological disorder which not only influences the lives of those affected but also their family. This study is an attempt to understand the caregiver's perception of burden due to patient's illness and its relation with the various socio-demographic parameters.

Majority of the patients belonged to age group of 18-45 yrs with mean age of 34.25 yrs. Almost equal number of male & female patients were assessed in the study. More than half of the patients were secondary educated. Sixty percent of the patients were either unmarried or single. A study done by Shrivastava S et al observed that 71% of the patients were literate and 76% of the patients were married. This is in contrast with findings of this study, where lower rate of marriage may possibly be due to early onset of illness in them.

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Majority of patients were unemployed followed by patients who were housewife. Early onset of illness & ongoing deficits may have resulted in unemployment in majority of patients. Nearly half of the patients belonged to nuclear family. This shows the changing trends in the modern Indian society where joint family structure is getting dissolved and majority of people stay in either nuclear or extended nuclear family. Similar findings were reported by study done by Chakrabarti S. et al which showed that 53% of the Indian patients belonged to nuclear families.

Amongst caregivers, mean age was 47.23 yrs. About half of the caregivers were from the age group 46-60 yrs. Female caregivers were more than male caregivers. Preponderance of female caregivers in this study is consistent with the tradition of the area. In most of the Asian countries, females and mothers are the traditional caregivers for patients with chronic illnesses.

Majority of the caregivers were married and housewife. These findings are in keeping with a study done by Talwar P et al which showed that in Indian sample, mean age of caregivers was 49 yrs. 62% of the caregivers were females. A study done by Creado et al show those majorities (61%) of the caregivers was females and approximately 50% of the carers were unemployed.

In the studied sample population, 52% of the caregivers perceived burden as assessed on BAS. This is in accordance with a study done by Yusuf and Nuhu who found that 47.3% of the caregivers experienced burden of care giving role. A similar study by Talwar P et al reported that 46% of the caregivers in India perceived low to moderate & 54% perceived high burden on BAS. In a study done by Pereira MG et al it was observed that 76% of the caregivers who were caring for severely mentally ill patients reported burden.

The mean scores of the patients were high on all domains of BAS which measures the negative aspects of caregiving. This clearly shows that family members of schizophrenic patients were significantly distressed. More than half of caregivers reported burden on Factor 1 i.e. impact on well being in terms of feelings of exhaustion, frustration, depression and impact on health in general. This was followed by nearly half of the spouses reporting burden on factor 2 i.e. marital relationship. Only 33% of the caregivers reported burden on Factor 3 i.e. appreciation for caring. This again highlights the characteristics of the Indian caregivers who offer caregiving without expecting appreciation in return.

Table 3 shows association between socio demographic variables of patients and caregivers & burden in caregivers. Maximum burden was perceived by caregiver caring for patients of age group 46-60 yrs. This finding is similar to the study by Gopinath et al which shows that relative's distress increases with an increasing age of the patient. Increasing age may bring along with it other medical problems, decreased work efficiency and increased dependency in patients, increasing burden in the caregivers. However, findings of the present study are in contrast to a

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study done by Dyck DG et al, where the age of the patient was inversely related to the burden in caregivers.

Findings of various studies shows that caregivers of female patients reported significantly higher level of emotional distress than caregivers of male patients supporting findings in the current study. In a male centred society of India, caring for single, unemployed, and mentally ill female patient can be considered a burden. However, these findings are in contrast with a study done by Sibitz et al, which showed that relatives of male patients perceived more burdens.

Caregivers of patients educated up to secondary school perceived more burdens compared to those caring for patients with higher education. This is in accordance with the findings of study done by Dominic U et al who found that caregivers of patients with lower levels of education experienced higher burden than caregivers of patients with higher educational attainment. A higher education guarantees better job opportunities and may convey some socioeconomic advantage, apart from influencing one's health seeking behaviour.

Cumulative percentage of the caregivers who were caring for single patients (unmarried/ separated/ widowed/ divorced) was maximum. In a country like India, where marriage is considered to be the measure of stability, caring for unmarried or single patients can be considered bothersome. A study by Thara and Srinivasan et al has found that married patients showed a remitting or stable course of illness.

Majority of caregivers of unemployed patient perceived burden than those caring for employed patients; thus supporting previous study findings that family members experienced lesser burden when the ill person was employed as shown in a study by Pickett SA et al.

A patient with schizophrenia is often unable to sustain employment due to which family members are often put in an additional financial burden of medical expenses. Caregivers of patients who belonged to nuclear family perceived higher burden than those belonging to joint family. However this association was not statistically significant. Most patients participating in this study were from nuclear families and lack of family and social support can make caregivers perceive more burdens.

Higher burden was perceived by caregivers of middle and older age as compared to caregivers of younger age. One explanation for the relation between middle & late age and high distress is that caregivers, particularly those in midlife, are more likely to have additional major social roles, such as work and other caregiving roles that include raising children and caring for others in family. Also emergence of various medical problems in them adds to the burden perceived.

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However these findings are in contrast to the study done by Sandy M et al which found that younger caregivers perceived maximum burden.

Female caregivers perceived significant burden of their caregiving role. This finding was similar to a study by Sefasi et al which showed that female caregivers perceived more burden than male caregivers. Commonly the female relatives engage in caregiving and have been reported as experiencing most of the associated burden as reported by Pring Le J et al.

One possible explanation could be the genetic makeup of the females making them more vulnerable. Also, the wife caregiver often has to double up as the breadwinner for the family and the dual role can lead to heavier burden. The mother as caregiver is often known to be very involved, remaining by the patient's side all the time and had difficulty detaching herself.

Significantly high burden was perceived by mother as a carer compared to other relations. Historically, parents have shouldered the responsibility for their offspring's illness. The blame of the illness usually comes on parents for their parenting style. The genetic slant to aetiology often hits hard on the parents who saw themselves as the transmitters of the illness.^[24] As parents, the loss of hope in their schizophrenic child can have greater impact on and a lifelong commitment to the care of the child can result in anxieties and burden. For parents who are older, the concern as to who would care for the patients after their time is often a heavy burden.

High burden of caregiving was perceived by the caregivers with lower education compared to those with higher education. In a research done by Zahid and Ohaeri et al, similar findings were noted. A caregiver with a low level of education would have limited access to mental health facilities because of limited resources, and may be at risk of developing emotional distress because of this additional disadvantage.

High prevalence of burden was felt by the caregivers who were housewife than by the caregivers who were employed. More the caregiver spends time with the patient more is the burden felt by the caregiver.

CONCLUSIONS

Mean age of the patient was 34.25 yrs. Maximum patients belonged to age group of 18-45 years. Almost equal numbers of male & female patients were studied. Majority of the patients were secondary educated, married, unemployed and belonged to nuclear family nuclear family.

Mean age of the caregiver in the sample was 47.23 yrs. Female caregivers predominated over males. Primary caregiver in majority of the patients was mother. More than half of the caregivers had secondary or less education and were married. About half of the caregivers were housewife.

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In present sample population, 52% of the caregivers perceived burden of their caregiving role. Burden was found to be high in caregivers of female patients, patients of older age, single, less educated unemployed, and those belonging to nuclear family. Female caregivers, especially mother perceived significantly high burden.

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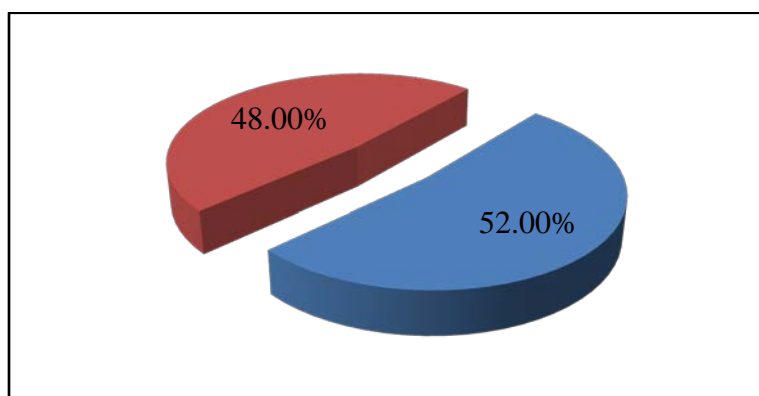
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Table 1: Socio demographic details of patients & caregivers

Socio demographic variables		Patients (n= 100)	Caregivers (n=100)
Age	18-30 yrs	45.0%	12.0%
	31-45 yrs	45.0%	37.0%
	46-60 yrs	10.0%	51.0%
Sex	Male	48.0%	41.0%
	Female	52.0%	59.0%
Education	Illiterate	13.0%	21.0%
	Primary	7.0%	24.0%
	Secondary	64.0%	46.0%
	Graduate & PG	16.0%	9.0%
Marital status	Unmarried	40.0%	8.0%
	Married	40.0%	73.0%
	Separated	11.0%	0.0%
	Divorced	5.0%	1.0%
	Widowed	4.0%	18.0%
Occupation	Unemployed	36.0%	6.0%
	Housewife	32.0%	41.0%
	Labourer	11.0%	14.0%
	Service	17.0%	23.0%
	Self employed	4.0%	16.0%
Relationship of caregivers with patients	Spouse	33.0%	
	Mother	40.0%	
	Father	16.0%	
	Siblings, children	11.0%	

Chart 1: Perceived burden on BAS



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Table 2: Perceived burden on various domains of BAS

Domains of BAS	Mean score	Standard deviation	% of caregivers having burden (n=100)
F1	8.04	2.605	55%
F2	7.97	2.710	51.5%
F3	6.58	2.221	33%
F4	7.20	2.387	43%
F5	7.20	2.420	40%
BAS	31.64	9.975	52%

Table 3: Association between socio demographic variables of patients & burden in caregivers

Socio demographic variables		Burden on BAS		'p' value
		Yes: n=52	No: n=48	
Age	18-30 yrs	21 (40.4%)	24 (50.0%)	NS
	31-45 yrs	25 (48.1%)	20 (41.7%)	
	46-60 yrs	6 (11.5%)	4 (8.3%)	
Sex	Male	25 (48.1%)	23 (47.9%)	NS
	Female	27 (51.9%)	25 (52.1%)	
Education	Illiterate	6 (11.5%)	7 (14.6%)	NS
	Primary	5 (9.6%)	2 (4.2%)	
	Secondary	31 (59.6%)	33 (68.8%)	
	Graduate & PG	10 (19.2%)	6 (12.5%)	
Marital status	Unmarried	16 (30.8%)	24 (50.0%)	NS
	Married	22 (42.3%)	18 (37.5%)	
	Separated	8 (15.4%)	3 (6.2%)	
	Divorced	3 (5.8%)	2 (4.2%)	
	Widowed	3 (5.8%)	1 (2.1%)	
Occupation	Unemployed	24 (46.2%)	12 (25.0%)	NS
	Housewife	14 (26.9%)	18 (37.5%)	
	Labourer	6 (11.5%)	5 (10.4%)	
	Service	7 (13.5%)	10 (20.8%)	
	Self employed	1 (1.9%)	3 (6.2%)	
Family type	Joint	8 (15.4%)	14 (29.2%)	NS
	Nuclear	25 (48.1%)	17 (35.4%)	
	Extended nuclear	19 (36.5%)	17 (35.4%)	

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Table 4: Association between socio demographic variables of caregiver & burden in caregivers

Socio demographic variables		Burden on BAS		'p' value
		Yes: n=52	No: n=48	
Age	18-30 yrs	4 (7.7%)	8 (16.7%)	NS
	31-45 yrs	24 (46.2%)	13 (27.1%)	
	46-60 yrs	24 (46.2%)	27 (56.2%)	
Sex	Male	15 (28.8%)	26 (54.2%)	0.008**
	Female	37 (71.2%)	22 (45.8%)	
Relationship with patient	Spouse	20 (38.5%)	13 (27.1%)	0.020*
	Mother	25 (48.1%)	15 (31.2%)	
	Father	4 (7.7%)	12 (25.0%)	
	Siblings, children	3 (5.8%)	8 (16.7%)	
Education	Illiterate	13 (25.0%)	8 (16.7%)	NS
	Primary	15 (28.8%)	9 (18.8%)	
	Secondary	22 (42.3%)	24 (50.0%)	
	Graduate	2 (3.8%)	7 (14.6%)	
Occupation	Unemployed	1 (1.9%)	5 (10.4%)	NS
	Housewife	24 (46.2%)	17 (35.4%)	
	Labourer	10 (19.2%)	4 (8.3%)	
	Service	12 (23.1%)	11 (22.9%)	
	Self employed	5 (9.6%)	11 (22.9%)	
Marital status	Unmarried	1 (1.9%)	7 (14.6%)	NS
	Married	37 (71.2%)	36 (75%)	
	Separated	0 (0%)	0 (0%)	
	Divorced	1 (1.9%)	0 (0%)	
	Widowed	13 (25%)	5 (10.4%)	

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