

Socio-demographic Correlates of Care Burden in Primary Caregivers of Persons with Schizophrenia: A Study from Northeast India

Abhijeet Singh^{1*}, Arif Ali²

ABSTRACT

Schizophrenia is a major mental disorder and requires a lot of care in the process of treatment. Thus, the role of primary caregiver becomes important and challenging, because they had to face both objective and subjective burden of care throughout the process of recovery. The study was designed to see the association of sociodemographic correlates with care burden in primary caregivers of persons with schizophrenia in northeast part of India. Across sectional correlational descriptive study design was used for the present study and convenient sampling was used to collect responses from 200 adult primary caregivers of persons with Schizophrenia from LGBRIMH, Tezpur, Assam. They were assessed on a socio-demographic data sheet and Zarit Burden Interview. Permission to conduct the study was taken from the Institute Ethics Committee, LGBRIMH, Tezpur. Analysis was done using Statistical Package for the Social Sciences (SPSS) version - 25. Severe level of care burden was found in the majority primary caregivers (63.0%). Correlation analysis showed that the age of patient was significantly negatively correlated with the care burden ($r=-0.275$, $p<0.05$) and was negatively correlated with the duration of care giving ($r=-0.022$). Care burden was found to be significantly positively correlated with the age of caregiver ($r=0.180$, $p<0.01$). Regression analysis showed that gender, the age of the patient, education and occupation of the caregiver significantly predicted the care burden perceived by caregivers of persons with Schizophrenia [$F(6,193)=15.935$, $p=0.005$]. Care burden is a major problem in long term caregiving; hence, proper psychosocial intervention may be planned to combat such difficulties in future.

Keywords: *Psychosocial Care, Burden, Mental Health, Family Caregivers, Persons With Schizophrenia*

Schizophrenia is a chronic mental condition where the individual though process is impaired severely resulting in delusion, hallucination, disorganized speech or behavior, decreased participation in daily activities, difficulties in attention and

¹Ph.D. Scholar, Department of Psychiatric Social Work, LGB Regional Institute of Mental Health, Tezpur, Assam, India.

²Assistant Professor, Department of Psychiatric Social Work, LGB Regional Institute of Mental Health, Tezpur, Assam, India.

*Corresponding Author

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concentration and memory impairment (ICD 10). Family plays an important role in providing care for the person with schizophrenia (Tsui & Tsang, 2017). Care burden in Schizophrenia found to be more challenging because it had been estimated that patients with Schizophrenia were found to be at a high risk of committing suicide during their lifetime, because of impairment in the functioning (Hor & Taylor, 2010).

Primary caregivers of persons with Schizophrenia have to face physical health problems like-sleep deprivation, high blood pressure, poor diet, chronic headache (Kızılırmak & Küçük, 2016; Jagannathan et al., 2014), psychological problems such as depression, anxiety, stress, suicidal thoughts, chronic sorrow, tension and burn out issues (Koujalgi & Nayak, 2016; Kalita et al., 2017) and social problems such as poor support from the community, stigma attached to schizophrenia, social withdrawal (Chen et al., 2019, Bhat et al., 2020).

The Economic burden of care also plays a huge role in making the care burden more complex (Deshpande et al., 2018). According to a research article on the economic impact of family caregiving by Schulz, Eden & National Academies of Sciences, Engineering, and Medicine (2016), it was found that around 61 % of the caregivers had to compromise office duty such as reaching late in the office, giving office responsibilities to others, leaving for home early so that they can take care of their patients. But these arrangements have a negative impact on their financial status such as fewer paying days, poor inter-personal relation in the office due to frequent leaves, low savings, and continuous fear of job loss.

According to Li et al (2015), care burden found to be higher in male patients, whereas, Richard et al. (2017) highlighted that the care burden is significantly high in female patients. Studies have also stated that apart from patient's gender, caregivers' gender also need to be considered when it comes to care burden (Jenkins & Schumacher 1999; Loganathan & Murthy, 2011). Educational background plays an important role in the entire caregiving process. Studies have highlighted that low educational status, may lead to high expressed emotion, depression, poor coping, poor functioning, reduced quality of life in the family. This overall negatively augments the chance of relapse and poor prognosis in patients resulting in care burden (Ozkan et al., 2013; Verma et al., 2019).

Both the age of the patient and caregiver also contributes significantly in the severity of the care burden. Studies have shown that with the increase in age of the patient and caregiver various health related problems and stressors comes out. Psychological problems such as ideas of hopelessness, helplessness takes place, leading to care burden and poor prognosis of patient's illness. These studies also highlighted that in rural settings there are manifold reasons of increased caregiver burden. Due to lack of necessary amenities, resources & much needed ground level awareness regarding mental illness, the distress gets heightened. Moreover, the stigma associated with mental health issues often posits a high risk of psychological breakdown of the family members since they feel ashamed and accountable for the same (Kumar et al. 2015; Yu et al. 2017).

Thus, it seemed to be clear that socio-demographic determinants tend to affect the overall care burden, when it comes to long term caregiving in Schizophrenia. Talking of North east region, no specific hospital-based research study on the association between socio-demographic variables and care burden are available. Hence, the researcher designed the present study to see the correlates of socio-demographics variables on care burden in a

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north-east hospital-based population. So that, in future hospital based psychosocial intervention could be planned to address the care burden issues in the northeast region.

Objectives of the study

- To identify the level of care burden in primary caregivers of persons with Schizophrenia in Northeast part of India.
- To understand the relationship between selected socio-demographic variables and care burden in primary caregivers of persons with Schizophrenia in Northeast part of India.

METHODOLOGY

A cross-sectional descriptive study designed and convenient sampling was used to collect a total of 200 samples. The targeted population were the adult caregiver of persons who were diagnosed with Schizophrenia according to the guidelines of International Classification of Diseases 10th Revision (ICD 10), with more than two years a history of illness was selected from LGB Regional Institute of Mental Health, Tezpur, Assam. Adult caregivers staying at hospital premises with the patient and fulfilling > 3 criteria to be a caregiver proposed by Pollak and Perlick (1991), which include [(spouse, parent or spouse equivalent, b) most frequent contact with patient, c) supports patient financially, d) most frequent collateral participant in patient's treatment, e) is the person contacted in case of an emergency)] were included in the study. Patients and caregivers with comorbid physical illness, intellectual disability, and substance use disorder were excluded from the study. Permission to conduct the study had been taken from the Institute Ethics Committee, LGBRIMH, Tezpur. A proper instruction about the procedure involved in the study was provided to the caregivers. Those who were willing to participate in the study, signature/thumb impression on informed consent were taken from them. Statistical Package for Social Sciences (SPSS) version 25.0 was used for analysis and interpretation of the data.

Tools used in the study

- **Socio-demographic and clinical data sheet:** A socio-demographic and clinical data sheet and consent were self-designed by the researcher to obtain socio-demographic information of both patient and caregivers, which include age, gender, religion, domicile (residence), community, marital status, education, occupation, family income and family type. The Clinical Profile of the patient includes onset of the illness, total duration of illness, total duration of caregiving and family history of any psychiatric illness.
- **The Zarit Burden Interview (ZBI)** (Zarit, Reever & Bach-Peterson, 1980): ZBI is a 22-item comprehensive assessment of both objective and subjective burden. Cut off: 0 – 21 is indicative of little or no burden; 21 – 40 is indicative of mild to moderate level of burden; 41 – 60 is indicative of moderate to severe level of burden and 61 – 88 is indicative of severe level of burden.

RESULTS

Table 1: Level of care burden in primary caregivers of persons with Schizophrenia (N=200).

Care burden category	Frequency (n)	Percentage (%)
Little/No burden	02	1.0
Mild Burden	45	22.5

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Care burden category	Frequency (n)	Percentage (%)
Moderate Burden	27	13.5
Severe Burden	126	63.0

This table showed that severe level of burden was present in majority of caregivers (63.0%) (Table 1).

Table 2: Care Burden and its association with socio-demographic variables (N=200).

Socio demographic variables	Little/no burden	Mild to Moderate Burden	Moderate to severe burden	Severe burden
	%	%	%	%
Gender				
Male	0.7	25.0	10.8	63.5
Female	1.9	15.4	21.2	61.5
Religion				
Hindu	0.8	13.3	12.5	73.3
Muslim	1.3	36.4	14.3	48.1
Christian	0.0	33.3	33.3	33.3
Marital Status				
Unmarried	0.0	33.3	15.2	51.5
Married	1.3	21.9	14.2	62.6
Background				
Rural	1.5	0.0	0.0	98.5
Urban	0.0	30.2	23.3	46.5
Semi urban	1.1	35.2	18.7	45.1
Education				
Illiterate	3.6	46.4	25.0	25.0
Primary	0.0	0.0	7.1	92.9
Middle	2.5	20.0	22.5	55.0
High	0.0	32.9	12.3	54.8
Occupation				
Daily	2.9	11.4	2.9	82.9
Domestic	0.0	14.7	17.6	67.6
Private	0.0	34.1	7.3	58.5
Government	0.0	15.4	15.4	69.2
Agriculture	0.0	22.9	14.3	62.9
Business	0.0	18.2	0.0	81.8
Unemployed	3.3	33.3	30.0	33.3
Type of caregiving				
First degree Relative	1.3	15.0	11.3	72.5
Second degree relative	0.0	52.5	22.5	25.0
Family Income				
Lower	1.5	7.7	9.2	81.5
Upper-lower	1.0	29.2	13.5	56.3
Lower-middle	0.0	31.6	21.1	47.4

%= percentage (100%)

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This table showed that severe level of care burden was present in first degree relatives (72.5%), burden was at a severe level in a male primary caregiver (63.5%), those who belong to Hindu religion (73.3%), mostly in married caregivers (62.6%), belonging to rural background region (98.5%), those who are educated up to primary level (92.9%). Care burden was high among daily wage workers (82.9) with a family income of less than 10,000 per month (lower) (81.5%) (Table 2).

Table 3: Correlates of caregiver’s burden with various variables (N=200).

Variable	Caregiver’s age	Patient’s age	Duration of Caregiving	Duration of illness
Care Burden	0.180*	-0.275**	-0.022	0.017

* $p < 0.05$; ** $p < 0.01$

This table showed that age of the patient was significantly negatively correlated with care burden ($r = -0.275$, $p < 0.05$) and negatively correlated with duration of care giving ($r = -0.022$). Care burden was found to be significantly positively correlated with the age of the caregiver ($r = 0.180$, $p < 0.01$) (Table 3).

Table 4: Regression analysis of gender (P), education (C), occupation (C), family income, age (P) and total duration of illness with care burden (N=200).

Multiple R	R ²	Adjusted	Standard
0.576	0.331	0.310	14.890

ANOVA Table

	df	Sum of square	Mean of square	F	Significant
Regression	6	21196.1	3532.6	15.935	0.000
Residual	193	42787.5	221.6		

Variables in the equation

Variables	B	SE	Beta	t	Significant
Gender (P)	-8.501	2.311	-0.228	-3.679	0.000
Education (C)	4.604	0.863	0.336	5.333	0.000
Occupation (C)	-1.369	0.594	-0.139	-2.303	0.022
Family Income	-1.276	1.559	-0.051	-0.818	0.414
Age (P)	-0.300	0.074	-0.243	-4.061	0.000
TDI (P)	0.313	0.537	0.035	0.584	0.560
Constant	74.514	6.61	-	11.271	0.000

*** $p < 0.001$; * $p < 0.05$; P = Patient; C = Caregivers; SE = Standard Error

This table showed that gender and age of the patient, education and occupation of the caregiver contribute significantly to the prediction of care burden among caregivers of persons with Schizophrenia [$F(6,193) = 15.935$, $p = 0.005$] (Table 4).

DISCUSSION

In the present study care burden was found to be at a severe level in the majority of the primary caregiver (63.0%) of persons with Schizophrenia taking in-patient treatment from a mental hospital. A similar study conducted by Hajebi, Naserbakht & Minoletti (2019) reported moderate to severe level of care burden in the majority (73.0%) of their samples.

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They explained that severe care burden in primary caregivers is due to multiple relapses in the patient, high level of expressed emotion in the family and lesser awareness of the illness. Further, they explained that stressors for patient act as a burden for the primary caregiver. Moreover, the study by Kuchhal et al. (2019) showed a severe level of care burden in 42.3% of their caregivers and put socio-demographic variable like (low education, unemployment) as a reason for care burden in the families of persons with Schizophrenia.

In the present study, a severe level of care burden was present in male primary caregiver (63.5%), belonging to the Hindu religion (73.3%), mostly married (62.6%). According to Yazici et al. (2016), gender differences in patients and caregivers had a significant effect on care burden. A study conducted by Yu et al. (2019) found anxiety to be prominent in male patients, whereas depression was found to be prominent in female patients. Violent behavior found to be more common in male patients and it majorly affects the physical and mental health of the family caregivers resulting in a higher burden. If talking of the female patients, they found to be unemployed and financial dependence on family. Moreover, as depression is common in females, due to which the household activities are severely disrupted resulting in again severe care burden in family caregivers. This overall increase's caregiver burden in areas like social, vocational, family, cognitive, and personal areas.

The present study highlighted the severe level of care burden in first degree relatives (72.5%). Studies (Lasebikan & Ayinde, 2013; Mora-Castañeda et al., 2018) conducted in past also depicted similar results, and highlighted higher care burden (60.0% to 82.3%) in first degree relatives, because, they (caregiver) stay with the patient for a much longer time. Patient with Schizophrenia requires long-term treatment and are prone to show suicidal behaviour. Thus, the first-degree relative (or primary caregiver), had to supervise the daily activities of the patients. As a result, they neglect personal life, family, friends, community participation, and career. They also face stigma related to mental illness and experience avoidance from peer group and society, which becomes the core cause of burden.

In the present study majority of the caregivers belong to rural background region (98.5%), educated up to the primary level (92.9%) working as a daily wage worker (82.9%) with a family income of less than 10,000 per month (lower) (81.5%). Studies conducted in past by also came up with similar finding and commented that socio-demographic variables like (education, occupation, family income and residence) play an important role in deciding the severity of care burden (Adeosun, 2013 & Dere et al., 2017). Studies came up with an explanation that a low level of education was indicative of low insight of patient's illness, lesser utilization of available resources, frequent absence in follow updates, no hospitalization, dependence on faith healers, which overall increases the burden of care (Li, Lambert & Lambert 2007; Koujalgi & Nayak 2016).

Studies (Brinda et al., 2014; Crouch, Probst & Bennett, 2017) have explained that caregiving in rural setting becomes more challenging due to lack of resources, the difficulty is maintaining hygiene due to small kuccha houses and larger families residing in a small house, every family member indulged in agriculture activities to earn their livelihood, thus the patient's caregiving is compromised. Other factors included far off distance from health care centers, stigma related to mental health, lack of awareness among the masses are some common issues making caregiving more complex and challenging in rural settings.

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Care burden was found to be positively correlated with the age of caregivers. A similar study by Chan(2011) on the global perspective of burden of family caregivers for persons with schizophrenia highlighted that care burden becomes more severe for older caregivers because, with time and added responsibilities they (older caregivers) found to be weak in all aspects like-physically, psychological, emotionally and financially. Moreover, Study by Shamsaei, Cheraghi & Bashirian (2015) found the level of anxiety, apprehension and depression in older caregivers. As schizophrenia requires long-term care, caregivers tend to drain out all their savings, pensions in medications and other caregiving expenses resulting in financial burden.

Furthermore, in the present study age of the patient was significantly negatively correlated with care burden. Li, Lambert& Lambert (2007) also found similar result and highlighted that younger patient, requires more attention of the caregivers, because, they have a poor insight of the illness, poor coping skills, high tantrums, rigidity in taking medication resulting in higher care burden. A study by Caqueo-Urizar & Gutiérrez-Maldonado (2006) showed that younger patients are dependent on their caregivers for all their domestic activities and requires prompting, care, guidance, parental supervision around the clock, which increases the duration of caregiving leading to high burden.

Limitation of the study

The present study had some limitation. All the scales applied were self-reported and were quantitative in nature, hence, the researcher lacked in obtaining a qualitative aspect of caregiver's burden through one-to-one interaction and focus group discussions, a mixed-method study design could had been a better choice. The sample size was limited; a larger sample size could have given a better generalization of the result. The study does not evaluate the association between family functioning and care burden.

CONCLUSION

The present study investigated that socio-demographic variables plays a vital role in deciding the level of care burden in caregivers of persons with schizophrenia. The contributing socio-demographic variables in this study were age and gender of the patient, type of caregiving, duration of caregiving, caregiver's educational background, occupation, family income and residence. Thus, the finding of this study calls for psychosocial care to the caregivers providing long-term caregiving to their relatives (patients) in a hospital-based setting. It is high time for the clinicians, policymakers, medical fraternity and allied health care professionals to frame an intervention module to help the caregivers during the treatment of the patient. This study highlighted that long term caregivers of persons with Schizophrenia are at high risk of developing mental illness due to various stressors. From the time, a patient is admitted to the hospital, his/her caregivers should be given proper assessment and psychosocial care should be extended. Group interaction, recreational activities, motivational sessions, role plays, psychoeducation, the introduction of support groups, supportive counselling, tele-helpline services, hospital-based awareness programmes should be the mainstay of psychosocial care in caregivers of persons with Schizophrenia.

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Conflict of Interest

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