

Research Paper

A Study to Assess the Level of Caregivers' Burden and Associate with the Socio Demographic Factors of Caregivers of Patients with Schizophrenia- A Cross Sectional Study

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ABSTRACT

Background: Schizophrenia is one of the most debilitating psychiatric disorders worldwide. Caring for patients with schizophrenia is a significant burden on the families and caregivers. The role of the patients' families is dominant in the treatment process. Hence, the related problems are experienced more in the family environment, which affects their daily life. **Aim:** To find out the level of caregivers' burden and associate with the socio-demographic factors of caregivers of patients with schizophrenia. **Methods:** A cross-sectional descriptive study, by convenience sample of 175 primary family caregivers was taken from selected Psychiatric Hospital at Dharwad, Karnataka. Tools included a socio-demographic information sheet and the Burden assessment schedule for assess the level of care givers burden. **Results:** The results reveals that majority 108(61.7%), caregivers had high level of burden and 67(38.3%) had average level of burden and associated with socio-demographic variable of caregivers, the findings depicts that all selected socio-demographic variable are associated with level of caregiver burden. **Conclusions:** The findings highlighted the importance of sense of social-demographic characteristics of caregivers' and their hardiness is in individual towards to coping to burden. Special attention needs to focus on therapeutic interventions that enhance sense of coping towards burden, individually and, thereby decreases the level of burden of care and effective family functioning.

Keywords: Burden, Schizophrenia, Caregivers, Socio-Demographic Variables.

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Every human being is born brought up in family; it is an architect of an individual's of personality. A family prepares an individual to perform this multiplicity of roles, which requires stable states of mind and good family environment. Historically, the proposition that family was the cause of a child's developing Schizophrenia based primarily on the concepts on the "double bind" on "marital skew" and on "pseudo mutuality"; these concepts created an extremely non-therapeutic and destructive atmosphere between hospitalized clients and their family members and mental health professional.

The term "burden of care" emerged after the closure of mental hospitals when patients were followed-up outside of the hospital setting and family members assumed responsibility for these patients, thereby becoming the primary caregivers within the home environment. This construct can be conceptualized as a syndrome of varying clustering affecting the general and mental health of caregivers. (**Victoria Olufolahan Lasebikan, 2013**)

Mental health resources in India are limited. The treatment primarily focused on symptoms with drugs. Rehabilitation and psychological interventions are frequently neglected and rarely available (**Ranga swamy Thara & Sujit John 2006**). There have not been found methodologically refined, prospective, follow-up studies of schizophrenia in India. Mortality rates were quite high with the average age of death being 34.2 years, much below the average Indian life span of 60.5 years in 2002. Suicides accounted for 7 out of 16 deaths (**SCARF-Rangaswamy Thara 2005**). Schizophrenia was found to be the population with the highest re-admission rate. Although such patients received drug therapy and psychological and social support in hospital. Once they were discharged, many of these treatments ceased. Many patients did not maintain follow-up appointments and preferred to return to routines they had followed prior to hospitalization. Returning for follow up-care or maintaining medication was often viewed as a sign of weakness or illness by both patients and their families. The hospital professional teams become very aware that the families and friends lack of knowledge about Schizophrenia and its treatment resulted in misunderstandings that triggered the Schizophrenia stress state making re-admission necessary.

This study, therefore, set to determine the prevalence of level of caregiver burden among caregivers of patients with schizophrenia, and to determine the association with socio-demographic characteristics of caregivers' and their level of burden towards caring. The eventual aims include using the findings in implementing programs to address the needs of the caregivers of schizophrenia patients.

MATERIALS AND METHODS

Aim

- To find out the level of caregivers' burden and associate with the socio-demographic factors of caregivers of patients with schizophrenia.

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Design

- A cross-sectional descriptive design.

Participants

The participants were 175 caregivers of patients with schizophrenia who were admitted at inpatient departments of selected Psychiatric Hospital at Dharwad, India. The participants were selected through convenience sample technique. The inclusive criteria were age between 15-54 years and caregivers of patients with schizophrenia who were diagnosis made by psychiatrist based on ICD -10 criteria.

Study Instruments

The section A: socio-demographic details of participants, includes 10 items such as age, gender, relationship with patient, residence, type of family, education, occupation, income, duration of respondents relative suffering from schizophrenia and source of information.

The section B: Burden Assessment Schedule (BAS) a standardized validated tool suitable for use in Indian context comprised 20 item representing five factors or concerns which reflect caregiver's main feelings about their care-giving role. The five factors are 1) Impact on well being 2) Impact on marital relationships 3) Appreciation for caring 4) Impact on relations with others 5) Perceived severity of the disease. The BAS had 3 point Likert scale to assess the caregiver's burden in terms of 'not at all', 'to some extent', 'very much'. The scores for 'not at all'(3) 'some extent'(2) and 'very much'(1) for positive items. The reverse score is for the negatively worded items. The highest score is 60. (**R Thara, R Padmavati, Shuba kumar, Latha Srinivasn. 1998**) The scores are divided in to three level for know the level of caregivers' burden are Low level=0-20 score (<35%), Average level=21-40(<65%), & High level=41-60(>65%) respectively. The English and Kannada version of the questionnaires were used to collect the data.

Data collection

Study subjects were selected based on inclusive criteria from the IPD of Selected psychiatric hospital in Dharwad, India. Data collected from December- 2014 to April- 2015. The investigator personally visited to each respondent, introduced her to the participants, explained the purpose of the study and ascertained the willingness of the participants. The respondents were assured anonymity and confidentiality of the information provided them. Spending 30 to 45 minutes to each participants collected information.

Ethical consideration

The study was approved by the institutional ethical committee. The information was provided both orally and in written form.

Data analysis

Descriptive and inferential statistics were used and results were narrated in the form of tables.

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RESULTS

Findings related to socio-demographic characteristics

The distribution of samples revealed majority 68 (38.86%) in the age between 25-34 years, followed by 64(36.57%) were in age between 35-44 years, 22 (12.57%) are in 15-24 years, 21 (12%) are in age between 45-54 years, of care givers of patients with schizophrenia out 175 caregivers. The data presented in the form gender of caregivers, majority are 115 (65.71%) are females and 60 (34.29%) are males out of 175 care givers of patients with schizophrenia. In relation to the relationship with patient, the majority 77 (44%) are parents, followed by 36 (20.57%) are siblings, 34 (19.43%) were spouse, 17 (9.71%) are other relatives and only 11 (6.29%) are children's of patients with schizophrenia's caregivers out of 175. Distribution of samples according to place of residence, the majority caregivers 98(56%) are placed in rural and 77 (44%) are from urban out of 175 care givers of patients with schizophrenia. The distribution of samples based on types family, majority of caregivers in 108 (61.71%) were belong to joint family and 67 (38.29%) are nuclear family out 175 caregivers of patients with schizophrenia. The distribution of samples according to educational status that majority caregivers in 75(42.86%) are having 10+2 and diploma education out of 175, followed by 31 (17.71%) are primary and high school education, 27(15.43%) are found having graduate/post graduate level of education, 23 (15.14%) are had no formal education and 19(10.86%) were having professional education. In relation to the type of occupation, majority 55(31.43%) are private employee, 37(21.14%) are un-employed, 31(17.71%) are former/labour and 10(5.71%) are having business /small scale business employees. The samples distributed according to the income wise of caregivers, majority 40(22.86%) are belong to 10,001-20,000, 36(20.57%) belong to 20,001-30,000, 34(19.43%) are 5501-10,000, 29(16.57%) are 30,001 to 40,000, 24(13.71%) are above 41,000 and 12(6.86%) are belong to less than 5500 rupees income annually out of 175 caregivers. The data presented caregivers relatives' duration of illness. Majority 69 (39.43%) are 1 to 3 years of duration of illness, 60(34.29%) are 4 to 5 years, 31(17.71%) are more than 6 years and 15(8.57%) are suffers from less than one year duration out of 175 caregivers. The data presented the care givers gets information about schizophrenia by different sources, 66(37.71%) are getting information from medical professionals, 49(28%) from television, 21(12%) from news paper, 20 (11.43%) from radio and 19(10.86%) from magazines and books out of 175 caregivers.

Level of care givers burden

The analyzed data reveals that majority 108(61.7%), caregivers had high level of burden and 67(38.3%), had average level of burden and none of them had low level of burden. (Table-2)

Table-2 Level of caregivers burden n=175

Levels of burden	No. of participants	%
Low level	0	0.0
Average level	67	38.3
High level	108	61.7

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Association between levels of caregivers' burden with the selected socio-demographic variables.

Association between socio- demographic characteristics, the results shows that obtained chi-square values were, age group($\chi^2=21.06$, $df=3$, $p\text{-value}=0.0000^{**}$) is significant at level of $p<0.01$, Gender ($\chi^2=5.22$, $df=1$, $p\text{-value}=0.0224^{**}$) is significant at level of $p<0.01$, relationship with patient ($\chi^2=64.50$, $df=4$, $p\text{-value}=0.0000^{**}$) significant at the level of $p<0.01$, place of residence ($\chi^2=17.84$, $df=1$, $p\text{-value}=0.0000^{**}$) significant at level of $p<0.01$, type of family ($\chi^2= 9.44$, $df=1$, $p\text{-value}=0.0020^{**}$) significant at the level $p<0.05$, education level ($\chi^2= 63.94$, $df= 4$, $p\text{-value}= 0.0000^{**}$) significant level of $p<0.01$, type of occupation ($\chi^2=21.74$, $df=4$, $p\text{-value}=0.0002^{**}$) significant at the of $p<0.01$, the level of income ($\chi^2=44.07$, $df=5$, $p\text{-value}=0.0000^{**}$) significant at level $p<0.01$, duration of illness ($\chi^2=14.07$, $df=5$, $p\text{-value} =0.0028^{**}$) significant at level of $p<0.01$, source of information ($\chi^2=33.73$, $df=4$, $p\text{-value}=0.0000^{**}$) significant at the level of $P<0.01$. The majority of socio-demographic variables are associate with level of caregivers' burden. (Table-4)

Table-4 Association between socio-demographic characteristics with levels of caregivers' burden caregivers of patients with schizophrenia n=175

Characteristics	Burden levels					Chi-square	df	p-value
	Average level	%	High level	%	Total			
Age groups								
15-24 yrs	7	31.8	15	68.2	22	21.06	3	0.0001**
25-34 yrs	37	54.4	31	45.6	68			
35-44 yrs	23	35.9	41	64.1	64			
45-54 yrs	0	0.0	21	100.0	21			
Gender								
Male	16	26.7	44	73.3	60	5.22	1	0.0224*
Female	51	44.3	64	55.7	115			
Relationship with patient								
Spouse	0	0.0	34	100.0	34	64.50	4	0.0000**
Parent	51	66.2	26	33.8	77			
Siblings	16	44.4	20	55.6	36			

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Children	0	0.0	11	100.0	11			
Others	0	0.0	17	100.0	17			
Place of residence								
Urban	16	20.8	61	79.2	77	17.84	1	0.0000**
Rural	51	52.0	47	48.0	98			
Family type								
Nuclear	16	23.9	51	76.1	67	9.54	1	0.0020**
Joint	51	47.2	57	52.8	108			
Education								
Professional	9	47.4	10	52.6	19	63.94	4	0.0000**
Graduate/postgraduate	7	25.9	20	74.1	27			
10+2 and diploma	51	68.0	24	32.0	75			
Primary and higher	0	0.0	31	100.0	31			
No formal education	0	0.0	23	100.0	23			
Occupations type								
Business/small scale employees	0	0.0	10	100.0	10	21.74	4	0.0002**
Government employee	23	54.8	19	45.2	42			
Private employee	28	50.9	27	49.1	55			
Farmer / labour	9	29.0	22	71.0	31			
Un employed	7	18.9	30	81.1	37			
Income groups								
<5500	7	58.3	5	41.7	12	44.09	5	0.0000**
5501-10000	0	0.0	34	100.0	34			
10001-20000	28	70.0	12	30.0	40			
20001-30000	9	25.0	27	75.0	36			
30001-40000	14	48.3	15	51.7	29			
>41000	9	37.5	15	62.5	24			
Duration of illness								
<1 year	0	0.0	15	100.0	15	14.07	3	0.0028**
1-3 years	28	40.6	41	59.4	69			
4-5 years	30	50.0	30	50.0	60			
6+ years	9	29.0	22	71.0	31			
Sources of information								
Radio	0	0.0	20	100.0	20	33.73	4	0.0000**
Television	23	46.9	26	53.1	49			

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News papers	0	0.0	21	100.0	21			
Magazines and books	9	47.4	10	52.6	19			
Medical professionals	35	53.0	31	47.0	66			
Total	67	38.3	108	61.7	175			

*p<0.05, **p<0.01

DISCUSSION

The Schizophrenia is one of the most serious forms of mental illness among people being treated in psychiatric hospitals in developing countries. Providing care for people diagnosed with schizophrenia can be stressful for their caregivers. Caring of their relatives with schizophrenia may results in feelings of burden or strain for caregivers. Indian families have been typically describes as often believing in causes like supernatural forces and help seek from magi co -religious healers was observed.

This study identified the socio demographic factors related to the caregiver burden of those family members giving care to patients with schizophrenia. The factors predicting caregiver burden in this study were the age, gender, relationship with patient, residence, type of family, education status occupation, income, duration of participants' relative suffering from schizophrenia and source of information who receive regarding schizophrenia of caregivers were found to be associated the level of caregivers' burden.

The study result supports with the review literature, the caregiver burden caused by schizophrenia is evaluated in a multidimensional way. The negative effects of persons with a serious mental illness on their family members have been explored since the 1950s, and the term “caregiver burden” began to be used in the 1970s. The scope of this concept was broadened after the 1980s. The “caregiver burden” concept that is widely accepted includes all of the physical, mental, social, and economic problems experienced by the relatives of an individual with a chronic mental disease .(**Hsiao CY, Tsai TF 2015**)

The factors affecting the burden on caregivers can be related to the patient but can also be related to the caregivers themselves. The present study results were supported with many studies. The World Federation of Mental Health estimates that 80% of the caregivers in the world are female. Studies have shown that women who have a patient they are liable to look after have 6 times more depressive and anxiety symptoms than those who have no such liability. (**World Federation of Mental Health (WFMH); 2010**) Studies have shown that factors influencing the caregiver burden include male sex of the patient, youth, severity of the disease, cultural factors, stigma , duration of the disease, and disability Studies exploring the relationship between economic condition and caregiver burden have shown that a lower socioeconomic level is associated with increased caregiver burden.(**Ohaeri JU 2001 & Jagannathan A,2014**) These studies have also stressed the importance of caregiver age, education level, and time spent with the patient in determining the caregiver burden. (**Hulya A, Adana F 2011& Awad AG,2008**)

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Other study result supports the present study result that the Family care giving is a great concern in mental illness. Yet, the correlates of caregiver burden and family functioning in primary family caregivers of individuals with schizophrenia still remain unclear. Female caregivers, additional dependent relatives, increased family demands and decreased sense of coherence significantly increased caregiver burden, whereas siblings as caregivers reported lower degrees of burden than parental caregivers. (Hsiao CY, Tsai TF 2015)

The results of the present study suggest that the level caregiver burden is associated with many socio demographical factors of caregivers and also related to patients so, reducing the caregivers burden only enhancing the knowledge is not sufficient; additionally, structured psycho-education programs should include the teaching of coping strategies for the illness and its consequences.

The important limitation of this study is that its sample size was small. A larger sample would probably reveal sufficient data for generalization of the results. Another limitation of the study is the random selection of the caregivers of the patients who had more than one caregiver so that the sampling of the study was not homogenous. There should be a difference between the caregiver burden of caregivers who give care alone or with the help of another caregiver. This study did not evaluate the relationship between the number of the caregivers and the burden of care giving; therefore, this is a topic that should be evaluated in future.

Despite its limitations, we believe that present study results meet the two targets that can be addressed immediately in the short run to decrease the burden on caregivers of patients with schizophrenia: developing rehabilitation programs to improve functioning of schizophrenic patients and addressing the socioeconomic concern of the patient and their care givers in the aspect of treatment. Moreover, issues to be kept in the agenda should include day care centers to reduce the time patients and their caregivers spend together, sheltered employment, and provision of professional care that would help younger and more educated persons engage in the work of providing care.

LIMITATIONS:

The study is limited to caregivers of patients with schizophrenia, generalization of the results were limited, and also long term effects could not be established due to time constraint.

CONCLUSION

In conclusion, it seems to be important to emphasize on psycho-social interventions for increasing patient functioning in treatment and rehabilitation programs for patients with schizophrenia and also their families and arrange the psycho-education programs to caregivers at hospitals are very essential.

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Conflict of interest

No conflict of interest has been declared by the authors.'

Author contributions

All the authors have agreed on the final version and meet the criteria of journal.

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