

Living with schizophrenia: A cross-sectional study to measure family care burden

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ABSTRACT

Objective: To determine the frequency of high burden of care on family members of patients with Schizophrenia.

Study Design: Descriptive, Cross-sectional study.

Place and Duration: Department of Psychiatry, Civil Hospital Karachi for Six months from 15th September, 2014 till 15th March, 2015.

Methodology: Caregivers fulfilling the selection criteria were enrolled. "Zarit Burden Interview" (ZBI) was used for assessment of high burden over caregivers of schizophrenic patients. Different demographic factors like gender, age, education and employment status were also assessed.

Results: Out of 150 caregivers, majority 83.3% were married followed by 9% being single and 9% being widow. In this study 58% caregivers had high burden as measured on ZBI. Out of those having high burden 52.8% were males while 47.2% were females. While gender distribution in caregivers having no burden 65% was males and 35% were females.

Conclusion: This study reveals a high burden among caregivers living with patients of Schizophrenia.

Keywords: Schizophrenia, Family care, Burden, Caregivers, Psychosis, Zarit burden interview (ZBI), Mental health

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INTRODUCTION

Schizophrenia is a serious, devitalizing psychiatric disorder that affects not only the patients but also their family members. Schizophrenia affects 29 million people around the world. On follow-up outside the hospital setting the interaction with professional health personnel is minimized and the "burden of

care" is now shifted to the family members, who now bear the onus of primary caregiver¹. Over half of the individuals affected by schizophrenia and related psychiatric disorders inhabit or consistently interact with a related caregiver². The caregivers assuming responsibility report discernibly high levels of burden related to their schizophrenia-affected family members. The demands of caregiving is a wide spectrum which encompasses fiscal (paying for treatment), temporal (time spent in supervision), social (sharing and combating the social stigma associated with mental disorders) and emotional (personal distress) facets that are a consequence of caring for a family member's illness³. Caregivers' involvement in direct and indirect care changes over time, in response to the stage of illness and treatment, and caregivers must be able to adapt to changes in the amount, level, and intensity of care demands⁴. One study potentiates this point: describing that it is not the amount of care, but rather its dynamic and fluctuating nature (unforeseen rises and falls) that resulted in caregiver distress⁵. One study in Pakistan concluded that in estimating economic burden of mental illness, productivity cost more than medical care. This productivity also included family care burden⁶. Change requires constant adaptation and adjustment by the caregivers, which translates into adapting to different schedules, changing routines, and accommodating other roles, although care-giving may have numerous personal and societal compensations, extensive and exhaustive studies indicate that the potency and multiplicity of care leads to the individual responsible for it feeling considerable strain and burden: relationship impairment, feelings of grief, acrimony, resentment, frustration, and guilt are all part of the undesirable consequences spawning from caring for a relative at one's home^{7, 8}. Every year WHO

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celebrates World Mental Health Day on 10th October, with the overall objective of raising awareness of mental health issues around the world and mobilizing efforts in support of mental health. The theme for year 2014 was titled as “Living with Schizophrenia”. This title had two meanings: patients living with diagnosis schizophrenia and their caregivers living with patients of Schizophrenia.

Keeping these facts in mind this study was aimed at measuring the burden on caregiver of patients of Schizophrenia. The objective of study was to determine the frequency of high burden of care on family members of patients with Schizophrenia.

METHODOLOGY

This descriptive cross sectional study, conducted at Civil Hospital, Karachi. This research study was planned with title theme of ‘World Mental Health Day, 2014, Living with Schizophrenia’. In this study caregivers refer to family members who were living with patients and directly involved in care of patient. The data of study was calculated from 15th September 2014 to 15th March 2015. Sample size was 150 and collected through non-probability consecutive sampling technique. Inclusion criteria were caregivers of patients diagnosed with Schizophrenia for at least 02 years, who gave voluntarily consent for the study and who aged between 20 to 80 years. Caregivers who themselves had psychiatric or medical illness were excluded from the study. Ethical issues considering informed consent and confidentiality were addressed. All the subjects were interviewed by primary investigator. Demographic data of the participants was collected by principal investigator and co-authors on semi-structured performa. Caregivers were evaluated for care burden by using the “Zarit Burden Interview” (ZBI)/“Burden Interview” (BI) ⁹ Urdu version 14 (Annexure 02). ZBI is a Self-reported 5 point, like type questionnaire comprising of 22 items ranging from (0-4), where 0= Never and 4= nearly always. Total scoring of this scale ranges from 0 to 88, where 0 indicated “low burden” and 88 “high burden”. Interpretation of this scale is as 0-20= little or no burden, 21-40= mild to moderate burden, 41-60= moderate to severe burden, 61-88= severe burden. The ZBI scale determines the psychological, physical, social and economic burden on the life of the caregivers.

Data Analysis: Data was entered into Epi-data software v 3.1 and analyzed in SPSS v 16. Mean and standard deviation were

calculated for the age, duration of disease and ZBI score. Frequency and %age of age was calculated for gender, level of education, occupation, relationship with patient, marital status, high burden and severity of burden.

RESULTS

A total 150 caregivers were enrolled in this study with 87 (58%) males and 63 (42%) females having a mean age of 32.1 ± 7.3 years. Majority of caregivers 125 (83.3%) were married followed by 12 (9%) being single and 12 (9%) being widow.

Table-I: Stratification between burden vs factors affecting burden (N=150)

	BURDEN			P Value*	
	YES (>21) n=87	NO (<21) n=63	Total		
Gender of Caregiver	Male	46	41	87	0.185
	Female	41	22	63	
Age of Caregiver	20-30	12	8	20	0.137
	31-40	24	22	46	
	41-50	29	26	55	
	51-60	10	2	12	
	61-70	12	5	17	
Marital Status of Caregiver	Married	73	52	125	0.671
	Single	8	4	12	
	Widow	5	7	12	
	Divorced	1	0	1	
Education of Caregiver	Illiterate	31	32	63	0.453
	Primary	23	11	34	
	Secondary/metric	22	9	31	
	Intermediate	5	5	10	
	Graduate	4	6	10	
Occupation of Caregiver	Postgraduate	2	0	2	0.001
	Self employed	38	39	77	
	Government	6	13	19	
	Unemployed	43	11	54	

*p Value was considered significant if less than or equal to 0.05

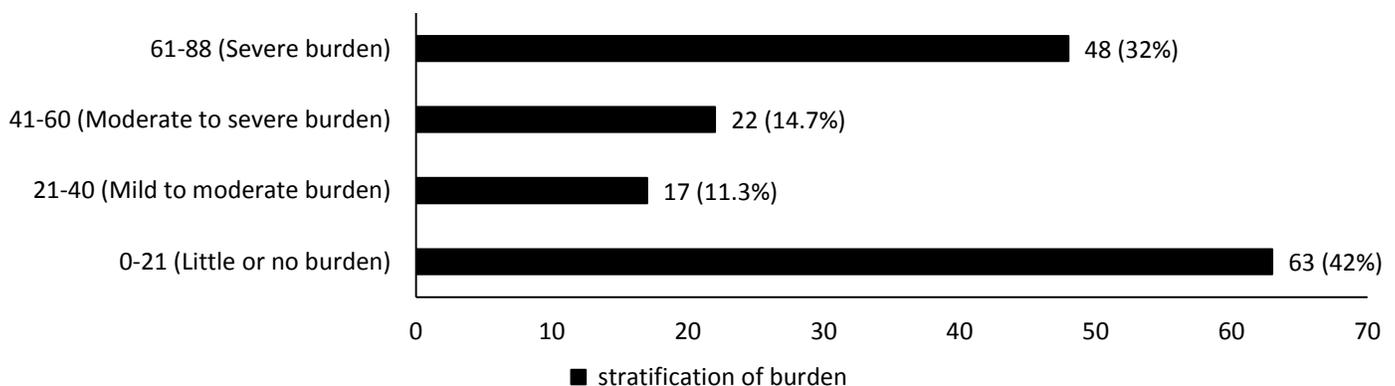


Fig-1: Severity of care burden on family members (N=150)

Among total 42% of caregivers were not formally educated followed by 23% having primary education. Among all 76 (50.7%) of caregivers were self-employed with 55 (36.7%) being unemployed as shown in table I. Patients had a mean duration of 8.50±5.3 years of illness with males having 9.20±5.5 years and females having 7.54±4.8 years. 59 (39.3%) and 53 (35.3%) of caregivers were parents and siblings respectively to the patients. Only 27 (18%) were spouses. In this study, 87 (58%) caregivers had high burden. Out of those having high burden, 46 (52.8%) were males while 41 (47.2%) were females. While gender distribution in caregivers having no burden was 41/63 (65%) were males and 22/63 (35%) were females. (Table-I)

Statically occupation was significantly related with care burden having p value of less than 0.05. According to definition in this study, caregivers having high burden were divided into mild to moderate, moderate to severe and severe high burdens. Among those having mild to moderate burden, 17 (11.33%) of caregivers had a severity score of 21-40 followed by 22 (14.7%) caregivers having a moderate to severe score of 41-60 and majority or 48 (32%) having a severe score of 61-88 (Fig-1).

DISCUSSION

Schizophrenia is a distressing disorder for patients as well as their family members since most schizophrenic patients remain in close contact with their families who are also the main caregivers. Due to the dependable support of these patients and continuous care for years, the caregivers are at risk of developing psychological distress and depression^{10,11}. Madianos et al has reported a burden of 45% in caregivers while Geriani et al's study reported 7.3% of high burden among caregivers^{12, 13}. According to one study in Pakistan, 40% caregivers are at risk of developing depression and anxiety¹⁴ while our study reported 58% care givers having high burden on Zarit-Burden Interview Scale. The difference between Pakistan and other countries can be due multiple factors; importantly it can be due to denial or guilt among Pakistani caregivers when unable to cope in handling the care for the patients.

In our study 39.3% and 35.3% caregivers were parents and siblings respectively. This is similar to Imran et al's study where parents were reported as majority care givers in Pakistani society¹⁵. However our study reported more males as caregivers (58%) compared to females (42%). While Nasr et al's study along with other related studies reported more females as caregivers in a Pakistani set up¹⁶.

Financial burden has been reported as a major contributor for burden among caregivers. Discontinuation of work because of extra responsibilities, treatment and transportation to hospitalization away from home are major factors incurred by caregivers for schizophrenia patients' financially¹⁷. Similar results of financial burden among family of schizophrenia patients by Rouget et al were also reported¹⁸. In a study in India, 86% families were affected financially while Nasr et al also had high prevalence of finances among Pakistani families¹⁹ while our study did not exactly report financial burden among caregiver as also evidenced by Schene et al²⁰. who did not find a significant correlation between the age of patient and the caregiver's

domains of tension or worry, but found an item-total correlation for factors about financial worries regarding the patient's management; concern about future finance is one of the items in the responsibility-taking factor.

In this study 49.4% of the care givers that had high burden were unemployed. This was also found to be statistically significant ($p < 0.05$).

Most of the caregivers having high burden were among age groups of 31-40 and 41-50. The age groups mentioned having high burden are usually sole bread earners of their households in our society. High burden among such age groups may affect financial constraints of whole households. Interestingly, there are some studies that reported different findings. They revealed that age has a negative relationship with burden²¹. From their findings, as caregivers aged, their burden was decreased. The possible explanations for this is that as time goes by, the older caregivers were more familiar with their care giving roles as well as being able to accept their roles as caregivers.

In our study, 32 caregivers having high burden were illiterate, while 23 and 22 care givers had primary and secondary education respectively. Literacy rate in Pakistan is not good with only 38% people literate. High illiteracy or low education causes many problems especially in psycho education of caregivers for long term illnesses²². This can be one of the reasons why low education or illiteracy was shown to have high burden in our study.

CONCLUSION

This study reveals a high burden among more than half of caregivers living with such patients.

RECOMMENDATION

Strategies should be implemented in our setups to work along with caregivers as well during treatment of schizophrenia patients. Educational seminars, supportive counseling and other psychological interventions for caregivers are also necessary to relieve them of this burden.

CONTRIBUTION OF AUTHORS

Das K: Conceived idea, Data collection and Data analysis.
Washdev W: Manuscript writing, Data analysis and Results writing.
Kazi AN: Literature search, Data entry and Methodology.
Jat MI: Data collection, Discussion writing and Manuscript editing.
Siddiqi MN: Manuscript review.
Rehman RU: Critical review and Final approval.

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