Original Article

Caregiver Burden in Relatives of Patients with Schizophrenia: A Cross Sectional Study at Government Khawaja Muhammad Safdar Medical College Sialkot

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ABSTRACT

Objective: The objective of the current study was to assess caregiver burden in relatives of patients with schizophrenia.

Study Design: Cross sectional study.

Place and Duration of Study: This study was conducted at the Department of Psychiatry & Behavioural Sciences Govt. KMS Medical College Sialkot, Pakistan from March to May 2016.

Materials and Methods: 100 adult consenting patients of schizophrenia and their primary care givers coming to OPD were included through non-probability convenience sampling technique after psychiatric assessment. Demographic information was recorded. Zarit Burden Interview (ZBI) was administered to the caregivers to assess burden. The results were analyzed using SPSS version 21.

Results: The mean age of the caregivers was 41.17±12.37 years with range from 18-63 years. The mean age of patients was 31.89±10.11 years with age range of 18-62 years. There were 50 (50%) males and 50 (50%) females as caregivers. Out of the 100 caregivers 45 (45%) had no burden. 20 (20%) had mild to moderate burden, 26 (26%) had moderate to severe burden while 9 (9%) had severe burden. The mean caregiver burden was 45.23±11.37 on ZBI. 48% males and 62% females were experiencing burden. 33% of the caregivers above 40 years of age had burden as compared to 22% of the caregivers with age below 40 years. It was equal (24%) in single and married caregivers. Caregivers with lower income and education had more burden.

Conclusion: 55% of the relatives of patients with schizophrenia were experiencing caregiver burden. Caregivers with female gender, older age, lower educational and economic status were experiencing more burden.

Key Words: Caregiver burden, schizophrenia, psychiatric outpatients

Citation of article: Khan RMS, Butt MQ, Latif A, Nawaz K. Caregiver Burden in Relatives of Patients with Schizophrenia: A Cross Sectional Study at Government Khawaja Muhammad Safdar Medical College Sialkot. Med Forum 2017;28(6):2-5.

INTRODUCTION

Families play a vital role to support their family members in the community who are having major psychiatric illnessess[1]. The major mental disorders like schizophrenia adversely not only impact on an individual's life but also influence their family members especially for those who act as family caregivers[2]. As literature depicts the global ratio of schizophrenia is 1 out of 100 people[3]. A number of studies have shown the 90% of people who are having mental disorders living with their families or relatives that are giving them long term practical social support frequently experience some sort of burden[4]. As earliest studies indicated that mental illness impacts on number of aspects in the family life as income, work hours, leisure activities, mental and physical health because the difference in the behaviors of caregivers and mentally ill person e.g., needs and wishes. Individuals with schizophrenia require more supervision than the healthy people[5].

Family burden is defined as caregivers have to cost the illness in different forms like social segregation, financial hardships and mental strain. Burden is considers as an emotional response of demanding care situation[6]. Burden on the caregiver is one of the correlates and important element effecting cognitive and affective domains of the individuals caring for patients with schizophrenia. It also hinders the coping of the caregivers. It has adverse effects when an individual is nonpaid and facing the number of

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Received: April 20, 2017; Accepted: May 10, 2017

unexpected responsibilities that cause the mental health issues in caregiver[7].

The term burden is used as an embracing because of the entire need of patient depends on caregiver in which physical care, economic support, psychological and social support are included. In other studies they have shown some objections and they are using the term "burden" as positive emotion when caregiver plays a vital role to fulfill the needs of patients and uplifting them in their life[8-9]. In the under developed countries, there are few mental health services with inadequate facilities, ineffective formal setups, no community based programs to accommodate the requirements of patients with schizophrenia. Therefore, the responsibility shifts to caregiver after shorter stay in hospitals from formal and trained caregivers to informal untrained caregiver at home. Taking care of a patient with schizophrenia is huge and many caregivers feel a lot of burden in providing continuous and unrelenting care to their patients who is usually their family member. Care giving and burden has many facets and roles to be played by the caregivers. There are many differences of opinion on the definition of burden. One example is subjective and objective burden. There is a long debate on this concept. Caregiver burden is described as psychological conditions that precede the number of factors like physical, social, emotional pressure and psychological transactions that are concerned during this procedure[10].

No research till to date has been carried out in our hospital on caregiver burden in schizophrenia. The objective of the current study was to assess caregiver burden in relatives of patients with schizophrenia.

MATERIALS AND METHODS

The study was conducted in Psychiatry OPD of Government KMS Medical College Sialkot Pakistan from March to May 2016. Guidelines related to research involving humans in the declaration of Helsinki were followed. It was a cross sectional study. Non-probability convenience sampling technique was applied. Inclusion criteria for patients were age 18 years or above, having schizophrenia for at least 1 year. Exclusion criteria for patients was those having other psychiatric illnesses, substance induced or general medical condition effecting brain, sever co-morbid physical illness and severe cognitive impairment. Caregiver aged 18 years or above who had stayed with the index patient for most of the time during the last 1 year, providing informal care for at least 35 hours per week and identified by the patient to be primary caregiver was included. Exclusion criteria for caregiver were those suffering from any current or past psychiatric illness, on current psychotropic medication, having severe physical illness, taking care of another patient with chronic physical or psychiatric illness. 100 patients and their primary caregivers meeting inclusion and exclusion criteria were include in the study. Title and purpose of the study were explained to caregiver of the patients. They were assured of the confidentiality and anonymity of their data. Written informed consent was taken from both patients and caregivers.

Socio-demographic data of patients of caregivers was collected on a data sheet. Age, gender, years of education, marital and economic status was recorded. A consultant Psychiatrist conducted the detailed clinical assessment to confirm the diagnosis of schizophrenia according to ICD-10 criteria in all patients.

Zarit Burden Interview (ZBI)[11] was then administered to the caregivers. ZBI has 22 items and has been used as self rated questionnaire as well as in form of an interview. It was translated into Urdu language using standard procedure. Five bi-lingual qualified psychologists were involved in the forward and then backward translation process. Emphasis was given to conceptual rather than literal translation and ambiguities were removed between the translators and the authors after detailed discussion on each item of the ZBI. The inter-rater reliability after pilot testing on 20 caregivers was .89. For illiterate caregivers data collectors read out the items and the responses were recorded according to the consent of the caregivers. ZBI was developed to assess burden in caregivers of dementia but over the years it has been used in schizophrenia research in South America, Asia and Africa[10] because of its good psychometric properties, adjustability in different cultures and ease of use. It has questions like "Do you feel that your relative asks for more help than he/she needs? "which are scored on a Likert scale from (0=never to 4=almost always). Range of scores is 0-88. It is interpreted in two ways. In first method higher scores means higher burden. In second method it is scored in categories. 0-20, 21-40, 41-60 and 61-88 indicating little or no burden, mild to moderate burden, moderate to severe burden and severe burden respectively. We used both methods. The cronbach's alpha for current study was .89. Data was analyzed using SPSS version 21. For continuous variables Mean±SD while frequency and percentages were calculated for categorical variables.

RESULTS

There were 100 caregivers in the sample. The mean age of the caregivers was 41.17 ± 12.37 years with range from 18-63 years. The mean age of patients was 31.89 ± 10.11 years with age range of 18-62 years. There were 50 (50%) males and 50 (50%) females as caregiver from the sample taken while 57 (57%) males and 43 (43%) females were in the patient sample. Most of the caregivers were from low and middle income categories. 31% were illiterate while 43% had 10 years of education. More than half were married. The details are shown in table 1.

Out of the 100 caregivers 45 (45%) had no burden. 20 (20%) had mild to moderate burden, 26 (26%) had moderate to severe burden while 9 (9%) had severe burden. The mean caregiver burden was 45.23 ± 11.37 on ZBI. In total 55% of the caregivers were experiencing burden as seen in table 2.

Table No.1: Demographic details of the caregivers N=100

Variables	Caregivers Frequency (%age)
Gender	
Male	50 (50%)
Female	50 (50%)
Age in years	
18-30	32 (32%)
31-40	30 (30%)
41-60	25 (25%)
> 60	13 (13%)
Marital status	
Single	35 (35%)
Married	54 (54%)
Widowed	7 (7%)
Divorced	4 (4%)
Economic status	
Low	41 (41%)
Middle	47 (47%)
High	12 (12%)
Education	
Illiterate	31 (31%)
10 years	43 (43%)
11-12 years	19 (19%)
>12 years	7 (7%)

Table No.2: Frequency of burden in caregivers N=100

Variable	Frequency	Percentage
No burden	45	45%
Mild to moderate burden	20	20%
Moderate to severe burden	26	26%
Severe burden	9	9%

Table No.3: Frequency of caregiver burden according to demographic variables

Variable	No Burden n (%)	Mild to Moderate Burden n (%)	Moderate to Severe Burden n (%)	Severe Burden n (%)
Gender				
Male	26 (26%)	9 (9%)	11 (11%)	4 (4%)
Female	19 (19%)	11 (11%)	15 (15%)	5 (5%)
Age				
18-30	15 (15%)	3 (3%)	4 (4%)	2 (2%)
31-40	17 (17%)	5 (5%)	6 (6%)	2 (2%)
41-60	10 (10%)	9 (9%)	11 (11%)	4 (4%)
> 60	3 (3%)	3 (3%)	5 (5%)	1(1%)
Marital status				
Single	19 (19%)	9 (9%)	11 (11%)	4 (4%)
Married	22 (22%)	8 (8%)	13 (13%)	3 (3%)
Widowed	3 (3%)	2 (2%)	1 (1%)	1 (1%)
Divorced	1 (1%)	1 (1%)	1 (1%)	1 (1%)
Economic status				
Low	20 (20%)	10 (10%)	12 (12%)	4 (4%)
Middle	21 (21%)	7 (7%)	10 (10%)	3 (3%)
High	4 (4%)	3 (3%)	3 (3%)	2(2%)
Education				
Illiterate	15 (15%)	5 (5%)	7 (7%)	4 (4%)
10 years	19 (19%)	9 (9%)	14 (14%)	1 (1%)
11-12 years	7 (7%)	5 (5%)	4 (4%)	3 (3%)
> 12 years	4 (4%)	1 (1%)	1 (1%)	1(1%)

When burden was further analyzed keeping in view the demographic variables of the caregivers mild to moderate burden, moderate to severe burden and severe burden was seen in 9%, 11% and 4% in male caregivers while it was 11%, 15% and 5% in female caregivers respectively. 33% of the caregivers with age more than 40 years had burden as compared to 22% of the caregivers with age below 40 years. Caregiver burden was equal in single and married caregivers. Both groups showing 24% burden each. Caregivers from lower and middle income groups had more burden. The same was the case with educational status. Caregivers with lower education were experiencing more burden. The details are shown in table 3.

DISCUSSION

Caring for a patient with schizophrenia in a cultural setting in a low and middle income country like Pakistan is largely by one or the other family members. The objective of the current study was to assess caregiver burden in relatives who are primary and informal caregivers in a setting where community mental health services are non-existing. The first finding from current study was that 55% of the caregivers were experiencing some sort of burden. In 20% it was mild to moderate, 26% had moderate to severe and 9% had severe burden. This is in accordance with studies carried elsewhere which show similar burden. [10]

When gender of the caregivers was analyzed more female caregivers were experiencing burden as compared to males n=31 Vs 24 (62% Vs 48%). This may be because of factors related to local culture where there is higher expectation from females to take care of any person who becomes ill. Females have to provide care to the person with illness in addition to the responsibilities related to her domestic work. There might be a perception that females accept care giving responsibilities more easily than males in local culture. The findings of our study are supported by a study carried out in Nigeria which has similar social and cultural profile as of Pakistan.[10]

Caregivers with older age had more burden than caregivers with younger age. In our study out of the 55% caregivers who were experiencing burden, 33% were more than 40 years old and 22% were less than 40 years old. This is in corroboration with studies carried out elsewhere.[12] Marital status showed no difference in burden in our study. In studies carried out elsewhere mixed results have been reported. Some studies report higher burden in married caregivers and some studies report higher burden in unmarried caregivers while some studies do not show any difference. [10,12,13] The caregiver burden was higher in relatives who belonged to lower and middle income categories as compared to higher income category. Studies carried out elsewhere have also shown similar findings. Caregiver with financial strains and low income may experience higher burden.[14] In Pakistan there is no or little health insurance leading to expenses of care and medicine being paid by the caregiver or family. This finding corroborates with findings from other studies.[15] Out of the 55% caregivers who were experiencing burden 40% were either illiterate or educated up till 10 years, while 15% had more than 10 years of education. Caregivers with lesser education experience more burden than caregivers with higher education. There are many studies that support this finding in our study. [16,17] Some authors are of the opinion that higher educational achievement leads to better social and economic status, wider and better social support networks reducing the effect of burden of care giving.

Our study has some strengths and limitations. The strength of the study is that it is one of the few studies carried out in Pakistan. Caregivers were responding on a Likert scale. It reduces choices and may be considered a limitation. Small sample size which was only hospital based, cross sectional nature of the study design are also limitations of the current study. Future studies needs to address patients and caregivers who were admitted in the hospital and prospective in nature.

CONCLUSION

55% of the relatives of patients with schizophrenia were experiencing caregiver burden. Caregivers with female gender, older age, lower educational and economic status were experiencing more burden.

Conflict of Interest: The study has no conflict of interest to declare by any author.

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