

Assessing Caregiving Burden in Family Caregivers of Depression & Schizophrenia in Pakistan

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Background & Objective: Care for family members is a significant characteristic of families in South Asia. A family is one unit, and every other member is emotionally connected and expected to take care of each other. However, the provision of care to a family member with mental illness can be physically as well as emotionally exhausting and distressing for the Family Caregiver. The present study aimed to investigate the caregiving burden in family caregivers of depression and schizophrenia. **Method:** For this cross-sectional research, a purposive sample of 80 Family caregivers taking care of at least one family member with mental health problems of depression (n=40) and schizophrenia (n=40) were recruited for the present study. The age range of the sample was 15 to 60 years. All the respondents were literates who could read and write in Urdu. The scale used to measure the caregiving burden was Zarit Caregiving Burden Scale. The data was collected from the male (n=22) and female (n=58) family caregivers. To access data, family caregivers were approached at the psychological services clinics of Rawalpindi and Islamabad in private and public sector hospitals. **Results:** The data were analyzed through descriptive and t-test analysis. Analyses of the data revealed that family caregivers of schizophrenia had a greater caregiving burden as compared to family caregivers of depression. Results also showed that females reported a higher caregiving burden as compared to male family caregivers. **Conclusion:** Family caregivers of schizophrenia undergo the severe burden of care and distress, and they may be considered a high-risk group for the development of mental health problems. Comprehensive intervention programs may be developed to involve them and safeguard their mental health.

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Keywords: caregiving burden, family, caregivers, depression, schizophrenia

INTRODUCTION

For physical and mental illnesses, caregiving is essential, especially when these illnesses are chronic or disabling or depend on another member of the family. The dynamics involved in caregiving include spending time with the person having an illness, financial burden, lesser time for self-related activities, staying home most of the time due to caregiving, lesser social activities, and distress. All these have connections with the physical, social and psychological deterioration of care providers (Ferrario et al. 2003; Rodrigo et al., 2013; Thronton & Travis, 2003). Still, various pathologies generate specific effects on caregivers because of the symptomology and social reaction; thus, these differences produce special needs for care of patients suffering from mental illnesses (Magliano et al., 2005).

People diagnosed with mental illness are frequently dependent on family members and are required to be taken care of for their daily routine activities. Thus, most often, the Caregivers are the members within the family who take care of the person with mental illness. Caregiving can be described as a considerable amount of responsibility, which comprises physical, psychological, and financial duties, and difficulties a family member takes for a psychiatric patient (Freedman & Spillman, 2014).

Depression is one of the most common psychological problems experienced by people all over the world. Moreover, it has been predicted to be the 2nd most common mental disorder across the globe by the year 2020 (Desjarlais, 2001). Pakistan is one of the most populous countries in the world. Currently, it is ranked sixth, whereas it is expected to be the fourth most populous country until the year 2050 (Katz et al., 1997). Being a developing country, Pakistan is on a threat, as 10-44% of people from developing countries experience depression, and around 50.8 million people suffer from depression. There is a high prevalence of depression and anxiety in Pakistan (Husain et al., 2010; Husain et al., 2000; Asad et al., 2010).

Schizophrenia is one of ten top psychiatric illnesses leading to the loss of ability in people, which calls for Caregiving (Kızılrırmak & Küçük, 2016). Schizophrenia is a considerably incapacitating and chronic psychiatric disorder that upsets all major functioning areas of the life of an individual. The prevalence rate of schizophrenia is about 3-6.6 of 1000 persons (Yu et al. 2017).

A report by the World Health Organization gives accounts of 29 million people within the age range of 15 to 20 years of age who have been affected with

schizophrenia across the globe. It also narrates that almost 450 million people in the world experience some form of mental illness. Being psychotic patients and having chronicity of mental illness, these patients are dependent on the family members for their routine activities. Furthermore, these family members play a vital role as their care providers and spend most of their time in caring for the mentally ill family member (Chan, 2011).

Caregiving burden is a state of heaviness or stress for the people involved in taking care of a person diagnosed with mental illness. There are two categories of caregiving burden; one is called objective burden that deals with the unconstructive effects of the negative symptoms of a mental illness patient and disruption in the daily routine of a caregiver. Subjective burden denotes emotional stress in the form of fear, grief, sadness, or anger in the caregiver. Research indicates that the burden of psychological patients is guesstimated as 14% all over the world, and statistics suggest that it is higher in the developing countries (Ae-Ngibise, et al. 2015). Caregiving to people with mental health problems deteriorates the physical and psychological health of the Care provider (Schulz, & Sherwood, 2008). Caregiving adversely affects the mental health and well-being of informal caregivers (Ehsan et al., 2018). The family caregiver burden is considered a multidimensional concept covering aspects of social, emotional, and financial issues, relationships with a care receiver, and the shortage of time (Schene et al., 1994).

Concerning gender literature reports controversial results, some report that caring for male patients is more distressful (Jenkins & Schumacher, 1999; Li et al., 2015) while others report that caring for female patients (Maxwell et al., 2017; Richard et al., 2017) is more distressful and burdensome or had no significant association with gender (Reuther et al., 2014). In the present paper, we will assess that either it is female or males experience who more caregiving burden in Pakistan.

Caregivers for people with mental illness like schizophrenia or depression are usually the family members, in most cases, the parents or spouse, and in some cases, siblings or children. With each case and age of caregiver or patient, the nature of caregiving burden changes or augments. Even though depression is a neurotic psychological problem in which mostly self-care is present, thought and speech is coherent, the capacity to perform personal activities are intact, yet, there is a need felt to provide care. A few of the cases may be having psychotic features. Most of the

researches conducted has investigated depression in caregivers. However, in the present study, the aim was to measure the caregiver burden in family caregivers of depression. Moreover, it also aimed to compare the caregiving burden of family caregivers of depression and schizophrenia patients. Schizophrenia is a more severe and chronic form of mental illness in which a person has no contact with reality, thought, and speech is incoherent and is unable to perform daily routine tasks independently.

Several studies have been conducted on the family caregiver burden in patients with depression and schizophrenia; however, this study tends to compare the caregiver burden in both types of patients by making a comparison. To better comprehend and recognize the consequences of the care of the patient with schizophrenia, the concept of the family caregiver burden was used. An attempt was also made to assess whether or not females or males tend to take the role of family caregivers for depressive and schizophrenic patients. This article will also add to literature regarding the relationship of caregiver involved in caregiving.

Objectives

1. To assess the level of caregiving burden in family caregivers of depression and schizophrenia.
2. To compare caregiving burden in the family caregiver of depression and schizophrenia.
3. To compare gender differences in the caregiving burden in family caregivers of depression and schizophrenia.

Hypothesis

1. The caregiving burden is higher in family Caregivers of Schizophrenia as compared to family caregivers of schizophrenia.
2. The caregiving burden of female family caregivers is significantly higher as compared to male family caregivers.

METHOD

Sample

The present study was based on a cross-sectional survey research design. A purposive sample of 80 family caregivers taking care of at least one family member with mental health problems of depression ($n=40$) and schizophrenia ($n=40$) was recruited for the present study. The age range of the sample was 15 to 60

years ($M=37.5$, $SD=31.81$). All the respondents were literates in the Urdu language. The inclusion criteria also included that the caregiver was required to be the primary caregiver of the patient. The demographic information included age, gender, caregiving for mental illness, and duration of illness. The data was collected from the National Institute of Rehabilitation Medicine, Islamabad, Pakistan Institute for Medical Sciences, Benazir Bhutto Hospital, and Rawal Hospital.

Instruments

The following instruments were used for the present study.

Demographic Sheet

A self-developed demographic sheet was used measuring demographic variables like age, gender, caregiving for mental illness, and duration of illness.

Zarit Caregiver Burden Interview Short Form - Urdu

It is used as a scale to assess the burden in the caregivers, including physical and psychological illnesses (Zarit et al., 1980). It was translated into Urdu. It has 12 items that are responded on a 0 to 4 point scale; high scores indicate a higher burden as perceived by the caregiver. The summated score ranges from 0 to 48. It also provides burden levels a score of 0 to 10 indicates no to a mild burden, 10 to 20 indicates a mild to moderate, and >20 indicates a higher feel of burden in the caregivers. It has a Cronbach alpha reliability of 0.89 (Noor et al., 2018).

Procedure

Institutional approvals were sought to collect the data. The sample size of family caregivers was 80, comprised of 40 family caregivers of depression and 40 family caregivers of schizophrenia. The family caregivers were approached at the hospitals of Rawalpindi and Islamabad. They were explained the purpose of the study. They were informed that their responses will be kept confidential and that they may leave the participation at any point they like without any penalties. Participation in the study was voluntary. Their queries were handled. After their consent, they were handed over the questionnaires of the survey. The respondents were thanked for their participation. The data were analyzed with SPSS 22 version.

Table 1. Psychometric properties of Zarit Caregiver Burden Interview

Scale	No. of Items	M	SD	α	Range	Scale	No. of Items
Zarit Caregiver Burden Interview	12	24.39	11.07	0.87	0-48 4-44	-0.01	-1.35

Table 2. Descriptive analysis of demographics of the family caregivers

	f	%
Age of caregiver		
15 To 40	54	75.0
41 to 60	26	25.0
Gender		
Male	22	27.5
Female	58	72.5
Disorder		
Schizophrenia	40	50.0
Depression	40	50.0
Year of illness & caregiving		
1 to 5	12	6.3
5 to 10	42	62.5
10 to 15	20	22.5
15 and above	6	8.8
Status/relation of caregiver		
Mother	26	32.5
Father	7	8.7
Wife	15	18.7
Husband	3	3.7
Daughter	12	15.0
Son	6	7.5
Sister	5	6.2
Brother	5	6.2

Table 3. Caregiving burden level in family caregivers

Caregiving Burden	f	%
No to Mild Burden	10	12.5
Moderate Burden	27	33.8
High Burden	43	53.8

feel of burden (Table 3). Therefore, no matter what the psychological illness be, the person involved in caregiving experiences a burden.

Table 4 shows the results compiled by independent t-test analysis to compute a comparison of the level of caregiving burden between family caregivers of depression and schizophrenia. The results confirm a significant difference between the two groups at 0.01 level of significance. Results show that family caregivers of schizophrenia patients have a higher feel of burden compared to family caregivers of depressive patients.

Table 5 shows the results compiled by independent t-test analysis to compute a gender-wise comparison of the level of the caregiving burden in family caregivers of depression and schizophrenia. The results confirm a significant difference between the two groups at the level of .001 level of significance. Results show that female family caregivers have a higher feel of burden in comparison to male family caregivers of patients with mental illness.

RESULTS

Table 1 shows the psychometric properties of the Zarit Caregiver Burden Scale, which shows a Cronbach alpha reliability of 0.87. Thus, the scale has a suitability for the study population, and the results obtained are reliable. Furthermore, the table shows that the distribution is normal and symmetrical. Table 2. shows the descriptive analysis of demographics of the family caregivers.

The results show that the family caregivers involved in-home care of the members with mental illness perceive caregiver burden, which is a form of stress that is carried by them due to the home care situations. It indicates that 12.5% reported no to a mild burden, 33.8% had a moderate burden, and 53.8% had a higher

DISCUSSION

The purpose of the study was to assess the caregiving burden in family caregivers of patients with depression and schizophrenia. The descriptive analysis indicated that most of the Caregivers were 15 to 40 years of age. Females performed most of the Caregiving services for the patients of depression and schizophrenia, ranging from 1 to 15 years and above. Females performed most of the caregiving services for their family member having the psychiatric illness for about 5 to 10 years. Further, it also entailed that in most cases, caregiving was carried out by mothers, followed by wife, daughter, father, sister, brother, and husband. The results are in line with other studies (Kumar & Mohanty, 2007; Vermeulen et al., 2015). The findings of the present study were consistent with the Pakistani

Table 4. Comparison of caregiving burden between family caregivers of depression and schizophrenia

Variable	N	Family caregivers of depressive patients (n=40)		Family caregivers of schizophrenia patients (n=40)		t(78)	p	95% CI	
		M	SD	M	SD			LL	UL
Caregiving Burden	80	20.60	10.54	28.18	10.39	3.23**	0.002	2.91	12.23

Table 5. Gender-wise comparison of caregiving burden in family caregivers of patients with mental illness

Variable	N	Male (n=22)		Female (n=58)		t(78)	p	95% CI	
		M	SD	M	SD			LL	UL
Caregiving Burden	80	17.00	7.11	27.19	11.06	4.85***	<0.001	-14.39	-5.98

community's social and cultural background, where females are considered home-makers and caring for the family members.

The results related to levels of caregiving burden showed that the family caregivers of people with mental illness perceive caregiver burden, which is a form of stress that is carried by them due to continuous involvement in activities of the patient, neglecting their desires. The respondents reported no to a mild burden, moderate burden, and more than half of the respondents reported a higher/severe feel of caregiver burden. Thus, that no matter what the psychological illness be, the person involved in care provision experiences burden of caregiving. The results of comparative research revealed that the caregiving burden was higher in the caregivers of psychiatric patients than in chronic medical diseases (Ampalam et al., 2012). The findings of the present study are also in line with those of Navidian & Bahari (2008), which confirmed that 73% of caregivers had caregiving burden above the average. It also indicated that as the patients aged, the burden experienced by the caregivers is amplified (Navidian & Bahari, 2008).

Further, to find the differences between the two groups, a t-test analysis was computed. The present study aimed at finding the caregiving burden in family caregivers of depressives and schizophrenics. The results of the present study showed that the family caregivers of schizophrenia had a more exceptional caregiving burden than family caregivers of depression. Schizophrenia is a chronic mental illness that disturbs the thinking, feeling, and behavioural pattern of a person. The symptoms involve Hallucinations, delusions, Thought disorders, and Movement disorders. Thus, it makes it a more severe form of mental illness that hinders the patient

and, in turn, increases the caregiver's responsibility, leading to burden and stress. A study conducted in Pakistan revealed that 72% of the caregivers of schizophrenia patients were distressed (Shah et al., 2013). Caregiving burden is a complicated stressor that generates a higher degree of burden, which plays a part in the development of psychological problems in the caregivers (Wrosch, 2011).

The present study also investigated gender-wise differences in caregiver burden in family caregivers. Results also showed that females reported higher caregiving burden as compared to male family caregivers. The findings are similar to the results present in the literature (Prabhu et al., 2016).

CONCLUSION

The Caregivers of people with mental illness, explicitly experiencing schizophrenia patients, are vulnerable to stress development. Family caregivers of schizophrenia undergo the severe burden of care and distress and may be considered a high-risk group for the development of mental health problems. Comprehensive intervention programs may be developed to involve them and safeguard their mental health. Further, the results reinforced the expected differences in the caregiving burden of mental health patients by gender.

Limitations

The present study had some limitations as the sample size of the study was small, owing to the availability and chronicity of this clinical population and their caregivers. The study focused on collecting data from diagnosed patients and untrained caregivers. The results may not be generalized to caregivers of

other physical and mental illnesses. Future studies may include other variables like distress, mental health, or well-being of the caregivers and to find their association with caregiving burden. Future interventions may be gender-specific to lighten the family caregiving burden.

ETHICAL APPROVAL: Ethical approval was attained from the Ethical Review Board Department of Psychology at the International Islamic University, Islamabad.

INFORMED CONSENT STATEMENT: Informed consent was obtained from all subjects involved in the study.

DATA AVAILABILITY STATEMENT: The raw data supporting the conclusions of this manuscript will be made available by the authors, without undue reservation, to any qualified researcher.

CONFLICT OF INTEREST STATEMENT: The authors of this study certify that they have NO affiliations with or involvement in any organization or entity with any financial interest (such as honoraria; educational grants; participation in speakers' bureaus; membership, employment, consultancies, stock ownership, or other equity interest; and expert testimony or patent-licensing arrangements), or non-financial interest (such as personal or professional relationships, affiliations, knowledge or beliefs) in the subject matter or materials discussed in this manuscript.

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A gondozói teher vizsgálata depressziós és szkizofrén betegek családi gondozóinál Pakisztánban

Háttér és cél: A családtagokról való gondoskodás a dél-ázsiai családok fontos jellemzője. A család olyan egység, amelynek minden tagja érzelmileg kötődik egymáshoz, és elvárás, hogy gondoskodjanak egymásról. A mentális betegségben szenvedő családtag gondozása azonban fizikailag és érzelmileg is kimerítő és megterhelő lehet a gondozó családtag számára. Jelen kutatás célja a depresszióban és szkizofréniában szenvedő családtagot ápoló családtagok gondozási terheinek vizsgálata volt. **Módszer:** A keresztmetszeti kutatáshoz 80 olyan gondozó családtagból álló célzott mintát vontunk be, akik legalább egy depresszióban (n=40) vagy szkizofréniában (n=40) szenvedő, mentális problémákkal küzdő családtagot ápolnak. A minta életkora 15 és 60 év között volt. A válaszadók mindegyike tudott írni-olvasni urdu nyelven. A gondozási teher mérésére a Zarit Caregiving Burden Scale eszközt használtuk. Az adatokat a 22 férfi és 58 női gondozó családtag körében gyűjtötték. Az adatgyűjtéshez a gondozó családtagokat Rawalpindi és Iszlámábád magán- és állami kórházainak pszichológiai szolgálatai segítségével vontuk be. **Eredmények:** Az adatokat leíró statisztikai módszerekkel és t-próbával elemezték. Az adatok elemzése azt mutatta, hogy a szkizofrén pácienszt ápoló családtagok gondozási terhe nagyobb volt, mint a depressziós pácienszt ápoló családtagoké. Az eredmények azt is kimutatták, hogy a nők nagyobb gondozási terhet tapasztaltak, mint a férfi gondozó családtagok. **Következtetés:** A szkizofrén pácienszt ápoló családtagok súlyos gondozási terhet és distresszt tapasztalnak, és a mentális egészségügyi problémák kialakulása szempontjából magas kockázatú csoportjának tekinthetők. Átfogó intervenció szükséges kidolgozni mentális egészségük megőrzése érdekében.

Kulcsszavak: gondozási teher, család, gondozók, depresszió, szkizofrénia