https://doi.org/10.36570/jduhs.2022.2.1198

JDUHS

ORIGINAL ARTICLE

Psychosocial Burden among Family Caregivers of Schizophrenic Patients in Tertiary Care Hospital of Peshawar, Pakistan

Riffat Ara,[1] Sardar Ali,[2] Asghar Khan,[3] Hamida Begum[4]

1. College of Nursing Lady Reading Hospital Peshawar, Pakistan.
2. Khyber Medical University Peshawar, Pakistan.
3. Batkhela College of Nursing, Batkhela Pakistan.
4. College of Nursing Bannu, Pakistan.

Correspondence to: Asghar Khan, Email: asghar802@gmail.com, ORCiD: 0000.0001.8704.1849

ABSTRACT

Objective: To assess the psychosocial burden of family caregivers of schizophrenic patients attending tertiary care hospitals of Peshawar Pakistan.

Methods: A cross-sectional study was conducted at psychiatric units of Lady Reading Hospital, Khyber Teaching Hospital and Hayatabad Medical Complex Peshawar from March 2019 to December 2019. Those family caregivers who had provided care to patients for at least 6 months were included. Psychological burden was assessed by using Zerit Burden Interview which included 22 questions, having options, 0 = Never, 1 = rarely, 2 = sometimes, 3 = quite frequently and 4 = nearly always. The scale categorizes psychological burden as 0-20 "no burden", 21-40 "Mild to moderate" 41 to 60, "moderate to severe" and 61 to 80 "severe burden".

Results: Of 118 caregivers, the mean age was 42.25 ± 13.8 years. There were 61 (51.1%) males and 57 (48.3%) females. Severe burden was observed in 55 (46.6%) patients. The likelihood of severe psychosocial burden was 3.75 times significantly higher among males as compared to females (aOR 3.75, 95% CI 1.05 – 13.38). Similarly, chances of severe psychosocial burden were 4.79 times significantly higher among caregivers having monthly income of ≤ 40,000 PKR as compared to caregivers having monthly income of >40,000 PKR (aOR 4.79, 95% CI 2.05 – 11.16). Lastly, severe psychosocial burden was 3.45 times significantly greater among unemployed caregivers as compared to employed caregivers (aOR 3.45, 95% CI 1.35 – 8.84).

Conclusion: Majority of family caregivers experienced **s**evere psychological burden. The higher psychosocial burden was identified among unemployed or low monthly income males.

Keywords: Caregivers, Psychosocial Burden, Schizophrenic Patients, Zerit Burden Interview Scale.

This is an Open Access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (http:// creative commons. org/licenses/by-nc/4.0) which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.

INTRODUCTION

Schizophrenia is one of the most incapacitating psychiatric disorder, affecting 1.1% of the adult population worldwide.[1,2] More than 21 million peoples around the globe suffer from the disorder and it has negative consequences for both patients and caregivers.[3,4]

When schizophrenia occurs, one person from family assume responsibility of taking care of the patient.[5] In Pakistan, most patients live in their homes and are cared by their family members.[6] In one of the previous researches, 42.31% of the participants reported severe burden among informal caregiver of patients suffering from schizophrenia.[7] The caregivers experience changes in their lives which lead to economic difficulties.[8] These changes may be related to disruption of daily life, financial burden, and lack of time for family members and friends.[9] Moreover, the family caregivers find no time for personal daily activities and rest. Additionally, the caregivers are at risk of developing unfavorable health effects such as increased level of anxiety, physiological distress, hopelessness and depression.[10,11]

While looking after patients with schizophrenia in the developing countries, it is needed to understand the family caregivers and the problems confronted to them. The previous researchers have identified that healthcare workers focused on patients and ignore the main caregivers of patients.[12] Therefore, the findings of the present study will highlight the magnitude of burden being faced by the family caregivers and provide credible evidence to healthcare workers and hospital management to plan appropriate interventions. The objective of the present study was to assess the psychosocial burden of family caregivers of patients with schizophrenia in public sector hospitals of Peshawar, Pakistan.

METHODS

A cross-sectional study was carried out at the psychiatric units of Lady Reading Hospital (LRH), Khyber Teaching Hospital (KTH) and Hayatabad Medical Complex (HMC) Peshawar, Pakistan from March 2019 to December 2019. Ethical committee of Khyber Medical University (KMU) Peshawar had approved the study formally (DIR/KMU-EB-BF-000597). Moreover, signed informed consent had been taken from all the participants and the objective of the study had been explained to them.

Open Epi calculator was used for the estimation of sample size, taking into consideration confidence level: 95%, Absolute precision: 7% and the anticipated proportion of depression among caregivers of schizophrenia: 18.3%.[13] The total sample size comprised of 118 participants. All patients' caregivers were consecutively enrolled in this study. The family caregivers visited the psychiatric centers along with their patients and who had provided care to the patients for 6 months and above were included in the study. The caregivers less than 18 years of age and those who were suffering from psychiatric and medical disorders were excluded from the study. An adopted self-administered questionnaire was used for data collection by the primary investigator. The questionnaire of Zerit Burden Interview (ZBI) comprising of 22 questions, having options, 0 = Never, 1 = rarely, 2 = sometimes, 3 = quite frequently and 4 = nearly always. The total grading score on ZBI ranges from 0 to 88. On the scale, score from 0 to 20 was taken as little burden, 21 to 40 as mild to moderate, 41 to 60 as moderate to severe and 61 to 88 as severe burden.[14] The Content Validity Index for Scales (S-CVI) score was identified to be 20.3/22 = 0.92. The ZBI determine the negative physical, mental, social, and economic impacts of caregiving on the life of the caregiver. Level of family caregivers' psychosocial burden was merged into two categories, i.e., "little burden", mild to moderate burden and "moderate to severe burden" were labelled as "no severe psychosocial burden" whereas "severe burden" was labelled as "yes" for phsyco social burden.

Data entry and analysis were done using a Statistical Package for Social Sciences (SPSS) version 20.0. Mean ± SD were computed for quantitative variables like, age while frequency and percentages were computed for categorical variables of family caregivers' like, gender, marital status, level of education, monthly income, relationship with patient, and employment status. Inferential statistics were explored using Chi-square/Fisher exact test to compare severity of psychosocial burden with independent characteristics of the caregivers. The p-value of ≤ 0.05 was considered statistically significant. All those variables found significant in contingency table were included in binary logistic regression analysis. Both univariate and multivariate logistic regression were applied.

RESULTS

A total 118 family caregivers were included. The mean age was 42.25 ± 13.8 years. There were 61 (51.1%) males and 57 (48.3%) females. Majority 75 (63.6%) were married and 43 (36.4%) were unmarried. Most of the family caregivers were illiterate 52 (44.1%), unemployed 82 (69.5%), and had monthly income of ≤ 40,000 PKR 99 (83.9%). There were 55 (46.6%) family caregivers who were facing severe psychosocial burden, 35 (29.7%) family caregivers were having moderate to severe psychosocial burden, 19 (16.1%) were having mild to moderate psychosocial burden, and only 9 (7.6%) were facing little psychosocial burden. The comparison of four levels of psychosocial burden with their baseline characteristics is mentioned in table 1.

For 55 family caregivers with severe psychosocial burden, males 38 (62.3%) were more prominent as compared to females 17 (29.8%) (p-value <0.001). Similarly, severe psychosocial burden was found significantly higher in unemployed caregivers 44 (53.6%) as compared to employed caregivers 11 (30.5%) (p-value 0.027). Caregivers with monthly income of ≤ 40,000 PKR had significantly higher severe psychosocial burden as compared to those caregivers who had monthly income of > 40,000 PKR, i.e., 51 (51.5%) vs. 4 (21.1%) respectively (p-value 0.022). (Table 2)

The findings of the multivariable analysis showed that after adjusting the variable mention in table 3. The likelihood of severe psychosocial burden were 3.75 times significantly higher among males as compared to females (aOR 3.75, 95% CI 1.05 – 13.38). Similarly, the chances of severe psychosocial burden were 4.79 times significantly higher among family caregivers who had monthly income of ≤ 40,000 PKR oas compared to caregivers who had monthly income of >40,000 PKR (aOR 4.79, 95% CI 2.05 – 11.16). The severe psychosocial burden were 3.45 times significantly greater among unemployed family caregivers as compared to employed family caregivers (aOR 3.45, 95% CI 1.35-8.84). (Table 3)

Table 1: Comparison of family caregivers' psychosocial burden with their baseline characteristics (n = 118)

Baseline Characteristics	Total	Family Caregivers' Psychosocial Burden				p-value
		Little Burden (n=9)	Mild to Moderate Burden (n=19)	Moderate to Severe Burden (n=35)	Severe Burden (n=55)	
Age, Years						
18-34	32	3 (9.4)	5 (15.6)	11 (34.4)	13 (40.6)	0.974[˜]
35-51	33	2 (6.1)	6 (18.2)	10 (30.3)	15 (45.5)	
52-68	53	4 (7.5)	8 (15.4)	14 (26.4)	27 (50.9	
Gender						
Male	61	3 (4.9)	7 (11.5)	13 (21.3)	38 (62.3)	0.005[˜*]
Female	57	6 (10.5)	12 (21.1)	22 (38.6)	17 (29.8)	
Marital Status						
Married	75	1 (1.3)	12 (16.0)	23 (30.7)	39 (52.0)	0.007[^*]
Unmarried	43	8 (18.6)	7 (16.3)	12 (27.9)	16 (37.2)	
Level of Education						
[$]Illiterate	52	6 (11.5)	8 (15.4)	18 (34.6)	20 (38.5)	0.263[^]
Literate	66	3 (4.5)	11 (16.7)	17 (25.8)	35 (53.0)	
Monthly Income, PKR						
≤ 40,000	99	2 (2.0)	17 (17.2)	29 (29.3)	51 (51.5)	<0.001[˜*]
≥ 40,000	19	7 (36.8)	2 (10.5)	6 (31.6)	4 (21.1)	
Relationship with Patient						
Parents/ Spouse	73	1 (1.4)	11 (15.1)	22 (30.1)	39 (53.4)	0.008[˜*]
Siblings	45	8 (17.8)	8 (17.8)	13 (28.9)	16 (35.6)	
Employment Status						
Unemployed	82	5 (6.1)	9 (11.0)	24 (29.3)	44 (53.7)	0.044[^*]
Employed	36	4 (11.1)	10 (27.8)	11 (30.6)	11 (30.6)	

[$]Illiterate means unable to read and write

[^]Chi-Square/[˜]Fisher, Exact test applied, [*]p-value ≤ 0.05

DISCUSSION

The findings of current study revealed that nearly half of the family caregivers were suffering from severe burden. Numerous factors may be involved such as difficult daily living, need of assistance from other family members, frequent admissions of the patients, financial issues and feeling insecurity of patients' future. The same findings of severe burden have been reported in the previous research studies.[15,16] The similarity with the previous result can be best explained by the common socioeconomic background and the lack of facilities available to the psychiatric patients and their caregivers. Contrarily, an Italian study has reported the psychosocial burden, indicating moderate to severe range which is lower than our participants.[17] Similarly, a jamaican study reported mild-to-moderate-burden.[18] The difference might have occurred due to substantial variability in socio-demographic characteristics where most of the participants were graduated and employed. The severe burden in our study indicate that it may affect the physical, social and psychological health of family caregivers.

The relationship between sociodemographic factors and caregiving burden varies across studies. In the present study, no significant association was observed of caregivers burden with education level. The findings are in conformity with some of the previous studies.[11,19] On the other hand, some studies argue that education attainment has been associated with lower burden.[18,20,21] This may be related to being more informed about the disease and social resources for care of the patient. This finding may suggest that our education system need changes which could lead to improve our health. Similarly, no significant association was reported of caregivers burden with age. The finding is in agreement with the previous study.[7] On the other hand the finding is in contrast with previous literature which indicated that caregivers age was positively correlated with age of caregivers.[19,21,22]

Table 2: Comparison of severity of psychosocial burden with baseline characteristics of the family caregivers of schizophrenic patients (n = 118)

Baseline Characteristics	Total	Severe Psychosocial Burden		p-value
		Yes (n=55)	No (n=63)	
Age, Years				
18-34	32	13 (40.6)	19 (59.4)	0.649
35-51	33	15 (45.5)	18 (54.5)	
52-68	53	27 (50.9	26 (49.1)	
Gender				
Male	61	38 (62.3)	23 (37.7)	<0.001*
Female	57	17 (29.8)	40 (70.2)	
Marital Status				
Married	75	39 (52.0)	36 (48.0)	0.130
Unmarried	43	16 (37.2)	27 (62.8)	
Level of Education				
[$]Illiterate	52	20 (38.5)	32 (61.5)	0.139
Literate	66	35 (53.0)	31 (47.0)	
Monthly Income, PKR				
≤ 40,000	99	51 (51.5)	48 (48.5)	0.022*
≥ 40,000	19	4 (21.1)	15 (78.9)	
Relationship with Patient				
Parents/ Spouse	73	39 (53.4)	34 (46.6)	0.087
Siblings	45	16 (35.6)	29 (64.4)	
Employment Status				
Unemployed	82	44 (53.4)	38 (46.4)	0.027*
Employed	36	11 (30.5)	25 (69.5)	

[$]Illiterate means unable to read and write
Chi-Square test applied, *p-value ≤ 0.05

The present study found significant association between caregivers' burden and caregivers' gender, monthly income, and employment status. The finding is in conformity with the previous research, conducted in Taiwan found the same results for employment status and monthly income.[5] A study conducted in Katmandu also revealed association of family burden with gender of caregiver, working status, and monthly income.[21] One of the local studies has also identified financial difficulty as a main contributor of the psychological burden.[6] Unemployment of the caregivers, discontinuation of the job of the patient, and expenditure on treatment and hospitalization may all lead to the burden of the caregivers. The observations are closely related to our findings as most of our participants were jobless and monthly income was less than forty thousand. In local population, the financial status is dependent upon the male gender because man is the bread earner of the household. Therefore, if man takes responsibility of care, it leads to loss of job and financial strain and thus causing severe psychosocial burden among the male caregivers. The family caregivers with higher income may have enough resources to meet their needs thus tends to have lower psychosocial burden.

The current study included 51% male and 48.3% female participants. Similar findings were found in another local study.[23] Another local study also found more male participants then female participants.[15] Some of other researchers have identified more female participants then male participants.[24-26]

The participants in this study belong to one specific geographical region. Therefore, one of the limitations of the study may be the less generalization of the result because different populations, multiple psychiatric services, social groups, cultures may provide diverse findings. The finding of the study is important because it highlighted the burden faced by the family caregivers. Keeping in view these findings, the health care workers need to focus on the health of caregivers along with the patients. Additionally, interventional programmes and counseling sessions are required at the hospital as well

Table 3: Logistic regression analysis for variables predicting severe psychosocial burden in family caregivers of schizophrenic patients

	Univariate analysis		Multivariable analysis	
	OR (95% CI)	**p-value**	**aOR (95% CI)**	**p-value**
Gender				
Male	3.88 (1.80 – 8.38)	<0.001	3.75 (1.05 – 13.38)	0.041
Female	1		1	
Monthly Income, Rs				
≤ 40,000	3.98 (1.23 – 12.85)	0.021	4.79 (2.05 – 11.16)	<0.001
≥ 40,000	1			
Employment status				
Unemployed	2.63 (1.14 – 6.04)	0.023	3.45 (1.35 – 8.84)	0.010
Employed	1		1	

aOR: adjusted odds ratio, CI: confidence interval, OR: odds ratio

as at community level. Finally, interventional studies are needed for best psychological therapies.

CONCLUSION

The finding of this study demonstrated that caring for a patient with schizophrenia exposes family to a heavy burden. Results also contributed the credible evidence that male gender of caregiver, low monthly income and employment status have significant impact on the caregivers' psychosocial burden. Consequently, these findings highlight that there is a need for appropriate interventions for family caregivers on the part of policy makers, hospital management and health care professionals.

ETHICAL APPROVAL: This study was approved by Advanced Study and Research Board of Khyber Medical University Peshawar, Pakistan (DIR/KMU-AS&RB/BF/000878).

AUTHORS’ CONTRIBUTION: RA & SA: Substantial contribution to the conception, design of the acquisition, analysis and interpretation of data for the work. AK: Drafting the work for revising it critically for important intellectual content and final approval of the version to be published. HB: Acquisition, analysis and interpretation of data for the work. All authors approved final version of the manuscript to be published.

CONFLICT OF INTEREST: The authors declare no conflict of interest.

FUNDING: None.

Received: June 26, 2021
Accepted: January 21, 2022

REFERENCES

1. Zhou Y, Rosenheck R, Mohamed S, Ou Y, Ning Y, He H. Comparison of burden among family members of patients diagnosed with schizophrenia and bipolar disorder in a large acute psychiatric hospital in China. BMC Psychiatry 2016; 16:1–10. doi:org/10.1186/s12888-016-0962-y
2. Tamizi Z, Fallahi-Khoshknab M, Dalvandi A, Farhnaz, Mohammadi-Shahboulaghi, Mohammadi E, et at. Caregiving burden in family caregivers of patients with schizophrenia: A qualitative study. J Educ Health Promot 2020; 9:1-6. doi: 10.4103/jehp.jehp_356_19
3. Martin-Carrasco M, Ndez-Catalina PF, Dominguez-Panchon AI, Gonc¸alves-Pereira M, Lez-Fraile EG, Munoz-Hermoso P, et al. A randomized trial to assess the efficacy of a psychoeducational intervention on caregiver burden in schizophrenia. Eur Psychiatry 2016; 33:9–17. doi:10.1016/j.eurpsy.2016.01.003
4. Opare-addo MN, Mensah J, Aboagye GO. A Case of Schizophrenia in a young male adult with no history of substance abuse: impact of clinical pharmacists' interventions on patient outcome. Case Rep Psychiatry 2020; 2020:3419609. doi: 10.1155/2020/3419609
5. Hsiao CY, Tsai YF. Factors of caregiver burden and family functioning among Taiwanese family caregivers living with schizophrenia. J Clin Nurs 2015; 24:1546–56. doi:10.1111/jocn.12745
6. Nasr T, Kausar R. Psychoeducation and family burden in schizophrenia: A randomized controlled trial. Ann Gen Psychiatry 2009;8:1–6. doi: 10.1186/1744-859X-8-17
7. Kuchhal AK, Kuchhal A, Arya V, Pardal PK. Psychiatry a study of psychological stress and burden on caregivers of schizophrenic patients. Int J Contemp Med Res 2019;6:1–6.
8. Bademli K, Lök N. Feelings, thoughts and experiences of caregivers of patients with schizophrenia. Int J Soc Psychiatry 2020; 66;452–9. doi: 10.1177/0020764020916211

9. Saeed A, Kiani S, Javed S. Caregivers of mentally ill patients: role of coping style and emotional intelligence. PAFMJ 2019; 69:665-70.
10. Miller S, Dell'Osso B, Ketter TA. The prevalence and burden of bipolar depression. J Affect Disord 2014; 169;S3–11. doi: org/10.1016/S0165-0327(14)70003-5
11. Shah STH, Sultan SM, Faisal M, Irfan M. Psychological Distress among caregivers of with of Patients with Schizophrenia. J Ayub Med Coll Abbottabad 2013; 25:27–30.
12. Akbari M, Alavi M, Irajpour A, Maghsoudi J. Challenges of family caregivers of patients with mental disorders in Iran: A narrative review. Iran J Nurs Midwifery Res 2018; 23:329–37. doi: 10.4103/ijnmr.IJNMR_122_17
13. Jeyagurunathan A, Sagayadevan V, Abdin E, Zhang Y, Chang S, Shafie S, et al. Psychological status and quality of life among primary caregivers of individuals with mental illness: a hospital based study. Health Qual Life Outcomes 2017; 15:106. doi: 10.1186/s12955-017-0676-y
14. Bedard M, Molloy DW, Squire L, Dubois S, Lever JA, O'donnell M. The Zarit Burden Interview: A new short version and screening version. Gerontologist 2001; 41:652–7. doi: 10.1093/geront/41.5.652
15. Yu Y, Liu ZW, Tang BW, Zhao M, Liu XG, Xiao SY. Reported family burden of schizophrenia patients in rural China. PLoS One 2017; 12:1–18. doi: org/10.1371/journal.pone.0179425
16. Das K, Washdev W, Kazi AN, Jat MI, Siddiqi MN, Rehman R. Living with schizophrenia: A cross-sectional study to measure family care burden. ISRA Med J 2019; 11:20–3.
17. Di Lorenzo R, Girone A, Panzera N, Fiore G, Pinelli M, Venturi G, et al. Empathy and perceived burden in caregivers of patients with schizophrenia spectrum disorders. BMC Health Serv Res 2021; 21:1–13.
18. Alexander G, Bebee CE, Chen KM, Vignes RM Des, Dixon B, Escoffery R, et al. Burden of caregivers of adult patients with schizophrenia in a predominantly African ancestry population. Qual Life Res 2016; 25:393–400.
19. Hidru TH, Osman MH, Lolokote S, Li X. Extent and pattern of burden of care and its associated factors among Eritrean families of persons living with schizophrenia: a cross-sectional study. BMJ Open 2016; 6:e012127.
20. Adeosun II. Correlates of Caregiver Burden among Family Members of Patients with Schizophrenia in Lagos, Nigeria. Schizophr Res Treatment 2013; 2013:1–7. doi: org/10.1155/2013/353809
21. Kunwar D, Lamichhane S, Pradhan N, Shrestha B, Khada S, Gautam K, et al. The study of Burden of family caregivers of patients living with psychiatric disorders in remote area of Nepal. Kathmandu Univ Med J 2020; 18:144–8. doi: 10.3126/kumj.v18i2.33224
22. Ayalew M, Workicho A, Tesfaye E, Hailesilasie H, Abera M. Burden among caregivers of people with mental illness at Jimma University Medical Center, Southwest Ethiopia: a cross-sectional study. Ann Gen Psychiatry 2019.1-11.
23. Irfan B, Irfan O, Ansari A, Qidwai W, Nanji K. Impact of Caregiving on Various Aspects of the Lives of Caregivers. Cureus 2017; 9:8–13. doi: 10.7759/cureus.1213
24. Mahmoud S. Association between Burden of Care, and Resilience among Family Caregivers Living with Schizophrenic Patients. IOSR J Nurs Health Sci 2018; 7;42–55. doi:10.9790/1959-0702054255
25. Hsiao CY, Lu HL, Tsai YF. Caregiver burden and health-related quality of life among primary family caregivers of individuals with schizophrenia: a cross-sectional study. Qual Life Res 2020; 29:2745–57. doi.org/10.1007/s11136-020-02518-1
26. Shamsaei F, Cheraghi F, Bashirian S. Burden on family caregivers caring for patients with schizophrenia. Iran J Psychiatry 2015; 10:239–45.