

Duration of caregiving and psychiatric disorders among the caregivers of schizophrenia patients

M M Jalal Uddin, Mohammad Tariqul Alam, Helal Uddin Ahmed, Niaz Mohammad Khan, A S M Kowser

Abstract

Background: Chronic mental illness like schizophrenia has far-reaching consequences for both patients and caregivers and they also experience lots of distress and disorders like depression and anxiety. Caregivers' burden and stressors cause functional impairment and hinder the caregiving of their patients. These stressors and burdens are also related with the duration of caregiving.

Objectives: To assess the duration of caregiving and the psychiatric disorders among the caregivers of schizophrenia patients.

Methods: A cross-sectional study was conducted in National Institute of Mental Health (NIMH), Dhaka, Bangladesh during the period of June 2016 to January 2017 among the caregivers of schizophrenia patients. Socio-demographic characteristics were collected by using a semi-structured questionnaire and psychiatric diagnoses were made using the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) diagnostic criteria. The data were analyzed with SPSS version 20. Ethical issues were addressed appropriately.

Results: There were 272 caregivers of schizophrenia patients in this study. Among the caregivers, most of them were female (86.0%), married (88.2%) and housewives (72.4%) of lower or lower-middle class social status. In this study, 22.4% of the caregivers were suffering from different types of mental disorders. Among them depressive disorders were the most prevalent (11.8%) and generalized anxiety disorder was the second most (4.8%) common disorder. Mean (SD) duration of caregiving in depressive disorders was found 70.3 (39.9) months, generalized anxiety disorder 58.2 (21.3) months, panic disorder was 96 months, social anxiety disorder 24.0 months and adjustment disorders 6.0 months. The mean time spent daily on feeding and medicine intake was 1.0 (0.1) hours, cleaning was 1.1 (0.2) hours and gossiping/other tasks were found 1.3 (0.6) hours.

Conclusions: Study revealed that significant proportion of the caregivers of schizophrenia patients were suffering from psychiatric disorders and the proportion increased with the increase in duration of caregiving. Findings of the present study will encourage the service providers, policy makers and planners to address the issue carefully.

Declaration of interest: None

Copyright and usage: ©Archives of NIMH 2020

Keywords: Psychiatric disorders; caregiver; schizophrenia

Introduction

Psychiatric patients usually need assistance and supervision in their daily activities and this often cause a major burden on their family members who usually take the caregiving role, thereby placing them at a great risk of mental health problems and burden.¹ Caregiving of schizophrenia patients has far-reaching consequences for both patient and their family members who are the main source of patients' care giving.² Families are an integral part of the care system for

persons with chronic mental illnesses such as schizophrenia.³ In Bangladesh prevalence of mental disorders is 16.05% and mentally ill patients mostly live with their families due to societal norms and as they are members of extended families; and these families play a critical role in taking care of the patients.⁴ An important determinant of psychological health of an individual is interpersonal relationships. Disturbed relationship could be the cause, effect or even the aggravating factor for mental illness. Rabbani MG also

found that the caregivers of persons with chronic mental illnesses suffer from a number of stresses and high level of burden and found more than half of those who provided major care for their patients experienced stress and burden.⁵ Another study found that 40% of men and 46% of women with long standing mental illnesses lived with their families who provided major-supporting roles.⁶ Patients' caregivers and their relatives experience feeling of loss, guilt, shame and anger. They are confronted with uncertainty and they feel stigmatized and socially isolated. Caregivers' burden and stressors cause functional impairment and hamper caregiving of their patients.^{7,8,9} The level of a caregiver's distress has been related directly to the stress of the relative's psychosis, disturbed behaviors and comorbidities such as depression, substance abuse, suicidal behavior among patients with psychiatric disorders.¹⁰ Caregivers' distress is also related with the duration of caring and time spent with the schizophrenia patients. There is evidence that a large number of caregivers have rate of depressive symptoms as high as 38 to 68% along with other psychosomatic complaints and symptoms of anxiety.² This stress and burden mostly depend on the duration of time spent for caring and duration of illness of the patient. The caregiver burden was found to increase with the duration of psychiatric illness and with the age of caregivers. There is not enough report about duration of caregiving and psychiatric illnesses among the caregivers of schizophrenia patients in Bangladesh. With regard to the importance of these in our country, the aim of the study was to evaluate the duration of caregiving and psychiatric disorders among the caregivers of schizophrenia patients.

Methods

This descriptive cross-sectional hospital-based study was conducted in the outpatient and inpatient departments of National Institute of Mental Health (NIMH), Dhaka during the study period of June 2016 to January 2017 among the caregivers of schizophrenia patients. NIMH is a 200 bed tertiary care specialized psychiatric hospital with emergency service, outpatient and inpatient departments. Patients from all over the country visit here for proper treatment. Different levels of socioeconomic population are represented here. Adult caregivers of schizophrenia patients (e.g.

parents, spouse, offspring, sibling, etc.) aged between 18 to 55 years who were staying for at least six months with the schizophrenia patients and who were the main caregivers of the patients were included in the study. Purposive sampling technique was applied for sample collection. Caregivers of schizophrenia patients with acute physical illnesses, known psychiatric illnesses and who were unwilling to participate in the study were excluded. At first, caregivers of schizophrenia patients were explained about the study and informed written consent were taken and thereafter face to face interviews were done. Socio-demographic characteristics and relevant information were collected from the participants using a semi-structured questionnaire and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)¹¹ was used for the diagnosis of psychiatric disorders. All collected data were checked thoroughly to reduce any inconsistency. The data were analyzed with SPSS version 20. Ethical issues were considered and addressed appropriately.

Results

There were 272 caregivers of schizophrenia patients in this study. Most of them were female (86.0%), married (88.2%) and housewives (72.4%) of lower or lower-middle class social status. Mean (SD) age of the caregivers was 44.9 (10.1). The socio-demographic characteristics are depicted in Table 1.

Table 1: Socio-demographic characteristics of the caregivers of schizophrenia patients (N=272)

Characteristic	Frequency (n)	Percentage (%)
Age group (year)		
≤20	20	7.3
21-30	76	27.9
31-40	75	27.5
41-50	68	25.0
≥51	33	12.1
Sex		
Male	38	13.9
Female	234	86.0
Marital status		
Married	240	88.2
Unmarried	28	10.2
Divorced	4	2.4
Education		
No formal education*	46	16.9
Primary	55	20.2
Secondary	119	43.7
Higher secondary	38	13.9
Graduate and above	14	5.1
Occupation		
Unemployed	15	5.5
Service	23	8.4

Characteristic	Frequency (n)	Percentage (%)
Agriculture	15	5.5
Business	8	2.9
Housewife	197	72.4
Retired	4	1.4
Students	8	2.9
Others	2	0.7
Monthly expenditure- ≤5000	22	8.0
5001-10000	129	47.4
10001-20000	117	43.0
≥20001	4	1.4

* No institutional background

A total of 61 caregivers (22.43%) were diagnosed with psychiatric disorders out of 272 caregivers of schizophrenia patients. Among them more than 52% were diagnosed with depressive disorders. Other findings are showed in Table 2.

Table 2: Psychiatric disorders among the caregivers of schizophrenia patients (n=61)

Diagnosis*	Frequency (n)	Percentage (%)
Depressive disorders	32	52.5
Generalized anxiety disorder	13	21.3
Panic disorder	8	13.1
Social anxiety disorder	2	3.3
Adjustment disorders	2	3.3
Somatic symptom disorders	2	3.3
Insomnia disorders	2	3.3

*Diagnosis according to DSM-5

In the present study, psychiatric diagnoses were found among caregivers who had been staying and taking care of the schizophrenia patients for prolonged period. Table 3 shows the duration (in months) of caregiving according to psychiatric diagnosis.

Table 3: Duration of caregiving according to diagnosis of the caregivers of schizophrenia patients (n=61)

Diagnosis	Frequency (n)	Min-max (months)	Mean (SD) (months)
Depressive disorders	32	20-80	70.3 (39.9)
Generalized anxiety disorder	13	24-96	58.2 (21.3)
Panic disorder	2	96-96	96.0 (0.0)
Social anxiety disorder	2	24-24	24.0 (0.0)
Adjustment disorders	2	6-6	6.0 (0.0)
Somatic symptom disorders	8	24-84	51.0 (24.6)
Insomnia disorders	2	42-42	42.0 (0.0)

Caregivers spent time taking care of their schizophrenia patients. They spent time for feeding, cleaning/bathing, gossiping with the patients. Table 4 depicts the tasks done by caregivers.

Table 4: Daily tasks and time spent by caregivers of schizophrenia patients (n=61)

Task	Min-max (hours/day)	Mean (SD) (hours/day)
Feeding (food and medicine)	1.0-1.5	1.0(0.1)

Task	Min-max (hours/day)	Mean (SD) (hours/day)
Cleaning (bathing, dressing)	1.0-2.0	1.1(0.2)
Gossiping/others	1.0-4.0	1.3 (0.6)

Family members were the usual caregivers of schizophrenia patients. In this study, female members of the family were the main caregivers of the schizophrenia patients. Table 5 shows the relationship of the caregivers with the patients.

Table 5: Caregivers' relationship with the schizophrenia patients (N=272)

Relationship	Frequency (n)	Percentage (%)
Father	19	6.9
Mother	123	45.2
Brother	6	2.2
Sister	10	3.6
Son	2	0.7
Daughter	11	4.0
Husband	11	4.0
Wife	90	33.0

Discussion

This descriptive cross-sectional study was done among the caregivers of schizophrenia patients with an aim to assess duration of caregiving and psychiatric disorders among the caregivers of the schizophrenia patients. The study findings were compared with previously published relevant studies. In this study it was observed that the mean age of the caregivers was 44.9 (10.1) years. More than three-fourth of the caregivers (80.5%) were between 20 to 50 years of age. Study conducted by Rammohan et al. found a higher mean age of the caregivers which was 54.4 (7.9) years and Perlick et al. observed a mean of 49.9 (14.6) years which were comparable with the present study.^{9,12} In this study, it was observed that 86% of the caregivers were female members of the family which was comparable to study findings by Jenkins and Schumacher where female Latinos were 85% and Euro-Americans 90%,¹³ which is consistent with the present study. Similar findings were also observed by other researchers.^{9,12} Present study observed that about 44% of the caregivers completed secondary education and a study conducted by Martyns-Yellowe found that majority (68.2%) of the caregivers completed post-primary and higher education.¹⁴ In the present study it was observed that most of the caregivers (72.4%) were housewives but study conducted by Hosseini observed that 44.0% caregivers were housewives which was lower than that of present study findings.¹⁵ The differences may be due to family bonding in our country or there may be other factor(s). A total of 61 (22.43%) out of 272 caregivers of schizo

phrenia patients were diagnosed with psychiatric disorders. Common psychiatric disorders found were depressive disorders, generalized anxiety disorder, somatic symptom disorders at 11.8%, 4.8% and 2.9% rates, respectively. Among the disorders found, more than 52% were depressive disorders. In a study conducted by Hosseini et al among the caregivers of chronic psychiatric patients 35% had psychiatric disorders whereas Pereira and Almeida found 41% had mental illnesses, both of the findings were higher than the present study.^{15,16} Agermeyer et al found 33.5% anxiety disorders and 13.5% depressive symptoms in their study among the caregivers of chronic psychiatric patients.¹⁷ In Bangladesh, a study conducted by Banu found that 23.7% of the caregivers of psychiatric patients had severe stress and another study conducted by Chowdhury found 55% had depression and 18% had anxiety.^{18,19} The different findings may be due to difference in tools for evaluation, selection criteria, study periods, study places, number of respondents and also due to cultural variation.

In the present study, it was observed that mean duration of caregiving was 61.2 (33.5) months which ranged from 6 to 180 months. Rammohon et al found that mean duration of care was 73.44 (38.4) months, which was comparable with the current study.⁹ Hossenei observed that more than one-third (33.5%) has a duration of 120 months or more, followed by 36 to 60 months (28.0%) and 24 to 36 months (10.05%).¹⁵ In this study it was found that mean duration of time spent for care per day for feeding and intake of medicines was 1.0 (0.1) hours with a range of 1 to 1.5 hours, cleaning like bathing and dressing was 1.1 (0.2) hours with a range of 1 to 2 hours, gossiping with patient and other tasks was found 1.3 (0.6) hours with a range of 1 to 4 hours.

Regarding relationship of the caregivers with the schizophrenia patients, patients' mothers were the most common caregivers (45.2%) and second most were wives (33.0%). That means female members of the family were found to be most associated with caregiving of schizophrenia patients. Study conducted by Perlick et al found that 44.3% caregivers were parents, 23.5% were spouses, 7.8% were children, 11.5% were siblings and 12.9% were others.¹² Other study findings showed 80% were parents which support the current study findings.²⁰ There were few limitations in the present study, out of which small sample size, single center study, no comparison group and purposive sampling were the most important ones.

Conclusions

The present study revealed that significant proportion of the caregivers of schizophrenia patients were suffering from psychiatric disorders, mostly undiagnosed and were found to increase with the duration of caregiving. Findings of the study will help the service providers, policy makers and planners to address the issue carefully so that caregivers can get proper psychiatric services. Further large scale, multicenter, in depth study is recommended in this regard.

M M Jalal Uddin, Associate Professor, Psychiatry, National Institute of Neurosciences & Hospital, Dhaka, Bangladesh; **Mohammad Tariqul Alam**, Associate Professor, Psychiatry, National Institute of Mental Health (NIMH), Dhaka, Bangladesh; **Helal Uddin Ahmed**, Associate Professor, Child, Adolescent and Family Psychiatry, NIMH, Dhaka, Bangladesh; **Niaz Mohammad Khan**, Associate Professor, Psychiatry, NIMH, Dhaka, Bangladesh; **A S M Kowser**, Graded Specialist in Psychiatry, Combined Military Hospital, Dhaka, Bangladesh.

Correspondence: M M Jalal Uddin, Associate Professor, Department of Psychiatry, National Institute of Neurosciences & Hospital, Sher-E-Bangla Nagar, Agargaon, Dhaka, Bangladesh-1207.
Email: jalal29march@yahoo.com

How to cite this article: Uddin MMJ, Alam MT, Ahmed HU, Khan NZ, Kowser ASM. Duration of caregiving and psychiatric disorders among the caregivers of schizophrenia patients. *Arch NIMH* 2020; 3(1): 13-7.

Received 18 Feb 2020, revised 29 Apr 2020, accepted 16 May 2020

References

1. Ampalam P, Gunturu S, Padma V. A comparative study of caregiver burden in psychiatric illness and chronic medical illness. *Indian J Psychiatry* 2012; 54(3): 239-43.
2. Hatfield A, Lefley H. *Families of the Mentally ill: Coping and Adaptation*. Guilford Press. New York, NY; 1987.
3. Shankar R MS. Interventions with families of people with schizophrenia : The issues facing a community — based rehabilitation center in India. *Psychosoc Rehabil J* 1993; 15: 85-91.
4. Firoz AHM, Karim ME, Alam MF, Rahman AHM, Zaman MM. Prevalence, medical care, awareness and attitude towards mental illness in Bangladesh. *Bang J Psychiatry* 2006; 20(1): 09-36.
5. Rabbani MG. Family burden of patients with schizophrenic illness. *Bangladesh J Medicine* 1992; 3: 21-6.
6. Mullen R, Bebbington P, Kuipers. L. A workshop for relatives of people with chronic mental illness. *Psychiatr Bull* 1992; 16: 206-7.
7. Miller F, Dworkin J, Ward M, Barone. D. A preliminary study of unresolved grief in families of seriously mentally ill patients. *Hosp Com Psychiatry* 1990; 41: 1321-5.

8. Wahl OF, Harman CR. Family views of stigma. *Schizophr Bull* 1989; 15(1): 131-9.
9. Rammohan A, Rao K, Subbakrishna DK. Burden and coping in caregivers of persons with schizophrenia. *Indian J Psychiatry* 2002; 44(3): 220-7.
10. Blanchard J, SA B, Horan W, Sherwood. A. Substance use disorder in schizophrenia: Review integration and a proposed model. *Clin Psychol Review* 2000; 20: 207-34.
11. *Diagnostic and Statistical Manual of Mental Disorders. 5th ed.* Arlington, VA , American Psychiatric Association: American Psychiatric Association; 2013.
12. Perlick D, Rosenheck RR, Clarkin JF, Sirey JA, Raue P, Greenfield S, et al. Burden experienced by care-givers of persons with bipolar affective disorder. *Brit J Psychiat* 1999; 175(1): 56-62.
13. Jenkins JH, Schumacher JG. Family burden of schizophrenia and depressive illness: Specifying the effects of ethnicity, gender and social ecology. *Brit J Psychiat* 1999; 174(1): 31-8.
14. Martyns-Yellowe IS. The burden of schizophrenia on the family. A study from Nigeria. *Brit J Psychiat* 1992; 161(6):779-82.
15. Hosseini SH, Sheykhmounesi F, Shahmohammadi. S. Evaluation of mental health status in caregivers of patients with chronic psychiatric disorders. *Pak J Biol Sci* 2010; 13(7): 325-9.
16. Gonçalves-Pereira M, Almeida. JMCd. The repercussions of mental disease in the family, A study of the family members of psychotic patients. *Acta Medica Portuguesa* 1999; 12: 161-8.
17. Angermeyer MC, Matschinger H. Burden of relatives of chronic psychiatric patients. *Psychiat Prax* 1997; 24(5): 215-20.
18. Banu S. Stress & burden of the Caregivers of Chronic Mental Adult Patients, 2001.
19. Chowdhury KP, Khan NM, Uddin MMJ, Sobhan MA, Chowdhury WA. Effect on Caregivers of Mentally Ill Patients. *Bang J Psychiatry* 2012 December; 26(2): 09-15.
20. Scazufca M, Kuipers E. Links between expressed emotion and burden of care in relatives of patients with schizophrenia. *Brit J Psychiat* 1996 May; 168(5): 580-7.