

Socio-demographic characteristics of the caregivers of schizophrenia patients – a study in a tertiary care psychiatric hospital in Dhaka

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Summary

Care giving and care receiving can occur at any point in the life course and is typically associated with chronic illness or disabilities which result in losses of independence and functioning. Families are an integral part of the care system for persons with a chronic mental illness such as schizophrenia. The aim of this study was to assess the characteristics of the caregivers of schizophrenia patients. This descriptive cross sectional study was done among the caregivers of all consecutive schizophrenia patients in outpatient and inpatient department of National Institute of Mental Health (NIMH), Dhaka, Bangladesh from September 2010 to February 2011. Diagnosis of schizophrenia was done by consultant psychiatrist following DSM-IV criteria. A semi-structured questionnaire was applied to the caregivers of schizophrenia patients who fulfilled the inclusion criteria. Ethical issues were maintained accordingly. Out of 272 caregivers of schizophrenia patients most were female (86.03%), housewife (72.43%), of rural area (56.25%). Most of the respondents (80.52%) belonged to the age range of 21 to 50 years. Regarding educational status more than 43% completed secondary level. Among the caregivers 81.25% lived with non-nuclear family. Female members of the family specially mothers (45.22%) and wives 33.09%) were the highest group among the caregivers of schizophrenia patients. Significant proportions of the caregiver of schizophrenic patients were the female members of the family. Information about other characteristics of the caregivers will help further broad based study regarding this issue and burden of the caregivers of schizophrenia patients.

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Introduction

Care giving and care receiving can occur at any point in the life course and is typically associated with chronic illness or disabilities which result in losses of independence and functioning. Severe mental illness like schizophrenia has far-reaching consequence for both patients and their relatives.¹ Families are an integral part of the care system for persons with a chronic mental illness such as schizophrenia.² In Bangladesh 16.05 % mentally ill patients mostly live with the family due to the societal norm as they are member of extended family and their families have a critical role in taking care of the patients.³ In most of the country the male members who may be the husband, father, son, brother provide the financial support, women members who may be mother, wife, daughter, sister of the family provide affection, time, physical labor. It is the female members who spend most of the time with the ill person. But it does not mean that the male members only provide financial support and do not spend time with the ill person. For schizophrenia successful family intervention decreases mean cost of patient care by 27% and reduces relapse rate and improves quality of life.⁴ In a survey conducted in Maudsley Hospital, London, 40 % of men and 46 % of women with long standing mental illness lived with their families who provided a major supporting role.⁵ The World Health Organization has estimated that about 40-90% of patients with schizophrenia live with their families.⁶ Other researches revealed that approximately 50% of the patients with serious mental illness live with the family especially parents and partner.⁷ Study conducted by Rabbani MG demonstrate that the caregivers of person with chronic mental illness 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 experiences stresses and burden.⁸ There were not sufficient reports about the characteristics of caregivers of schizophrenia patients. With regard to the importance of the caregiver's characteristics and limitation of study on this subject in our country, the aim of the study was to evaluate the socio-demographic characteristics of the caregivers of schizophrenic patients and associated variables.

Materials and methods

This descriptive cross sectional study was done in inpatient and outpatient department of National Institute of Mental Health (NIMH), Dhaka from September 2010 to February 2011 among the caregivers of schizophrenia patients. Caregivers are key relatives of the patients, parents, spouse, sibling, offspring between 18 years to 55 years of age, staying for last six months with the schizophrenia patients and who were the main care takers of the patients were included in the study. Caregivers of the schizophrenic patients who were in acute phase of illness, already diagnosed with any psychiatric illness and unwilling to participate in the study were excluded. Sample size was determined by using the appropriate formula and convenient sampling technique were followed for the study. Caregivers of the schizophrenia patients were explained about the purpose of the study and informed written consent were taken from them and then they were interviewed face to face by using semi-structured questionnaire to collect the socio-demographic and other relevant variables. All collected data were checked and verified thoroughly to reduce inconsistency. The data were analyzed with SPSS version 16 (sixteen) for windows. Clearance was taken from Institute and Review Board (IRB) of National Institute of Mental Health (NIMH), Dhaka.

Results

Two hundred seventy two caregivers of schizophrenia patients filled out the semi-structured questionnaire. Among them the following findings were observed.

Table 1: Age distribution of the study population (Caregiver) (n=272)

Age (in years)	Frequency	Percentage (%)
Below 20	20	7.35
21-30	76	27.94
31-40	75	27.58
41-50	68	25.00
Above 50	33	12.13
Total	272	100.00

Table 2: Sex distribution of the study population (Caregiver) (n=272)

Sex	Frequency	Percentage (%)
Male	38	13.97
Female	234	86.03
Total	272	100.00

Table 3: Distribution of the study population (caregiver) according to residence (n=272)

Residence	Frequency	Percentage (%)
Urban	117	43.01
Semiurban/slum	2	0.74
Rural	153	56.257
Total	272	100.00

Table 4: Distribution of the study population (Caregiver) according to marital status (n=272)

Marital status	Frequency	Percentage (%)
Married	240	88.24
Unmarried	28	10.29
Divorced	4	2.47
Total	272	100.00

Table 5: Distribution of the study population (Caregiver) according to educational status (n=272)

Educational status	Frequency	Percentage (%)
No education	46	16.91
Primary	55	20.22
Secondary	119	43.75
Higher secondary	38	13.97
Graduate and above	14	5.15
Total	272	100.00

Table 6: Distribution of the study population (caregiver) according to occupational status (n=272)

Occupation	Frequency	Percentage (%)
Unemployed	15	5.51
Service holder	23	8.46
Agriculture	15	5.51
Business	8	2.94
Housewife	197	72.43
Retired	4	1.47
Students	8	2.94
Others	2	0.74
Total	272	100.00

Table 7: Distribution of the study population (caregiver) according to type of family (n=272)

Family type	Frequency	Percentage (%)
Nuclear	51	18.75
Non-nuclear	221	81.25
Total	272	100.00

Table 8: Distribution of the study population (Caregiver) according to monthly family income (n=272)

Monthly income	Frequency	Percentage (%)
Below 5000	22	8.09
5000-10000	129	47.43
10001-20000	117	43.01
More than 20000	4	1.47
Total	272	100.00

Table 9: Distribution of the study population according to relationship with the patients (n=272)

Relationship	Frequency	Percentage (%)
Father	19	6.99
Mother	123	45.22
Brother	6	2.21
Sister	10	3.68
Son	2	0.73
Daughter	11	4.04
Husband	11	4.04
Wife	90	33.09
Total	272	100.00

Discussion

This descriptive cross sectional study was carried out with an aim to assess characteristics of caregivers of schizophrenic patients and to determine the relationship of the caregivers with the patients. A total of 272 caregivers of schizophrenic patients were included in the study.

In this study it was observed that more than 80% respondents were in 20 to 50 years age group. Rammohan et al found higher mean age of the caregiver, which was 54.4 ± 7.96 years and spouses was 47.29 ± 8.07 years.⁹ Similarly, Heru & Ryan found mean age of caregiver was 54.8 ± 13.2 years.¹⁰ Furhtemore, Jenkins & Schumacher found mean age of latino was 50.6 ± 18.4 years and euro-american was 49.7 ± 14.2 years.¹¹ Perlick et al. observed a mean \pm SD of 49.99 ± 14.61 years with a age ranging from 16 to 82 years of caregiver.¹² Hosseini et al however, found that more that almost a half (45.0%) of the caregivers was in more than 50 years age group, which are comparable with the current study.¹³ Martyns-Yellowe observed that most (68.2%) of the caregivers age was in between 21-40 years old which are a little lesser with the current study.¹⁴

In this present study it was observed that 86.03% caregivers were female and rest were male and male female ratio was almost 1: 6. Study conducted by Jenkins & Schumacher observed female caregivers among Latino were 85% and Euro-American 90% which is consistent with the present study. Same findings were observed by Perlick et al., Heru & Ryan, Rammohan et al and Middelboe.^{11,12,10,9,15} Another study found 62.96% male and 37.04% female caregiver of schizophrenia patients.¹⁶ These variation may be due to different study places and different techniques used. It was observed that most of the patients came from rural area which was 56.25% and from urban area it was 43%. This result is consistent with our geographical distribution that most of the families live in rural area. In this research it was observed that about 88% respondents were married. Roychaudhuri et al observed that most (66.67%) of the caregivers were married.¹⁶ Similarly, Perlick et al found 61.8% care-giver married, 25.1% divorced/widowed and 13.1% never married.¹² Similar findings were observed by Gautam & Nijhawan, Jenkins & Schumacher and Rammohan et al.^{17,11,9} In this current study it was observed that illiterate (no education) caregivers were about 16%, caregivers with primary education 20%, secondary education more than 43%, about 14% completed higher secondary and only 5% were graduate or above. Study conducted by Gautam & Nijhawan found illiterate 60.0%, primary 16.0% and secondary 16.0%, which support the results of the present study.¹⁷ Similar result obtained by Hosseini and Jenkins & Schumacher (1999).^{13,11} Martyns-Yellowe found that majority (68.2%) of the caregivers had post-primary and over education.¹⁴ Jenkins & Schumacher found mean education years 8.4 in latino and 11.4 years in Euro-American.¹¹

In this present study it was observed that most of the caregivers were female and most of them were housewife, which were 72.43%. Hosseini observed that 44.0% caregivers were housewife and 24.0% worker or farmer which is consistent with the present result.¹³ However, Roychaudhuri et al found that majority (59.26%) of the caregivers were involved with a job.¹⁶ In this present series it was observed that non-nuclear family was more than nuclear family which was 81.25% and 18.75% respectively. Gautam & Nijhawan observed that, majority caregivers came from nuclear family (nuclear schizophrenia 56.0% and chronic lung disease 52.0% Joint 44.0% and chronic 48.0%), which differ with the current study, which may due to the cultural practice of our country.¹⁷ In this study it was observed that most of the family came from lower or lower middle class. Roychaudhuri et al found that more than half (55.56%) of the caregivers had low income.¹⁶ Similarly, Martyns-Yellowe found almost the same findings where half of the caregivers were below average income and half were average and above income.¹⁴

Regarding the relationship of the caregiver with the patient mother was more common and was higher among the caregivers and it was 45.22%, next was wife which was 33.04%. So it was observed that most of the caregivers were female member of the family who take care the schizophrenia patients. Perlick et al observed that, 44.3% caregiver was living with their parents; 23.5% with spouse, 7.8% with child; 11.5% with

sibling and 12.9% with other.12 Scazufca & Kuipers have shown that 80% were parents, which support the current study findings.¹⁸

A couple of limitations are thought to be inherent in the study. Due to small sample size, the results may not have generalized acceptability. The study place was National Institute of Mental Health (NIMH), Dhaka; the observation of this study may not be representative of the schizophrenic patients who are devoid of modern treatment facilities.

Conclusion

Significant proportion of the caregivers of schizophrenic patients were female members of the family who were the mother or wife of the patients and most of them came from lower or lower middle class family. For proper management of the schizophrenia patients within the family, attention should be given to the caregivers. So the service providers, policy makers and planners can address the issue carefully. Further in depth study is recommended in this regard.

References

1. Hatfield AB, Lefley HP. *Families of the Mentally Ill: Coping and Adaptation*. New York, NY : Guilford Press, 1987.
2. Shankar R, Menon S. *Interventions with families of people with schizophrenia : The issues facing a community – based rehabilitation center in India*. *Psychosoc Rehabil J* 1993;15:85-91.
3. 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).
4. Tarrier N, Lowson K, Barrowclough C. *Some aspects of family interventions in schizophrenia. II financial considerations 1991*;159:481-4.
5. Mullen R, Bebbington P, Kuipers L. *A workshop for relatives of people with chronic mental illness*. *Psychiatric Bulletin* 1992;16:206-7
6. *World Health Organization Report of WHOQOL Focus Group Work: WHO (MNH/PSF/934) 1993*.
7. Gibbons JS, Horn SH, Powell JM, Gibbons JL. *Schizophrenic patients and their families: A survey in a psychiatric service based on a DGH Unit*. *Br J Psychiatry* 1984;144:70-7.
8. Rabbani MG. *Family burden of patients with schizophrenic illness*. *Bang J Medicine* 1992;3:21-6.
9. Rammohan A, Rao K, Subbakrishna DK. *Burden and coping in caregivers of persons with schizophrenia*. *Ind J Psychiatry* 2002;44(3):220-7.
10. Heru A, Ryan C. *Depressive symptoms and family functioning in the caregivers of recently hospitalized patients with chronic/recurrent mood disorders*. *Int J Psychosoc Rehabilitation* 2002;7:53-60.
11. Jenkins J, Schumacher J. *Family burden of schizophrenia and depressive illness*. *Br J Psychiatry* 1999;147:31-8.
12. Perlick D, Clarkin JF, Raue P, Greenfield S, Struening E, Rosenheck R. *Burden experienced by caregivers of persons with bipolar affective disorder*. *Br J Psychiatry* 1999;175:56-62.
13. Hosseini SH, Sheykhmounesi F, Shahmohammadi SS. *Evaluation of mental health status in caregivers of patients with chronic psychiatric disorders*. *Pakistan J Biol Science* 2010;13:325-9.
14. Martyns-Yellowe IS. *The burden of schizophrenia on the family. A study from Nigeria*. *Br J Psychiatry* 1992;161:779-82.
15. Middelboe T. *Prospective study of clinical and social outcome of study in small group homes for people with mental illness*. *Br J Psychiatry* 1997;171:251-5.
16. Roychaudhuri J, Mohandad A. *Family burden among long term psychiatric patients*. *Ind J Psychiatry* 1995;37(2):81-5.
17. Gautam S, Nijhawan M. *Burden on families of schizophrenic and chronic lung disease patients*. *Ind J Psychiatry* 1984;26(2):156-9.
18. Scazufca M, Kuipers E. *Links between expressed emotion and burden of care in relatives of patients with schizophrenia*. *Br J Psychiatry* 1996;168:550.