

A clinical study of family burden in chronic schizophrenia

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Abstract

Background: The primary caregivers in particular and the family as a whole have to bear the burden and responsibilities of providing the treatment of schizophrenia patients from its early stages up to the rehabilitation and assimilation of the patient with the society at large.

Material and methods: The study was conducted in Silchar Medical College Hospital, Silchar, Assam, India and for a period of one year commencing from 2nd January 2007 with the aim to determine the sociodemographic patterns of chronic schizophrenia, and to ascertain the type and severity of family burden in chronic schizophrenia in the study population.

Results: The frequencies of type and severity of family burdens in our study were as follows—disruption of routine family activity (65%), financial burden (62%), disruption of family recreation (54%), disruption of family interaction (32%), effect on physical health of others (21%) and effect on mental health of others (11%). Correlation coefficient between different types of burdens faced by the family are highly positive irrespective of age, sex, religion, locality, family pattern, marital status, education, occupation and socio-economic status of the patients.

Conclusion: As it comes out that not only financial but the effects on other familial activities are equally burdensome, so, the aim of the treating physicians must also be directed to the issues of burden of the disease too.

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Introduction

The course of schizophrenia is not always predictable. Both health professionals and families are often frustrated and such frustrations are enhanced by an acute care model that lacks a longitudinal perspective and thus sets a relatively low value on maintenance treatment and rehabilitation. Over the last 50 years, the locus of care has shifted from long term hospital based care to acute hospital care and community based services. In Indian context the asylum based treatment is withdrawn by the Government of India and thus the burden of treatment and management has been shifted to families. The estimate of the overall financial burden to these families is increasing enormously. But the less fortunate patients may have no place to live, may be forced to live in circumstances of isolation and hopelessness, or may end up in jail. Given its severity, the illness affects the patient, his or her family, and society. Schizophrenia has been a long misunderstood condition to patients, their families, society and remarkably, too many in the medical and psychological fields.

There have been several estimates of the cost of schizophrenia over the last 50 years, beginning with Rashi Fein's landmark study for the Commission on Mental Illness.[1] Dorothy Rice broke down the direct costs in her paper on the economic impact of schizophrenia in the United States. [2] This was an update of her previous work with Leonard Miller on estimates in putting economic data and indicators.

[3] Direct cost included mental health organisations (i.e. community mental health centres, treatment centres etc.), short stay (acute) hospitals, physician and other professionals, nursing homes, medications and support costs. The indirect cost included the morbidity and mortality associated with such a pervasive, chronic illness. The indirect costs assumed estimates of loss of productivity and governmental support needed to maintain the patient.

Competitive employment has been estimated at less than 20% for severely mentally ill persons and probably less for patients with chronic schizophrenia. One important goal of any medical treatment is to maintain patients as functional and independent in the community as possible. Stigma can manifest itself internally by the patients as a belief that they are defective and undeserving; and it may place barriers to person's full integration in to their community. The lack of societal acceptance that this is an illness requiring emotional and financial support is extremely hurtful to the families.

The primary caregivers in particular and the family as a whole have to bear the burden and responsibilities of providing the treatment of schizophrenia patients from its early stages up to the rehabilitation and assimilation of the patient with the society at large. This is a long and tedious course in most of the cases and the family members have to face lot of stresses and burden during the whole process. So it is obvious that the family has got an important role to play in the overall management, both psychopharmacological and

psychological, of chronic schizophrenia patients. But this important area has never been examined systematically in this part of the country. So, with this study we tried to explore the various aspects of this particular subject in relation to our sociocultural setup.

Methods and materials

The study was conducted in Silchar Medical College Hospital, Silchar, Assam, India and for a period of one year commencing from 2nd January 2007 with the aim to determine the sociodemographic patterns of chronic schizophrenia, and to ascertain the type and severity of family burden in chronic schizophrenia in the study population. This institute caters to the people of the southern part of Assam, which comprises of the districts of Cachar, North Cachar, Karimganj and Hailakandi. In addition, people from the neighbouring states of Manipur, Mizoram and Tripura also came to this institute for treatment and related issues. The Department of Psychiatry also provides vital service to the people of this region. Annually about one thousand and five hundred new patients and approximately more than three thousand of old patients receive treatment in this department both as inpatients as well as outpatients.

The study population consisted of family members of patients of schizophrenia (according to the tenth revision of the International Statistical Classification of Diseases and Related Health Problems [ICD-10])[4] for duration of more than two years. The patients of both genders were taken into study provided they were above 18 years of age.

Exclusion criteria for the study were: Major chronic mental illness in other member in the family, presence of associated mental retardation, alcoholism and other drug use and personality disorders, significant long standing physical illnesses including diabetes mellitus, bronchial asthma, neurological diseases, epileptic disorders and patients in whom organic cause was suspected or when caregivers themselves suffered from any serious illnesses.

Free and voluntary consent for participation in the study was needed. The study was approved by the institutional ethical review board.

Sampling procedure: Cases were taken using serial sampling procedure i.e. all consecutive 100 cases attending the outpatient department (OPD) of psychiatry of the institute fulfilling the inclusion and exclusion criteria. In all cases detailed history was taken and all the cases were subjected to detailed physical and neurological examination to exclude organic causes.

Tools used were: Sociodemographic data collected using a proforma designed and standardised in the Department of Psychiatry of the institute, ICD-10 diagnostic criteria and family burden scale. The scale had been designed by Pai and Kapur[5]. Six categories of objective burden (each containing two to six items) were measured—financial burden, effect on family routine, effect on family leisure, effect on family interaction, effect on physical health and effect on mental health. Each category of item was assessed on a three point scale (no burden=0, moderate burden=1, severe burden=2). After completion of interview, the rater was expected to make an overall assessment of burden on similar

scale. This scale was tested on 30 patients by two different consultants of the department and validity of the scale was tested. Test-retest reliability and inter-rater reliability were also assessed between the two consultants before it was finally accepted as tool for the investigation.

Interview procedure: After obtaining necessary consent all the cases selected for the study were interviewed in detail using the tools (interview pattern was flexible to elicit maximum data). The time spent for each patient ranged between 45 to 60 minutes. While interviewing the patient, if the attention of the patient was found to be diverted, interview was stopped and resumed after a break. For all cases privacy of interview was strictly maintained.

Analysis of data: The sociodemographic variables were descriptively analysed. The collected data about burden scale were tabulated and the severity of burdens was calculated based on frequency. The correlation between the burden categories was calculated to the sociodemographic factors. Pearson's correlation coefficients were calculated to find the relationship between two variables. Analysis of variance (ANOVA) was done to study the difference in the variation of the variables.

Results and observations

Sociodemographic profile: In the study group it was observed that most (around 70%) fell below 40 years and divided almost equally in the 18-35 years (36%) and 31-40 years (35%). Only three percent of cases were above 60 years. Sixty two percent of the cases were male. Sixty seven percent were from Hindu religion, and 30% from Islam and the remaining followed other religions. Most of the cases (80%) were from a rural background. Fifty six percent of the cases were married and ten percent were either widow, widower, separated or divorced. Seventy nine percent were staying in a nuclear family. Almost half the cases (43%) had education from fourth to tenth standards, 23% had education above tenth standard and 12% had no formal education. None had postgraduate degrees. Highest majority of the cases (31%) were unemployed, 22% were housewives, 16% had small businesses and 13% were daily wage earners. None were professionals. Fifty three percent of cases were from low socioeconomic status and eight percent were from high socioeconomic group. It was found that 39% of cases had two to five years of illness, while 32% were suffering from a period of six to ten years. Twenty nine percent had illnesses of more than ten years duration.

Type and severity of family burden (tables 1 and 2): The frequencies of type and severity of family burdens in our study were as follows—disruption of routine family activity (65%), financial burden (62%), disruption of family recreation (54%), disruption of family interaction (32%), effect on physical health of others (21%) and effect on mental health of others (11%). Thus the least common with 11% was effect on mental health of others.

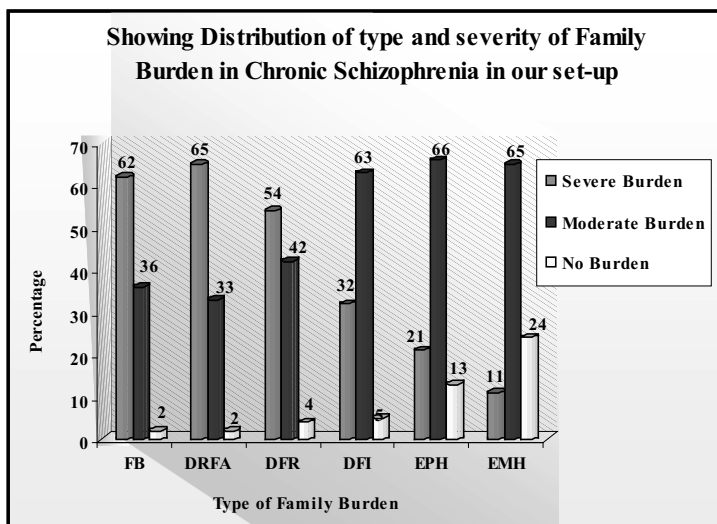


Figure 1 The type and severity of family burden in chronic schizophrenia cases.

FB=financial burden, DRFA=disruption of routine family activity, DFR=disruption of family recreation, DFI=disruption of family interaction, EPH=effect on physical health of others, EMH=effect on mental health of others

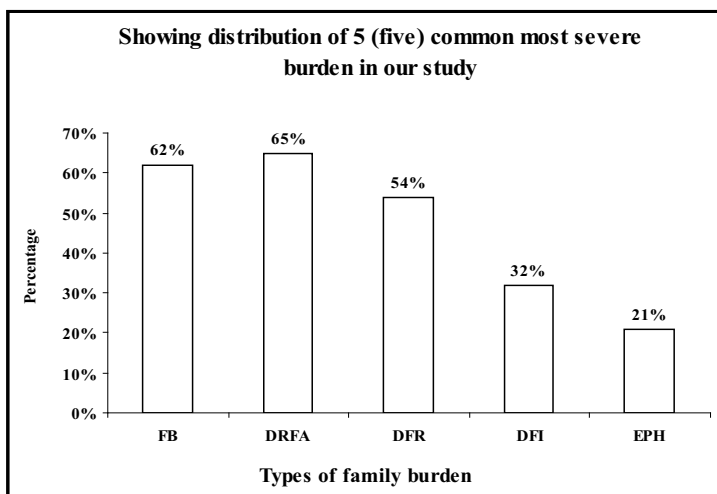


Figure 2 The five common most severe burdens.

FB=financial burden, DRFA=disruption of routine family activity, DFR=disruption of family recreation, DFI=disruption of family interaction, EPH=effect on physical health of others, EMH=effect on mental health of others

It was observed that correlation between different types of main burden of the family were positive irrespective of age distribution of the patients. In most cases correlation coefficient ranged from 0.99 to 0.79. The correlation coefficient of disruption of family interaction with effect on physical health recorded least. Disruption of routine family activity was found maximum in age group 18-30 years of the patients.

When burdens of family were tested for variation with age of the patient, the relation was found statistically significant ($5.893826 > F_{0.01} 4.77$ at (4, 16) d.f.). All the main sources of burdens of the family under study were found maximum of the patient in age group 18-30 years, followed by the age group 31-40 years and it was found least in the age group 41-50 years with 60 and above recorded least.

Correlation between patients' gender and family burden was found to have no positive statistical significance. Thus both sexes produce equal amounts of burdens on the family. However, there were differences in the type of burden. While for male patients, disruption of family activity came first, followed by financial burden the frequency was reversed in case of female patients. Similarly in religion distribution also overall burden was similar across all religions.

In terms of locality of the patients, it was noted the rural group reported financial burden and effect on family routine, while in the urban group more effect on family routine and leisure was noted. Effect on family interaction was recorded least in urban group.

Calculated F value for family pattern (nuclear or joint) was $28.40322 > F_{0.01} 8.65$ at (2, 8) d.f. Hence, the null hypothesis was rejected. All the main burdens of the family were found maximum in nuclear family of the patients and least in extended family. It was observed that correlations between different types of main burden of the family were positive (0.99) irrespective of family pattern of the patients.

Financial burden and effect on family routine were mainly faced by the married patients. All patients were found having high effect on family routine irrespective of the marital status. The correlation coefficients of the patients who were single with that of married, widower and divorced were highly positive irrespective of family burdens. The correlation coefficients between separated to other marital status were found minimum but with widow and married it recorded negative. Negative correlation meant movements in the opposite direction i.e. their attitude was different in respect of burdens. All the types of main sources of burden of the family were found in married patients followed by the single. Widower and separated recorded least.

All main burdens of the family were maximum in those having the educational qualification ranging from four to ten.

Discussion

In the study 70% of the cases were below the age group of 40. Average age of the patients was found as 36.68 years. The mean age in the study conforms to those conducted by Thomas et al.[6], who found the mean age to be 31.43 years, whereas Creado et al.[7] in their study at urban municipal general hospital in India, found the mean age to be around 36 years.

The gender distribution showed the same pattern as found by Creado et al.[7] in a psychiatry OPD based study of urban India where male:female ratio as 1.5:1 which was almost equal to our findings. Again Jungbauer et al.[8] from

Germany found 54% of the cases as male and 46% of the cases as female. But in another study conducted by Thomas et al.[6] in India found much higher cases from male (80%) in comparison to female (20%) only.

Eighty per cent of the cases we studied came from rural areas and 20% from urban. These also reflect the population pattern of this region. We had also found higher percentage (79%) of the cases coming from nuclear family. As the stress and strain along with economic burden and social insecurity are much more in nuclear family than in joint and extended family, the incidence of major mental disorders are probably more in nuclear families. It may also be attributed to the fact that the traditional way of joint family system is gradually going down in our society from what it was 25 years before.

In this study the highest percentage of cases were in “married” group (56%). Probably socioeconomic status of female, role of marriage as institution in society as well as other factors are much different in those Western countries than that of us. The lower mean age of the study population could also be contributing factor.

Occupation, education and socioeconomic status: In our study maximum number of cases i.e. 43% were educated between class four to ten and as a whole 77% of the cases had education below matriculation (including illiterate group) and high percentage were unemployed (31%). Since this is highly representative of the population data comparison to foreign studies would be unfair. An Indian study conducted by Thomas et al.[6] found 68.5% of their cases having monthly income less than 5000 rupees which is almost similar to our findings.

In our study, the duration of illness in 39% of the patients was from two to five years group followed by 32% from six to ten years group. In their study conducted by Roick et al.[9] in Germany and Britain found duration of illness in both the countries as 13 years. Jungbauer et al.[8] in Leipzig, Germany found duration of illness as 15 years. Socioeconomic background, affordability may be the reason behind this variation between our finding and that of others.

Type and severity of family burden in chronic schizophrenia: We used the scale “interview schedule for assessment of family burden”. We had found disruption of routine family activity have affected severely in 65% of the cases and moderately in 33% of the cases. On the other hand 62% of the cases felt the financial burden severely and 36% moderately. Family recreation was affected severely in 54% of the cases and moderately in 42% of the cases whereas family interaction was disrupted severely in 32% of the cases and moderately in 63% of the cases. Out of the six areas that we had explored in our study, the five areas that had affected the families most commonly and severely were as follows: disruption of routine family activity (65%), financial burden (62%), disruption of family recreation (54%), disruption of family interaction (32%) and effect on physical health of other family members (21%). So we found that in most of the areas, the family members or caregivers of chronic schizophrenia faced the severe crisis or burden.

Thomas et al.[6] found highest percentage of burden in disruption of family routine followed by disruption of fam-

ily interaction, financial burden, disruption of family leisure, effect on mental health of others than effect on physical health of others. This finding goes almost in the same line with that of ours. Of course the financial burden which ranks third in this study, ranked second. In our study this may be due to the difference in the status of financial conditions of these regions.

In another study conducted by Perlick[10] found 38% of burden for patient’s helplessness, 34% burden in problem behaviour and resource demands and 21% in impairment in activities of daily living. On the other hand in another study conducted in rural Ethiopia by Shibire et al.[11] found the highest family burden in the domain of financial difficulty (74.4%). This is partially higher findings than that of ours (62%) which may again be due to difference in financial conditions of the populations of the two countries. Again Grad and Sainsbury[12] reported that 33% of family problems were due to restriction of social and leisure activity, an equal number was affected by domestic routine and household work and only 25% are having financial constraints.

Limitations of our study were: We had taken only 100 numbers of cases which was very less in number as compared to the size of the population of catchment area. As the study was restricted only to the OPD of psychiatry of a tertiary care teaching hospital, this study may not reflect the exact picture of family burden in chronic schizophrenia in the community at large. Also, no control group was taken in our study.

In conclusion, the study was conducted to assess the burden of schizophrenia in the population served by the institution, and it was found the pattern and effects are as found in other studies conducted across the world. As it comes out that not only financial but the effects on other familial activities are equally burdensome, so, the aim of the treating physicians must also be directed to the issues of burden of the disease too. We would also like to urge health planners to incorporate these areas while drawing out health plans to make treatment of psychiatric patients a whole affair beyond reducing the symptoms.

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