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Study Of Caregivers Burden Of Patients With Schizophrenia.

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ABSTRACT

After the psychiatric revolution and the passage of deinstitutionalization laws, it was families that provided care for those with mental health conditions rather than psychiatric facilities. As a result, family caregivers were made fully accountable for caring for the patients, which presented issues for them. The difficulties that family caregivers have when caring for persons with schizophrenia have only been briefly examined in studies. In this cross-sectional study, each subject's complete medical and psychological exam results, as well as their relevant sociodemographic information, were recorded in a structured proforma. The Self-Reporting Questionnaire 20 (SRQ 20) and the Positive and Negative Symptom Scale (PANSS) were used to measure the psychological distress of the caregivers and the burden they were under. The study involved 40 individuals in total. The study's participants had an average age of 44.08 12.12; 12 (or 30%) of them were men, while 28 (70%) were women. With a range of 3 to 12 hours/day, the study population's mean total caring time was (7.63+2.37) hrs 25 carers (62.50%) felt no psychological discomfort, compared to 15 (37.50%) who did. Age, caregiver burden, total caring time (hours/day), negative symptoms, and overall PANSS score were found to be substantially related to psychological distress among caregivers on a univariate analysis. The odds of psychological distress increased 1.09 times (95% CI 1.108 to 1.186, P value 0.015) with each unit increase in the intensity of caregiver burden, after accounting for the effects of the other variables in the equation. The most important predictive factor of psychological distress in caregivers was the severity caregiving burden.

Keywords: Family, Caregivers, Burden, Psychological stress, Schizophrenia.

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INTRODUCTION

Schizophrenia, as a chronic, severe, and debilitating disorder affects about 3–6.6 cases/1000 persons [1]. its remarkable prevalence of 1.1% in adult, it is estimated that 51 million people around the world suffer from the disorder [2]. Since the deinstitutionalization policies, the responsibility for taking care of 50%–90% of psychiatric patients was shifted to their families. In Iran, 65%–75% of patients with schizophrenia return to their families after discharge from the hospital and their families took care of them [3]. Some results indicate that schizophrenia patients require 24-h home care [4, 5]. Another research reported that 57.4% of these patients could not stay at home alone for more than 3 h [6]. Schizophrenia is one of the psychiatric disorders that often have specific caregiving needs.[7]Studies reveal that family caregivers have various tasks and help patients to perform their daily and self-care activities [7, 8]. In general, family caregivers have many responsibilities for taking care of these patients. In addition to managing unexpected behaviors of the patients such as aggression and violence, they have to play multiple roles in caring for them which impose a heavy burden on them.[1] It was reported that 83%–95% of family caregivers of schizophrenia patients experience a significant burden, which decreases their quality of life and increases exposed the caregivers and patients to various risks [8]. The stress of being a family caregiver for someone with schizophrenia affected their physical and mental health as well as their social and economic standing, which in turn caused a number of disorders like depression, anxiety, obsessive-compulsive disorder, and other neurotic disorders [9]. They also have unfavourable attitudes and feelings toward the patient, as well as wrath, guilt, dread, hopelessness, and melancholy [10, 11]. The majority of this evidence comes almost exclusively from studies conducted in high-income nations, which presents additional difficulties for caregivers in low- and middle-income nations. The lack of adequate medical, educational, and social services is one of these difficulties [12]. The experiences of family carers in low- and middle-income nations are generally poorly documented [7]. On the other hand, while the experiences of family caregivers of psychiatric patients have been extensively documented, it is important to note that there are regional variations in how people perceive and judge mental illness and caring as well as caregiver experiences. Additionally, despite the fact that family caregiver burden scales have been used in the past with schizophrenia patients, there is little proof that their content validity has been established in this population in accordance with accepted standards for the creation and assessment of self-report scales [13]. As a result, there is a need to understand the caring problems from family caregivers themselves given the scant research on caregiving challenges in Iran. The purpose of the study is to better understand the caregiving burden experienced by family carers of schizophrenia patients in their environment and to identify the factors that are associated to it.

MATERIALS AND METHODS

The current study was a cross-sectional investigation carried out at the VikhePatil Memorial Hospital in Ahmednagar, Maharashtra, in the department of psychiatry. In this study, primary caregivers of mental inpatients and outpatients who had been diagnosed with schizophrenia with a duration of illness of more than two years and who were older than 18 years old were included. Except for those under F20 and under the age of 18, caregivers of patients with psychiatric illnesses were excluded from the study. After receiving fully informed written consent, each patient underwent a thorough history evaluation. Clinical and psychological assessment results, as well as pertinent sociodemographic information, were documented in a systematic proforma. The following rating scales were used.

- Burden assessment schedule (BAS) -A 40 item questionnaire assessing both the objective and subjective burden experienced by the caregiver of mentally ill patients. The scores range from 40 to 120 [14].
- Self-reporting questionnaire 20 (SRQ 20) to assess psychological distress.It is a 20-item mental disorder screening instrument developed by World Health Organization [15].
- PANSS (Positive and Negative symptom scale). This consist of 3 dimensions-Positive symptoms, Negative Symptoms and General symptoms to assess the severity of symptoms in patients with schizophrenia [16].

The study was conducted after obtaining ethical clearance Institutional Human Ethics Committee. All patients were given necessary treatment irrespective of their caregiver's participation in the study. In the case of the presence of psychological distress in the caregivers, further evaluation and appropriate management was done.

Sample size

Sample size was calculated assuming the proportion of psychological distress among the caregivers as 31.5% as per the study by Hui Chien Ong et al [17]. The other parameters considered for sample size calculation were 15% absolute precision and 95% confidence level. The following formula was used for sample size calculation. The required number of subjects as per the above-mentioned calculation was 37. To account for a non-participation rate of about 10 % (3 subjects), it was decided to sample about 40 subjects in to the study.

Statistical methods

For quantitative variables, the mean and standard deviation were used in the descriptive analysis, while frequency and proportion were used for categorical variables. The relationship between the explanatory variables and psychological distress was examined using univariate binary logistic regression analysis (Self-reporting questionnaire 20). The unadjusted odds ratio and 95% confidence interval are shown. Multivariate regression analysis was computed using variables that have achieved statistical significance in univariate analysis. The adjusted odds ratio and its 95% confidence interval are shown. Statistical significance was defined as a P value 0.05. The statistical evaluation was performed using IBM SPSS version 22.

RESULTS

The analysis covered 40 participants in total. In the research population, caregiving lasted an average of 7 ± 5.87 years, ranging from 2 to 30 years. The study population's average daily total caregiving time ranged from 3 to 12 hours and was 7.63+2.37. The patients' average length of sickness was 8.8 +/- 8.52 years, with a range of 2 to 40 years. 39 (97.50%) of the schizophrenia patients exhibited general symptoms, 40 (100%) had positive symptoms, and 22 (55%) had negative symptoms. The study population's mean PANSS score was 57.30 ± 12.74, with a range of 36 to 82. The study population's average caregiver load schedule score ranged from 20 to 80 and was 44.60 18.44. Utilizing the relf-reporting questionnaire, the study population's psychological discomfort was either present or absent. 20. Of the 20 patients, 15 (37.50%) were deemed to be in psychological distress, while 25 (625%) were not. With each additional year of age, the likelihood of psychological distress increased by 1.073 times, which is statistically significant (P value 0.044). When overall caregiving time increased by one hour, the odds of psychological discomfort increased by 1.392 times, a statistically significant increase (P value 0.039). When compared to patients who had good symptoms, caregivers who had negative symptoms were 1.08 times more likely to experience psychological discomfort.The association was statistically significant (P value 0.045).The odds of psychological distress was 1.083 times increased with one unit increase in PANSS total score and was statistically significant (P value 0.013).The odds of psychological distress was1.117 times increased with one unit increase in Care Giver Burden Schedule score which was statistically significant   (P value 0.001). The remaining parameters have not shown any statistically significant association with psychological distress (P value>0.05).

Table 1: Socio-demographic parameters of study population (N=40)

Demographic parameter	Mean/Frequency	SD/Percentage
Age (Mean ±STD)	44.08	± 12.12
Gender		
Male	12	30.00%
Female	28	70.00%
Marital status		
Married	35	87.50%
Unmarried	5	12.50%
Education		
Middle School	15	37.50%
Primary School	12	30.00%
High School	8	20.00%
Illiterate	5	12.50%
Occupation		
Unemployed	14	35.00%
Unskilled Worker	13	32.50%
Employed	13	32.50%
Family type		
Joint	5	12.50%
Nuclear	35	87.50%
Primary earning member of family		
Caregiver	14	35.00%
Patient	13	32.50%

Table 2: Univariate logistic regression analysis factors associated with psychological distressin the study population (N=322)

Parameter	Odds ratio	95% CI		P value
		Lower	Upper	
Age	1.073	1.002	1.149	0.044
Gender (baseline= Male)				
Female	2.250	0.499	10.143	0.291
Marital status (baseline = Married)				
Unmarried	1.128	0.166	7.665	0.902
Education (base line= Illiterate)				
Middle School	2.667	0.237	30.066	0.427
Primary School	2.857	0.241	33.902	0.406
High School	2.400	0.175	32.87.9	0.512
Occupation (baseline= Unemployed)				
Unskilled Worker	1.125	0.236	5.371	0.883
Employed	1.125	0.236	5.371	0.883
Patient primary earning member of the family (Baseline=No)				
Yes	0.646	0.158	2.637	0.543
Duration of caregiving(in years)	1.148	0.995	1.324	0.059
Total caregiving time (hours/day)	1.392	0.018	1.904	0.039
Duration of illness(in years)	1.044	0.966	1.129	0.279
Type of symptoms				
Positive symptoms	1.044	0.966	1.129	0.279
Negative Symptoms	1.087	1.002	1.178	0.045
General symptoms	1.086	0.957	1.233	0.200
PANSS total	1.083	0.017	1.154	0.013
Care Giver Burden Schedule	1.117	1.047	1.192	0.001

Table 3: Multivariate logistic regression analysis of factors associated with psychological distress (Self-reporting questionnaire 20) (N=322)

Parameter	Adjusted odds ratio	95% C.I. for the adjusted odds ratio		P value
		Lower	Upper	
Age	1.003	0.924	1.088	0.951
Total caregiving time (hours/day)	1.070	0.625	1.832	0.806
Negative Symptoms	0.988	1.851	1.146	0.870
PANSS total	1.060	0.962	1.168	0.237
Care Giver Burden Schedule	1.099	1.108	1.186	0.015

Only one measure exhibited a statistically significant association with psychological discomfort in the study when other factors' effects were taken into account. A one-unit rise in the caregiver burden schedule score resulted in a 1.09-times (95% CI 1.108 to 1.186, P value 0.015) increase in the risks of psychological distress.

DISCUSSION

Caregiver characteristics

The current study was carried out in a tertiary care teaching hospital in South India and assessed the load of carers using the Burden Assessment Schedule (BAS) scale and the presence of psychological distress using the Self Reporting Questionnaire 20 (SRQ 20). 70% of the caregivers were women, with a mean age of 44.08 12.12 years. Most of them were married, had completed their middle school education, and worked as either unskilled labourers or the unemployed. More over 50% of the time, a spouse provided care, with other family members providing care in the remaining situations. The study's sample populations included more than 80% members of nuclear households. The mean age of the caretakers in a study of a similar nature conducted by Shah, S. T., et al. 18 was 45.4414.25 years, which was consistent with the current study. There were 42 male caregivers (84%) and 8 female caregivers (16%). Twenty-eight people (or 56%) lacked a high school diploma, 16 had a primary education, 4 were in college, and 2 had graduated. 34 (68%) of the carers were married, and 8 (16% were single, widowed, or widowers. 18 (36%) were employed, while 32 (64%) were unemployed. These variables were a little different from those in the present study.

Disease-related characteristics

With a range of 2 to 40 years, the average duration of schizophrenia in the study sample was 8.8 8.52 years. The average time spent providing care was 7.63 2.37 hours per day for a mean of 7 5.87 years. 40 participants in the study (100%) had positive sensations, 22 participants (55%) had negative symptoms, and 39 participants (97.50%) had general symptoms. The study population's average caregiver load schedule was 44.60 18.44, and the average PANSS total was 57.30 12.74. The average (SD) length of the sickness in Kumar, C. N., et alstudy .'s was 154.8 (119.5) months. At the time of testing, symptoms were modest (Mean (SD) total PANSS score = 50.5(23.6)), and they had a Mean (SD) (SD) and they had a Mean (SD) total disability of 4.6 (4.2).. The average (SD) total burden of caregivers in the study by Jagannathan, A., et al. (20) was 80.02 (11.53), and the average (SD) total burden of caregivers who were the patients' wives was 74.94. (11.27). 1.94 was the average BAS score (0.31). The average PANSS score was 58.5. (18.9). These studies supported our findings. effect on the caretakers 22 (55%) of the participants in the current study had a moderate burden, and 18 (45%) had a severe burden. The study population's self-reporting questionnaire 20 average score was 8.78 3.98. 15 (37.50%) of the participants in the study experienced psychological distress, while 25 (62.50%) did not. Using the Self Report Questionnaire (SRQ-20), which has a cutoff score, the stress level was evaluated.The study's conclusions agreed with those of the one by Shah, S. T., et al. 14 people (28%) had no psychological suffering, while 18 out of 36 (72%) did. In contrast to the study by Shah, S. T., et al. 18 where 72% experienced distress, our study found that 37.50% of participants did. This was substantial in light of the present study. In the study by Ong, H. C., et al. (17), 31.5% of the carers reported psychological discomfort, which was consistent with our results.

Factors associated with caregiver burden and distress

Jagannathan, A., et al. [20]In their study of 137 carers of schizophrenia patients, Jagannathan, A., et al. 20 showed that overall burden score was significantly inversely correlated with perceived social support, disease duration, and levels of psychopathology and impairment. Psychopathology and disability had a strong link (p 0.001). Duration of illness and perceived social support were significant predictors of burden in addition to psychopathology and disability, according to two different regression models, each of which included total PANSS score (for psychopathology) or total IDEAS score (for disability).
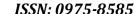
Kumar C. N., et al. [16] found In their study, the degree of load was significantly correlated with both the severity of psychopathology (Pearson's r =.21; p .01) and disability (Pearson's r =.35; p .01). There was an inverse relationship between treatment duration and burden (Pearson's r = -.16; p .01). The results of a multivariate analysis showed that the total score on the Indian Disability Evaluation and Assessment Scale (IDEAS) (Beta =.28; t = 4.37; p /=.01), the length of the treatment (Beta = -.17; t = -2.58; p =.01), the age of the family caregiver (Beta =.15; t = 2.4; p =.02), and the gender (14% of variance was explained by the model that included the overall IDEAS score; adjusted R (2) =.139; p .01). The authors came to the conclusion that the burden placed on family carers of schizophrenia patients.

There were several advantages to this study. There are very few Indian research that have examined caregiver load predictions in acute schizophrenia patients upon first admission. This study expands on more generalised features of mental diseases, where daily struggles for carers may also exist. To assist them in the continuum of care, we must speak with the carers. Second, despite the study's use of cross-sectional designs, validated standardised methods were employed in order to determine the degree of caregiver distress and to evaluate burden and disability.

The study did have some drawbacks, though. Because the study was cross sectional in nature, no causal conclusions could be drawn from the observed connection. The study had a modest sample size and was single-centered. Therefore, it was impossible to extrapolate the study's results to the broader population. The study used a technique called purposeful sampling, which does not accurately represent the broader population. Additionally, self-reported measurements frequently contain social desirability bias or response bias [18-20].

CONCLUSIONS

Parents and siblings only provided care for a small percentage of patients, and the majority of carers in the study were female, had no formal education, and were the patients' spouses. The average

time spent providing care was 7.63 2.37 hours per day over a period of 7 5.87 years. The study found that 37.50% of participants experienced psychological disturbance. 18 (45%) experienced a severe burden, while 22 (55%) reported a moderate burden. In our investigation, significant discomfort and burden were noted. The severity of the caregiving burden was the most crucial predictor of psychological discomfort in caregivers. A further longitudinal study, however, might offer more clarity on the hardship faced by schizophrenia caregivers.

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