

A Hospital Based Observational Assessment of the Psychological Distress and Caregiver Burden among Care Givers of Schizophrenia Patients

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Abstract

Aim: The study was conducted with the aim of assessing the psychological distress and caregiver burden among care givers of schizophrenia patients.

Methods: The current study was a cross-sectional study conducted in the Department of Psychiatry, Jannayak Karpoori Thakur Medical College & Hospital, Madhepura, Bihar, India for one year. A total of 50 subjects were included in the analysis. Primary Caregivers of psychiatric outpatients in Jannayak Karpoori Thakur Medical College & Hospital, Madhepura, Bihar, India with a diagnosis of Schizophrenia with duration of illness >2yrs classified under F20 according to ICD-10 and aged more than 18 years were included in the study.

Results: The mean duration of caregiving of study population was 7 ± 5.87 years with the range of 2 to 30 years. The mean total caregiving time per day of study population was 7.63 ± 2.37 with the range of 3 to 12 hours/days. The majority of patients were female (70%). The majority of the patients had low educational level with 12% of them being illiterate and 36% of the patients were unemployed. The mean PANSS score of the study population was 57.30 ± 12.74 with the range 36 to 82. The mean caregiver burden schedule score of the study population was 44.60 ± 18.44 with the range of 20 to 80. The odds of psychological distress were 1.073 times increase with each year increase age which was statistically significant (P value 0.044). The odds of psychological distress were 1.392 times increasing with each one hour increase in total caregiving giving time which was statistically significant (P value 0.039). The odds of psychological distress in caregivers were 1.087 times more in patients who had negative symptoms compare to those with positive symptoms. The association was statistically significant (P value 0.045).

Conclusion: Caregivers of schizophrenic patients suffered from significant burden. It thus becomes important to plan interventions that would reduce their burden of care and thus improving their psychological well-being.

Keywords: Family, Caregivers, Psychological Stress, Schizophrenia.

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Introduction

Schizophrenia is a disabling, chronic mental disorder that gives rise to numerous challenges in its management and consequences. It exerts a significant cost to the patient in terms of personal suffering, on the caregiver as a result of the shift of burden of care from hospital to families, and on society at large in terms of significant direct and indirect cost that include frequent hospitalizations and need for long-term psychosocial and economic support, as well as life-time lost productivity. [1] Patient's relatives feel wide range of emotions, from loss and grief to guilt and anger. They also feel secluded and stigmatized. [2]

The addition of the caregiving role to already existing roles becomes stressful physically, psychologically and financially. [3] Caregivers are often bound by kinship commitments to take up certain duties and responsibilities that are far in excess of those normally associated with a family role at a particular stage. [4-6] If caregiving is prolonged (and in many health conditions, it can last until one of the pair dies), problems can be aggravated, situation may not get better with time. A further difficulty is that caregivers find that they are left with no choice. [7]

The key carer is seen as the person who provides the most support of patient, often devoting substantial numbers of hours each day towards taking care of the patient. [8] Caregiver burden has thus been defined as "a psychological state that ensues from the combination of the physical work, emotional and social pressure, like the economic restriction that arises of taking care of the patients." [9] Burden has mainly two elements – objective and subjective. Objective burden refers to the quantifiable challenges faced by the family members in everyday life such as financial costs, loss of free time

and altered social relationships. Subjective burden refers to the abstract or emotional cost faced by the family as a result of the patient's illness. [10]

Caregivers often encounter increased psychological stress due to financial, psychological, and social demands of chronically ill patients. [11-13] Psychological stress is conceptually defined as a "unique, discomforting, emotional state experienced by an individual, in response to a specific stressor or demand, that results in harm, either temporary, or permanent, to the person". [14] Depression is more frequently reported by caregivers of patients with chronic mental illness. [15] Caregivers who have a persistent high stress level are more likely to have a lower quality of life and greater physical health risks in comparison with the general population. [16,17]

The study was conducted with the aim of assessing the psychological distress and caregiver burden among care givers of schizophrenia patients.

Materials and Methods

The current study was a cross-sectional study conducted in the Department of Psychiatry, Jannayak Karpoori Thakur Medical College & Hospital, Madhepura, Bihar, India for one year. A total of 50 subjects were included in the analysis. Primary Caregivers of psychiatric outpatients in Jannayak Karpoori Thakur Medical College & Hospital, Madhepura, Bihar, India with a diagnosis of Schizophrenia with duration of illness >2yrs classified under F20 according to ICD-10 and aged more than 18 years were included in the study. Exclusion of caregivers of patients with psychiatric illness other than those under F20 and less than 18 years age was done. After

obtaining informed written consent, all the subjects were evaluated by detailed history. Relevant sociodemographic details, clinical and psychological assessment findings were documented in a structured proforma. The following scales were administered:

1. 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. [18]

2. Self-reporting questionnaire 20 (SRQ 20) to assess psychological distress. It is a 20-item mental disorder screening instrument developed by World Health Organization. [19]

3. PANSS (Positive and Negative symptom scale). [20] This consist of 3 dimensions-Positive symptoms, Negative Symptoms and General symptoms to assess the severity of symptoms in patients with schizophrenia.

The study was conducted after obtaining ethical clearance from 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.

Statistical methods

Descriptive analysis was carried out by the mean and standard deviation for quantitative variables, frequency and proportion for categorical variables. Univariate binary logistic regression analysis was performed to test the association between the explanatory variables and psychological distress (Self-reporting questionnaire 20). Unadjusted Odds ratio along with 95% CI is presented. Variables with statistical significance in univariate analysis were used to compute multivariate regression analysis. Adjusted odds ratio along with their 95% CI is presented. P value < 0.05 was considered statistically significant. IBM SPSS version 22 was used for statistical analysis.

Results

Table 1: Socio-demographic parameters of study population

Demographic parameter	Mean/Frequency	SD/Percentage
Age (Mean ±STD)	44.08	± 12.12
Gender		
Male	15	30.00%
Female	35	70.00%
Marital status		
Married	43	86%
Unmarried	7	14%
Education		
Middle School	19	38%
Primary School	15	30.00%
High School	10	20.00%
Illiterate	6	12%
Occupation		
Unemployed	18	36%
Unskilled Worker	16	32%
Employed	16	32%
Family type		
Joint	6	12%
Nuclear	44	88%

Primary earning member of family		
Caregiver	18	36%
Patient	16	32%

The mean duration of caregiving of study population was 7 ± 5.87 years with the range of 2 to 30 years. The mean total caregiving time per day of study population was 7.63 ± 2.37 with the range of 3 to 12 hours/days. The majority of patients were female (70%). The majority of the patients had low educational level

with 12% of them being illiterate and 36% of the patients were unemployed. The mean PANSS score of the study population was 57.30 ± 12.74 with the range 36 to 82. The mean caregiver burden schedule score of the study population was 44.60 ± 18.44 with the range of 20 to 80.

Table 2: Univariate logistic regression analysis factors associated with psychological distress in the study population

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

The odds of psychological distress were 1.073 times increase with each year increase age which was statistically significant (P value 0.044). The odds of psychological distress were 1.392 times increasing with each one hour increase in total caregiving giving time which was statistically significant (P value 0.039).

The odds of psychological distress in caregivers were 1.087 times more in patients who had negative symptoms compare to those with positive symptoms. 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 was 1.117 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 3: Multivariate logistic regression analysis of factors associated with psychological distress (Self-reporting questionnaire 20)

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

The presence or absence of Psychological distress among the study population was determined using Self-reporting questionnaire 20. After adjusting for the effect of other variables in the equation, only one parameter had shown statistically significant association with psychological distress in the study. The odds of psychological distress were increased 1.09 times (95% CI 1.108 to 1.186, P value 0.015) with one unit increase in caregiver burden schedule score.

Discussion

Psychological distress is defined as the discomfort of a patient while experiencing symptoms of disorders or anxiety before and after treatment. [21] It refers to the context of strain, stress, and distress. Past research often described it as an emotional suffering condition with symptoms of depression and anxiety. [22,23] These symptoms can range from a person showing disinterest, feeling sad, or losing hope to depression, anxiety, nervousness followed by some somatic symptoms such as headache, fatigue, and insomnia. [24] Psychological distress is not merely associated with the inability to conduct daily chores, but it is also a measure of the other psychiatric disorder symptoms, such as major depression and generalized anxiety disorder. [25] Caregivers also tend

to experience social problems because of the people around them.

The current study which has evaluated the burden of caregivers using Burden assessment schedule (BAS) scale and the presence of psychological distress using Self-reporting questionnaire 20 (SRQ 20) was conducted. The mean age of the caregivers was 44.08 ± 12.12 years and 70% of caregivers were women. Majority of them were married and studied up to middle school and a major proportion of them were either unemployed or unskilled workers. In more than 50% of the cases, the caregiver was a spouse and in the remaining cases, it was other family members. More than 80% of the study populations were from nuclear families. In a similar study done by Shah, S. T., et al. [26], the mean age of the caregivers was 45.44 ± 14.25 years, which was in accordance with the current study. Forty-two (84%) caregivers were males, and 8 (16%) were females. Twenty-eight (56%) were uneducated, 16 (32%) had Primary education, 4 (8%) were matriculates and 2 (4%), graduates. Thirty-four (68%) of the caregivers were married 8 (16% each unmarried and widows/widowers. Thirty-two (64%) were unemployed, and 18 (36%) were employed. These parameters differed slightly from the current study.

Among the study population, the mean duration of the schizophrenia was 8.8 ± 8.52 with the range of 2 to 40 years. The mean duration of caregiving was 7 ± 5.87 years and mean time of care giving per day was 7.63 ± 2.37 hours per day. The mean PANSS total of the study population was 57.30 ± 12.74 , and the mean caregiver burden schedule of the study population was 44.60 ± 18.44 . In the study by Kumar, C. N., et al, [27] the mean (SD) duration of illness was 154.8 (119.5) months. Symptoms were mild at the time of assessment (Mean (SD) total PANSS score = $50.5(23.6)$), and they had a Mean (SD) total disability of 4.6 (4.2). In the study by Jagannathan, A., et al [28] the mean (SD) total burden of the caregivers (excluding spouses of the patient) was 80.02 (11.53), and the mean (SD) total burden of caregivers who were spouses of the patients was 74.94(11.27). The average BAS score was 1.94 (0.31). The mean PANSS (total) score was 58.5 (18.9). These studies were in according to ours.

Jagannathan, A., et al. [28] in their study of caregivers of 137 schizophrenia patients found that duration of illness and levels of psychopathology and disability had a significant direct correlation with total burden score; perceived social support had a significant inverse correlation with total burden score. There was a high correlation between psychopathology and disability ($p < 0.001$). Two separate regression analyses, each including total PANSS score (psychopathology) or total IDEAS score (disability) showed that duration of illness and perceived social support were significant predictors of burden in addition to psychopathology and disability.

Kumar C. N., et al. [27] found in their study that level of burden had a significant direct correlation with disability (Pearson's $r = .35$; $p < .01$) and severity of psychopathology ($r = .21$; $p < .01$). Duration of treatment had an inverse correlation with burden (Pearson's $r = -.16$; $p < .01$). Multivariate analysis revealed

that total Indian Disability Evaluation and Assessment Scale (IDEAS) score (Beta = .28; $t = 4.37$; $p \leq .01$), duration of treatment (Beta = $-.17$; $t = -2.58$; $p = .01$), age of the family caregiver (Beta = .15; $t = 2.4$; $p = .02$) and gender of the patient (Beta = $-.13$; $t = -2.1$; $p = .04$) were significant predictors of burden. The model including total IDEAS score explained 14% of variance (adjusted $R^2 = .139$; $p < .01$). The authors concluded that, Burden experienced by family caregivers of schizophrenia patients depends on the level of disability experienced by the patient, age of the family caregivers and gender of the patient. [29]

However, the study was not without limitations. The study was a cross sectional study; thus, the observed association could not be interpreted as causal inferences. The study was a single centred with small sample size. Hence the study findings could not be generalized to the rest of the population. Purposive sampling technique was employed for the study which is not a true representation of the general population. And self-reported measures often involve response bias or social desirability bias.

Conclusion

Caregivers of schizophrenic patients suffered from significant burden. It thus becomes important to plan interventions that would reduce their burden of care and thus improving their psychological well-being. High distress and burden were reported in our study. The most important predictive factor of psychological distress in caregivers was the severity caregiving burden. However further longitudinal study may provide a better insight on burden and distress among caregivers of schizophrenia.

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