

Living with Chronic Schizophrenia: A Study of Family Caregiver's Burden and Adjustment

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ABSTRACT

Background: Schizophrenia is a long-term, crippling mental illness that has a substantial impact on those who have been diagnosed as well as their families, especially primary caregivers. **Aim:** The purpose of this study is to examine the worldwide adjustment and the degree of hardship faced by family caregivers of people with chronic schizophrenia. **Methodology:** The study, which was carried out at the Maharashtra Institute of Mental Health in Pune, chose 152 caregivers using a purposive sampling technique and a descriptive cross-sectional design. The Global Adjustment Scale (GAS), the Family Burden Interview Schedule (FBIS), and a semi-structured sociodemographic sheet were used to gather data. **Results:** The results show that caregivers face significant emotional, financial, and social pressures that have an adverse effect on their everyday functioning, social interactions, and mental health. Family burden and global adjustment were shown to be significantly correlated, highlighting the connection between personal well-being and caregiving stress. **Conclusion:** The study emphasizes the necessity of focused support programs, mental health tools, and laws that take into account the psychosocial requirements of those who care for people with schizophrenia.

Keywords: Chronic Schizophrenia, family Burden, Adjustment

Introduction: Among all psychiatric disorders, schizophrenia is considered the most disabling, having long attracted significant medical, scientific, and societal attention. About 1% of people worldwide suffer with schizophrenia, a debilitating mental illness that ranks among the top 10 causes of disability globally (Marder et al., 2019). Schizophrenia is one of the most severe and incapacitating mental health disorders because of its chronic nature, which frequently causes significant disability for those who are impacted. It is common for family caregivers of people with schizophrenia to feel a lot of stress. Positive psychotic symptoms, like hallucinations, delusions, disordered speech, and disorganized or catatonic behavior, as well as negative symptoms, like decreased motivation and expressiveness, and cognitive impairments that impact executive function, memory, and mental processing speed, are characteristics of schizophrenia (Jauhar et al., 2022).

Schizophrenia has a wide range of effects on day-to-day functioning; many people have severe disability and only partial recovery. Even individuals with better results face obstacles like stigma, social exclusion, and less chances to build meaningful relationships. People with schizophrenia have very high unemployment rates.

Having a family member with a chronic illness, particularly a severe mental disorder like schizophrenia, can significantly affect family dynamics, limiting opportunities for career advancement, social engagement, and leisure activities. Chronic mental illness disrupts the equilibrium of family life, altering relationships, shared goals, and long-term aspirations (Dehghani et al., 2019). Due to the substantial functional limitations associated with schizophrenia, affected individuals often rely heavily on their families for support. As a result, families not only provide most of the day-to-day

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care but also live under constant stress, fearing relapse and the potential impact on other household members (Patel & Chatterji, 2015).

Sustained caregiving duties can lead to emotional exhaustion, often resulting in negative psychological effects such as hopelessness, guilt, depression, and helplessness (Leng et al., 2019). Caregivers are frequently challenged by erratic behaviors from the patient, and external stressors such as social stigma and discrimination exacerbate their burden, leading many to withdraw socially and feel isolated (Akbari, et. al., 2018). These conditions raise the likelihood of psychological distress among family members, especially those who serve as primary caregivers, such as parents and spouses (Von et al., 2016).

Research Design and Methodology:

Aim: The aim of the present study is to assess the level of family burden and global adjustment among caregivers of individuals living with chronic schizophrenia in Pune. **Objectives:** The study will examine the sociodemographic profile of schizophrenia caregivers, assess the family burden they experience, evaluate their global adjustment, and explore the relationship between family burden and global adjustment. **Study design:** A descriptive cross-sectional study was conducted with caregivers of schizophrenia patients as per ICD-10 (DCR) (WHO, 1992) at the Maharashtra Institute of Mental Health (MIMH) in Pune. **Sampling style and size:** Using purposive sampling, 152 caregivers were selected from the outpatient department of MIMH Pune. **Inclusion criteria** for patients were schizophrenia diagnosis for at least 2 years, aged 20-50 years, while caregivers had to be aged 20-55 years, with at least a 5th-grade education. Patients with comorbid conditions or epilepsy were excluded, along with caregivers with major psychiatric disorders or physical illnesses.

Socio-Demographic and Clinical Data Sheet:

The purpose of this semi-structured data sheet is to gather sociodemographic information about the participants, including age, gender, occupation, education level, marital status, religion, monthly income, family type, and pertinent clinical data.

Family Burden Interview Schedule (FBIS), developed by Pai and Kapur, is a semi-structured tool with 24 items across six areas, including financial burden, impacts on family activities, leisure, interactions, and effects on the physical and mental health of family members. Its validity is supported by a significant correlation of 0.72 between objective and subjective burden reports from family members (Pai and Kapoor, 1981).

Global Adjustment Scale (GAS), developed by Psycom Services assesses overall adjustment in adults (20+) and students (13-19). It covers six domains: family relationships, health, social environment, emotional factors, occupational factors, and sex-related behavior, evaluating individuals' perceptions of their adjustment in each area (Kumar and Kiran, 2024).

The Statistical Package for Social Sciences-25 (IBM-SPSS-25.0) was used to conduct the statistical analysis. Frequency, percentages, mean, and standard deviation were among the descriptive statistics utilized for clinical and sociodemographic data. The Pearson correlation coefficient (r), student "t" test, and chi square test were employed to examine the variance.

Results: Table no 1 show that the majority of the 152 caregivers were Marathi-speaking (90.8%) and male (60.5%). Regarding education, only 3.3% were illiterate, but a sizable percentage (34.2%) were graduates. The majority of caregivers (77.6%) were from nuclear families; the remaining caregivers were from joint families.

Table no 1: Socio Demographic Profile of the caregivers

Item	Category	Frequency	Percentage
Gender	Male	92	60.5
	Female	60	39.5
Education	Illiterate	5	3.3
	Primary	34	22.4
	Secondary	33	21.7
	H. Secondary	22	14.5
	Graduation	52	34.2
	PG & above	6	3.9
Occupation	Farmer	31	20.4
	Business	33	21.7
	Professional/Govt.	18	11.8
	Housewife	45	29.6
	Students	15	9.9
	Other	10	6.6
Mother Tongue	Marathi	138	90.8
	Hindi	11	7.2
	Other	3	2.0
Family Type	Joint	34	22.4
	Nuclear	118	77.6

Table no. 2: Socio-demographic details of individuals with schizophrenia

Item	Category	Frequency	Percentage
Gender	Male	91	59.9
	Female	61	40.1
Education	Illiterate	3	2.0
	Primary	23	15.1
	Secondary	45	29.6
	H. Secondary	34	22.4
	Graduation	45	29.6
	PG & above	2	1.3
Occupation	Farmer	17	11.2
	Business	29	19.1
	Professional/Govt.	3	2.0
	Housewife	37	24.3
	Student	9	5.9
	Other	57	37.5
Marital Status	Single	53	34.9
	Married	61	40.1
	Divorced	10	6.6
	Widow/Widower	11	7.2
	Separated	17	11.2
Domicile	Rural	31	20.4
	Semi-Urban	37	24.3
	Urban	84	55.3

Table 2 shows that the majority of the 152 patients (53.9%) were men, 29.6% had completed secondary or graduate school, and the majority worked as housewives (24.3%) or in other occupations (37.5%). The group was demographically diverse in terms of gender, education, occupation, marital status, and place of residence, with the majority of patients being married (40.1%) and living in cities (55.3%).

Table no. 3: Finding of Family burden caregivers of individuals with schizophrenia

Domain	Category	Frequency	Percentage
Financial Burden	No Burden	20	13.2
	Moderate Burden	35	23.0
	High Burden	97	63.8
Disruption of routine family activities	No Burden	15	9.9
	Moderate Burden	46	30.3
	High Burden	91	59.9
Disruption of family Leisure	No Burden	26	17.1
	Moderate Burden	27	17.8
	High Burden	91	65.1
Disruption of family interaction	No Burden	17	11.2
	Moderate Burden	48	31.6
	High Burden	87	57.2
Effect on physical Health	No Burden	1	0.1
	Moderate Burden	23	15.1
	High Burden	128	84.2
Effect on Mental Health of other family member	No Burden	7	4.6
	Moderate Burden	18	11.8
	High Burden	127	83.6

Table no 3 shows that the majority of caregivers reported a high burden, with significant disruption in routine family activities (53.9%), family leisure (65.1%), and family interaction (57.2%), alongside a major impact on their physical (84.2%) and mental health (83.6%), indicating that caregiving responsibilities heavily affect multiple aspects of their lives.

Table no. 4: Global Adjustment Assessment among Caregivers

Variables	Category	Frequency	Percentage
Emotional adjustment	Excellent	00	00
	Good	3	2.0
	Average	22	14.5
	Poor	118	77.6
	Unsatisfactory	9	5.9
Financial adjustment	Excellent	00	00
	Good	10	6.6
	Average	17	11.2
	Poor	106	69.7
	Unsatisfactory	19	12.5
Health adjustment	Excellent	00	00
	Good	5	3.3
	Average	18	11.8

	Poor	97	63.8
	Unsatisfactory	32	21.1
Occupational adjustment	Excellent	00	00
	Good	18	11.8
	Average	40	26.3
	Poor	91	59.9
	Unsatisfactory	3	2.0
Sexual adjustment	Excellent	00	00
	Good	8	5.3
	Average	28	18.4
	Poor	97	63.8
	Unsatisfactory	19	12.5
Social adjustment	Excellent	00	00
	Good	14	9.2
	Average	103	67.8
	Poor	35	23.0
	Unsatisfactory	00	000

Table no 4 shows that High levels of stress and psychological stress were reflected in the majority of caregivers' poor emotional adjustment (77.6%). The majority (69.7%) also had poor financial adjustment, indicating financial strain from caregiving. 63.8% of individuals rated their health adjustment as poor, indicating a detrimental effect on their physical well-being. Similarly, 59.9% of caregivers had poor occupational adjustment, suggesting difficulties juggling their jobs as caregivers and workers. Another area of difficulty was sexual adjustment, as reported by 63.8% of respondents. Conversely, social adjustment was comparatively better, with 23% still expressing poor adjustment, while the majority (67.8%) indicated average adjustment.

Table no 5: Correlation between Family Burden and Global adjustment among caregivers

Variables	Financial Burden	Routine Family Burden	Disruption of Family Leisure	Disruption of family interaction	Physical health	Mental Health Burden	Total burden
Emotional adjustment	.220**	.264**	.177*	.110	.001	.160*	.227**
Financial adjustment	.269**	.248**	.260**	.324**	.102	.322**	.364**
Health adjustment	.269**	.248**	.260**	.324**	.102	.322**	.364**
Occupational adjustment	.263**	.237**	.381**	.271**	-.057	.316**	.343**
Sexual adjustment	.269**	.248**	.260**	.324**	.102	.322**	.364**
Social adjustment	.215**	.141	.262**	.312**	-.004	.360**	.308**
Total adjustment	.339**	.313**	.359**	.372**	.055	.403**	.442**
**. Correlation is significant at the 0.01 level (2-tailed).							
*. Correlation is significant at the 0.05 level (2-tailed).							

Table no 5 shows that better adjustment is linked to less overall burden, according to the study's findings, which showed a strong correlation between total adjustment and both total burden and mental health burden ($p < 0.01$). Disruptions in regular family activities family leisure (and family interaction ($p < 0.01$) were strongly associated with changes in finances, health, and sexuality. Disruption of family relationship and overall burden ($p < 0.01$) were significantly correlated with occupational adjustment. Emotional adjustment was marginally connected to disruption of family leisure and overall burden ($p < 0.05$), but social adjustment was significantly linked to mental health burden and total burden ($p < 0.01$). These results demonstrate that increased caregiver stress, especially in relation to family relationships and mental health, is substantially correlated with poor caregiver adjustment in a number of domains.

Discussion:

The socio-demographic characteristics of caregivers and patients in this study align with findings from other studies on caregiver profiles. The majority of caregivers were male (60.5%) and had a graduate level education (34.2%). Similar studies have found that caregiver gender and educational background influence caregiving dynamics and challenges (Gaugler et al., 2015). The nuclear family structure (77.6%) seen in the study is consistent with previous research, where caregivers from nuclear families report higher caregiving burden compared to those from extended families (Pinquart and Sorensen, 2003). Furthermore, the Marathi-speaking majority and urban-dwelling caregivers (55.3%) reflect the demographic characteristics of the population in the study area, which may impact the availability and type of support systems for caregivers (Cohen and Zimmerman, 2020).

The study found significant caregiver burden across multiple dimensions. A high percentage of caregivers reported disruption of routine family activities (53.9%) and family leisure (65.1%), consistent with other studies that show caregiving leads to disruptions in daily routines and reduced social and leisure engagement. The impact on physical health (84.2%) and mental health (83.6%) also mirrors findings in the literature, where caregiving is associated with chronic stress, depression, and physical ailments (Kramer, 21997; Tamiya et al., 2019; Lacey et al, 2019). The negative effects on caregivers' well-being highlight the urgent need for interventions to alleviate the burden (Schulz et al., 2016).

The study found that emotional adjustment was the most problematic domain, with 77.6% of caregivers reporting poor emotional adjustment, which aligns with findings from other studies that have shown high levels of emotional strain among caregivers, (Zarit et al., 2014) Also, financial adjustment was poor for 69.7% of caregivers, one study reflecting similar research finding which found that financial strain significantly impacts caregiver well-being, often due to the costs associated with caregiving and loss of income (Barun et al, 2020). Similarly, health adjustment (63.8%) and occupational adjustment (59.9%) were reported as poor, reflecting the overwhelming physical and mental demands that caregivers experience (Pinquart and Sorensen, 2003; Cummings and Kropf, 2019). Sexual adjustment, reported as poor by 63.8% of caregivers, was an area less frequently explored in caregiving research but is gaining attention as a significant aspect of caregiver well-being. This finding suggests that caregiving may affect intimacy and relationships, a factor that could be addressed in future caregiving interventions.

The study found significant correlations between the different dimensions of caregiver adjustment and caregiver burden. For example, total adjustment showed a strong correlation with total burden ($p < 0.01$), which is consistent with the work found that better overall caregiver adjustment is linked to lower levels of perceived burden (Schulz et al., 2016). The correlation between financial, health, and sexual adjustments with family disruptions ($r = 0.248$ to 0.324 , $p < 0.01$) highlights the interconnectedness of

various aspects of caregiver well-being and family dynamics (Barun et al., 2020; Sorensen et al., 2002). Occupational adjustment was significantly correlated with disruption in family interaction ($r = 0.381$, $p < 0.01$) and total burden ($r = 0.343$, $p < 0.01$), reinforcing findings from other studies that show the strain of balancing work and caregiving responsibilities contributes to caregiver burden (Pinquart and Sorensen, 2003; Cummings and Kropf, 2019).

Social adjustment, although better than other areas, was correlated with mental health burden ($r = 0.360$, $p < 0.01$) and total burden ($r = 0.308$, $p < 0.01$), reflecting the role of social support in mitigating caregiver strain (Tamiya et al., 2019). These results are consistent with existing research that emphasizes the importance of strong social networks in reducing caregiver stress (Fiorillo and Mento, 2020).

CONCLUSION

This study underscores the significant impact of caregiving on both caregiver adjustment and burden, with emotional, financial, health, and occupational domains being particularly challenging. The correlations between poor adjustment and high burden highlight the need for comprehensive and targeted interventions that address these areas to improve caregivers' well-being. Given the multifaceted nature of caregiving stress, a holistic approach that includes emotional support, financial aid, and social networks is essential for reducing caregiver burden and enhancing their quality of life.

Conflict of Interest: None

Financial Recourse: None

Ethical Clearance: Taken

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