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Original Research Article

CAREGIVER STIGMA AND HELP-SEEKING AMONG CAREGIVERS OF PERSONS WITH SCHIZOPHRENIA: INFLUENCE OF SOCIAL SUPPORT IN AN INDIAN TERTIARY CARE SETTING

Sachin Tudur Sadashiva[1], Janaki Raman Kalyanasundaram[2]

[1]Psychiatric Social Worker, Department of Psychiatric Social Work, National Institute of Mental Health and Neuro Sciences (NIMHANS), Bengaluru, Karnataka, India
[2]Associate Professor, Department of Psychiatric Social Work, National Institute of Mental Health and Neuro Sciences (NIMHANS), Bengaluru, Karnataka, India

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Corresponding Author:
Dr. Janaki Raman Kalyanasundaram,
Associate Professor, Department of Psychiatric Social Work, National Institute of Mental Health and Neuro Sciences (NIMHANS), Bengaluru, Karnataka, India.
Email: janakitrichy@gmail.com

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ABSTRACT

Background: Schizophrenia is a chronic and severe mental disorder that profoundly affects an individual's thoughts, emotions, and behaviour, often leading to long-term disability and dependence. The illness places a significant emotional, social, and financial burden on family members who act as primary caregivers. The aim and objective is to assess caregiver stigma and help-seeking behaviour in schizophrenia and examine the influence of social support in an Indian tertiary care setting, and to evaluate caregiver stigma, help-seeking behaviour, and perceived social support, along with their interrelationship among caregivers of patients with schizophrenia.

Materials and Methods: The present study was an observational study conducted on 60 participants between July 2023 and February 2024 at the National Institute of Mental Health and Neuro Sciences (NIMHANS), Bengaluru, Karnataka, India.

Results: Stigma negatively correlated with help-seeking for emotional problems ($\rho = -0.401$, $p = 0.002$). Affective stigma ($\rho = -0.329$, $p = 0.010$) and behavioral stigma ($\rho = -0.311$, $p = 0.015$) were significant predictors of reduced help-seeking, while cognitive stigma was nonsignificant ($\rho = -0.227$, $p = 0.080$).

Conclusion: This paper shows that social support is critical in reducing stigma among caregivers of persons living with schizophrenia. Although affective and cognitive stigma have evidently a strong negative linkage with support, behavioral stigma has no linkage, which is why multi-level interventions are necessary.

Keywords: Caregiver stigma, schizophrenia, help-seeking behaviour, social support, caregivers, mental illness, psychiatric disorders.

INTRODUCTION

Schizophrenia is a chronic and severe mental disorder that profoundly affects an individual's thoughts, emotions, and behaviour, often leading to long-term disability and dependence.[1] The illness places a significant emotional, social, and financial burden on family members who act as primary caregivers.[2] In India, families are the cornerstone of care, often assuming lifelong responsibility for patients' well-being, which can cause stress and social isolation.[3]

Schizophrenia is a long-term mental condition, which has far reaching psychosocial implications to the patient and the caregivers. It is estimated to afflict about 20 million individuals worldwide, with lifetime prevalence rates of approximately 0.3-0.7%.[1] From an early age, social interaction, work, and education are all frequently disrupted by the illness. Because family members are the only resources available to provide psychiatric care, caregivers in the Indian context bear a great strain that may have a number of negative impacts.

Stigma as it pertains to caregivers has been demonstrated to have three dimensions that include affective (emotional reactions to caregiving such as shame), cognitive (beliefs and stereotypes) and behavioral (withdrawal or avoidance).[4] The three dimensions of caregiver stigma are known to impact the well-being of caregivers, but also the adherence to treatment and patient recovery.

The concept of social support is long-standing and solid in its ability to improve resilience and decrease the adverse impacts of stigma.[5,6] A high-quality support may provide caregivers with emotional support, practical help, and motivation to not leave social activities. The data on the Asian context and India, in particular, shows that extended family and community systems affect the experience of caregiving.[7,8] The networks, however, can be undermined when the stigma does not allow the caregivers to seek assistance. The Indian research done earlier highlights the dual nature of family networks as a source of empowerment and, in some cases, as a source of stigma.[9]

Despite an increasing amount of research on stigma with schizophrenic patients, not many studies have examined how it has affected the caregivers particularly in India. Furthermore, the connection between the perceived stigma and social support among the caregivers has not been adequately addressed. This paper thus set out to discuss the association between social support and stigma in the groups of caregivers to individuals with schizophrenia.

Caregivers frequently experience stigma, both directed towards themselves and associated with the person living with mental illness[4]. Stigma manifests through affective (shame or embarrassment), cognitive (beliefs about social rejection), and behavioural (avoidance or concealment) components, which collectively erode caregivers' confidence and willingness to seek help.[5] Research has consistently demonstrated that stigma is a major barrier to mental health help-seeking worldwide.[6]

In India, caregiving is further shaped by sociocultural factors such as poverty, faith-based beliefs, and community attitudes toward mental illness.[7,8] These influences often delay help-seeking and increase caregiver distress. Social support has been shown to act as a protective factor that buffers the negative effects of stigma and enhances psychological resilience.[9,10] Despite growing literature on caregiver burden, few quantitative studies have explored the specific relationship between stigma, help-seeking, and social support among Indian caregivers.

This study therefore aimed to examine the relationship between perceived stigma and help-seeking behaviour among caregivers of persons with schizophrenia and to explore relevant sociodemographic correlates in a tertiary mental health setting in South India.

MATERIALS AND METHODS

The present study employed a cross-sectional research design using purposive sampling. The study included 60 caregivers of persons with schizophrenia attending a tertiary mental health hospital in Bengaluru, Karnataka, India. Instruments Caregiver Perceived Stigma Scale (CPMI), Social Support Questionnaire (SSQ6). The SPSS v27 was used to analyse the data, Spearman rho and Mann Whitney U test were employed. caregivers of inpatients with schizophrenia at a tertiary mental health hospital in Bengaluru. Caregivers were considered to be relatives who were closely involved in patient care over a period of six months. Inclusion criteria included: age 18 years and above, primary caregiver of not less than six months and gave consent. Data were collected between July 2023 and February 2024. Participants included primary caregivers of persons diagnosed with schizophrenia who were aged above 18 years and had been living with and caring for the patient for a minimum period of six months. Caregivers who could communicate in English, Kannada and Hindi were included in the study. Caregivers with a history of psychiatric illness or intellectual and developmental disability were excluded from the study.

Aim and Objectives

To assess stigma among caregivers of persons with schizophrenia.

To assess perceived social support among caregivers.

To examine the relationship between stigma, social support, and help-seeking behaviour**.**

Instruments: Caregiver Perceived Stigma Scale (CPMI): rated the stigma in the domains of affective, cognitive, and behavioral.[16]

Social Support Questionnaire (SSQ6): Perceived social support, which is the availability and satisfaction.[17]

General Help-Seeking Questionnaire (GHSQ): Evaluates likelihood of seeking help from various sources for emotional problems or suicidal ideation.[13]

Statistical analysis: Data normality was assessed using the Shapiro–Wilk test. As the data were not normally distributed, non-parametric tests were employed. Spearman's rho correlation and Mann–Whitney U tests were used for analysis. Descriptive statistics including medians and interquartile ranges were calculated for study variables. Statistical significance was set at $p < 0.05$. Data were analysed using SPSS version 27

Ethical Considerations: The study was approved by the PSW Department Ethics Sub-Committee and Institute Ethics Committee (IEC), NIMHANS, Bengaluru (Ref No: NIMH/DO/IEC (BEH.sc. DIV)/2023; dated 11.08.2023). Written informed consent was obtained from all participants prior to recruitment. Confidentiality and anonymity of participants were strictly maintained throughout the study.

RESULTS

The [Table 1] depicted the socio-demographic details of the caregivers. More than 51.7% of the respondents were male, while 48.3% were female. The educational status of the respondents leaned toward higher education, with 36.7% having completed graduation and 28.3% having completed higher secondary education. A majority (78.3%) were employed in various capacities beyond self-employment for example, as auto drivers, vegetable sellers, or small shop owners. There was also diversity in marital status, with a high number of unmarried participants (43.3%). In terms of socio-economic status, 66.7% of the respondents fell into the lower socio-economic bracket.

Table 1: Sociodemographic profile of caregivers

Variables	Categories	Frequency (n=60)	Percentage (%)
Gender	Male	31	51.7
	Female	29	48.3
Education	Primary Schooling	9	15
	High School	7	11.7
	SSLC	4	6.7
	Higher Secondary Education	17	28.3
	Graduation	22	36.7
	Post Graduation	1	1.7
Employment	Self Employed	13	21.7
	Any other	47	78.3
Marital Status	Single	8	13.3
	Married	19	31.7
	Unmarried	26	43.3
	Separated	4	6.7
	Widowed	3	5.0
Socio Economic Status	LSES	40	66.7
	MSES	18	30.0
	USES	2	3.3

Table 2: Distribution of respondents on Social Support

Variables (frequency n=60)	Median	(Q1, Q3)
Social Support (SSQ)	25.50	(22.00,30.00)

[Table 2] revealed that the median score of the respondents were 25.50, with a range from 22 to 30, indicating a moderate level of perceived social support among caregivers.

Table 3: Correlation of social support with stigma among caregivers

Variable	Categories	Spearman's rho	(P- Value)
Social support vs. Stigma	Affective	-0.343	(0.007*)
	Cognitive	-0.296	(0.022*)
	Behaviour	-.0.106	(0.421)
	Total	-0.300	(0.020*)

Social support showed significant negative associations with affective stigma ($\rho = -0.343$, $p = 0.007$), cognitive stigma ($\rho = -0.296$, $p = 0.022$), and total stigma ($\rho = -0.300$, $p = 0.020$). No significant correlation was observed with behavioral stigma ($\rho = -0.106$, $p = 0.421$).

The above [Table 3] showed that the affective response had a statistically significant negative correlation (Spearman's rho = -0.343, p = 0.007) with social support, indicating that higher affective responses to stigma were associated with lower perceived social support.

Cognitive response had a significant negative correlation (Spearman's rho = -0.296, p = 0.022), suggesting that more stigma cognitions corresponded to less social support. Behavioral response showed no significant correlation (Spearman's rho = -0.106, p = 0.421), indicating that behavioral responses to stigma did not significantly relate to the level of social support received. When considering perceived stigma as a whole, there was a significant negative correlation (Spearman's rho = -0.300, p = 0.020) with social support across all stigma dimensions. The findings showed that higher affective and cognitive stigma were significantly associated with lower perceived social support among caregivers. However, behavioural stigma did not show a significant relationship with social support. Overall perceived stigma demonstrated a significant negative correlation with social support

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Table 4: Distribution of respondents on General Help-Seeking Questionnaire (n = 60)

Variables (frequency n=60)	Median	(Q1, Q3)
General Help-seeking Behavior Scale (Personal Emotions)	32.00	(29,37.75)
General Help-Seeking Behaviour Questionnaire (Suicidal ideation)	18	(18.00, 18.00)

Help-Seeking: For personal emotional problems, the median GHSQ score was 32.00 (IQR 29–37.75), indicating moderate help-seeking. For suicidal ideation, responses were uniform (median 18, IQR 18–18).

Table 5: Correlation between stigma and help-seeking (n = 60)

Variable	Categories	Spearman's rho	(P- Value)
General Help-seeking Behaviour Questionnaire (Personal Emotional)	Affective	-.329	(0.010*)
	Cognitive	-.0.227	(0.080)
	Behaviour	-.311	(0.015)
	Total	-.401	(0.002)

Correlations: Stigma negatively correlated with help-seeking for emotional problems (ρ = –0.401, p = 0.002). Affective stigma (ρ = –0.329, p = 0.010) and behavioral stigma (ρ = –0.311, p = 0.015) were significant predictors of reduced help-seeking, while cognitive stigma was nonsignificant (ρ = –0.227, p = 0.080).

The findings indicated that higher stigma was associated with lower help-seeking behaviour among caregivers. Significant negative correlations were observed in affective and behavioural stigma domains, whereas cognitive stigma did not show a statistically significant association.

Experiences of Stigma

Table 6 item in perceived stigma scale

Item in perceived Stigma Scale	Categories	Frequency (n=60)	Percentage (%)
2a. Have you ever seen a mental health professional (e.g., school counsellor, counsellor, psychologist, psychiatrist) to get help for personal problems?	Yes	3	5%
	NO	57	95.0 %
2b. How many visits did you have with the mental health professional?	1-5 session	1	33.3%
	5-10 session	1	33.3%
	More than 10 session	1	33.3%
2c. Do you know what type of mental health professional(s) you've seen	Counsellor	1	33.3%
	Psychologist	1	33.3%
	Psychiatrist	1	33.3%
	Other Mental Health Professionals	0	0%
2d. How helpful was the visit to the mental health professional?	Slightly Unhelpful	1	33.3%
	Significantly Helpful	1	33.3%
	Extremely Helpful	1	33.3%

In the above table, 6 –2a depicts majority of the participants of which 57 have not sought help from a mental health professional which is 95% and 3 have said yes which is only 5 %.

In the above table 6 -2b depicts, the distribution of session visits is evenly split across different ranges—1-5 sessions which is 1 (33.3%), 5-10 sessions is 1 (33.3%), and more than 10 sessions 1 (33.3%) each accounting for one-third of the visits.

In the above table 6 - 2c shows the type of mental health professionals had shown an equal distribution among those who have seen a counsellor 1 (33.3%), psychologist 1 (33.3%), and psychiatrist 1 (33.3%), indicating a diverse utilization of available mental health resources. No participants reported seeing other types of mental health professionals.

In the above table 6 - 2d shows the effectiveness of the visit here the effectiveness ratings varied, with one-third finding the visits slightly unhelpful 1 (33.3), one-third finding them significantly helpful 1 (33.3), and another third finding them extremely helpful 1(33.3%).

Only a small proportion of caregivers had sought professional mental health support. Among those who sought help, experiences regarding usefulness of services varied from slightly unhelpful to extremely helpful

DISCUSSION

The results suggest that increased affective and cognitive stigma among caregivers are associated with lower perceived social support. This can be compared with previous research findings regarding the use of supportive networks that lower the burden of care and distress due to stigma. In India, caregiving is based on family and community networks, although stigma tends to tarnish them.[6,7] Previous research also shows that affiliate stigma is associated with isolation of caregivers, poor coping and worse psychological health.[11,12] Community-based programs, psychoeducational programs, and peer networks could thus help address the effects of stigma in India. The absence of the relationship between behavioral stigma and social support in this research indicates that the external discriminatory behaviors might not be affected by perceived support of caregivers compared to internalized stigma areas. This result can be compared to the literature, which states that structural discrimination and community

prejudice are less susceptible to four personal or family-based support interventions.[13]

The findings of the present study are consistent with previous Indian studies which reported significant stigma and discrimination among caregivers of persons living with schizophrenia.[16,18] Caregivers frequently experience shame, social isolation, and difficulties in seeking support due to stigma associated with mental illness.[17,18] Similar findings were also observed by Loganathan et al., who highlighted experiences of embarrassment, concealment, and social discrimination among families of persons with schizophrenia within Indian sociocultural settings.[19] These findings further emphasize the importance of strengthening social support systems and implementing stigma reduction interventions for caregivers.

This study highlights that higher perceived stigma, particularly its affective and behavioural components, is associated with reduced help-seeking among caregivers of persons with schizophrenia. These findings are consistent with international research demonstrating that stigma diminishes willingness to seek mental health care.[6] The distinction between affective and cognitive components suggests that emotional and experiential aspects of stigma exert greater influence than mere beliefs.[14]

The strong positive correlation between social support and help-seeking underscores the protective role of supportive networks in mitigating the psychological burden of caregiving.[15] Similar findings have been reported in Indian and global studies linking family support with increased treatment engagement and reduced distress.[9,16]

Sociodemographic variations indicated that unmarried and lower-SES caregivers experienced higher stigma and reduced help-seeking, echoing earlier evidence that social disadvantage and isolation amplify caregiving stress.[8,17]

These findings emphasise the need for multifaceted interventions that combine stigma-reduction efforts, psychoeducation, and community-based support.[18] Integrating caregiver-focused psychosocial interventions within routine mental health services can improve both caregiver and patient outcomes.

The findings of the present study have important clinical implications for mental health professionals working with caregivers of persons living with schizophrenia. Strengthening caregiver psychoeducation, stigma reduction programmes, and family-based support interventions may help reduce caregiver burden and improve help-seeking behaviour. Regular caregiver counselling and community mental health services can further enhance coping, social support, and overall psychological well-being among caregivers. These interventions may contribute toward improving both caregiver outcomes and continuity of care for persons living with schizophrenia.

Strengths and Limitations: This research used tested measures and answered a question that had not been well studied in the Indian context. Strengths include use of validated measures and focus on an understudied caregiver population in India. Limitations include the cross-sectional design, which prevents causal inference, single-centre recruitment, and modest sample size (n = 60), which may limit generalisability. Potential response biases and limited variability in suicidal ideation (GHSQ) should also be noted.

Future Directions

Future longitudinal and multicentric studies are needed to better understand caregiver stigma and help-seeking behaviour across diverse cultural settings.

Implications: The findings highlight the need to come up with multi-level interventions. The strategies that can be integrated to increase the well-being of caregivers, which in turn leads to patient outcomes, are a reduction of stigma and the supporting system of caregivers. The programs should be cultural favoring both individual caregivers and the social context.[14,15]

CONCLUSION

This study emphasizes how important social support is in lowering stigma among those who care for people with schizophrenia. Behavioral stigma did not significantly correlate with reduced perceived social support, while higher affective and cognitive stigma did. Reduced help-seeking for emotional difficulties among caregivers was substantially correlated with perceived stigma, especially affective and behavioral stigma. In order to increase caregiver well-being, encourage help-seeking behavior, and advance recovery-oriented mental health care, these findings highlight the necessity of strengthenin social support networks and putting specific stigma-reduction interventions into place. Community-based mental health treatments, family-focused therapies, and caregiver psychoeducation may help caregivers manage the psychosocial burden of schizophrenia.

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