Caregiver Stigma and Quality of Life in Patients with Schizophrenia: An Exploratory Study

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ABSTRACT

Background: Schizophrenia is a chronic disease that impacts different aspects of patients' and their caregiver's lives. So, there's a need to assess how different aspects of illness such as stigma can affect the quality of life of patients diagnosed with schizophrenia.

Aim: To find out the impact of stigma faced by caregivers on the quality of life of patients diagnosed with schizophrenia.

Methodology: A cross-sectional study design and purposive sampling technique were used. A total of 160 patients and their caregivers who were diagnosed with schizophrenia taking regular treatment and were stable from a minimum last six months attending the outpatient department of the Department of Psychiatry, PGIMS, Rohtak. The level of stigma faced by caregivers and the quality of life of patients was assessed using the Jaipur stigma questionnaire and WHO-QoL BREF scale respectively.

Results: The findings of this study showed that the domains of stigma such as false belief, coercive treatment, shame, and marriage have a significant relationship with the quality of life of patients with schizophrenia.

Conclusion: Despite the continuous awareness, there's still a gap that persists in the field of mass awareness regarding mental illness. This can be done with the help of various policymakers and stakeholders.

Keywords: Schizophrenia, Quality of Life, Stigma, Caregiver.

INTRODUCTION

Schizophrenia is a widespread issue both globally and in India. The global prevalence of schizophrenia is 0.32% (Ebrahim et al., 2020). In India, findings from the National Mental Health Survey of India 2015-2016 indicate that common mental disorders affect approximately 5.1% of the population, with a lifetime prevalence of schizophrenia estimated at 1.41% (Hegde et al., 2023).

In countries like India, access to rehabilitation services for individuals with mental illnesses is scarce. Consequently, the primary source of caregiving typically comes from informal support provided by family members. Family members frequently play a pivotal role in decision-making regarding treatment-seeking and various related matters such as accompanying the patient during hospitalization, monitoring medication intake, assisting with daily activities, addressing basic needs, and determining the continuation or cessation of treatment (Grover et al., 2017). Certainly, it's commonly observed that factors like stigma, which caregivers may perceive, could potentially influence the aforementioned areas. The pervasive discrimination and stigma associated with mental illnesses are quite prevalent (Ebrahim et al., 2020). Stigma is defined as prejudice, avoidance, rejection, and discrimination directed at people believed to have an illness, disorder, or other trait perceived to be undesirable (Southgate, 1993). Stigma affects self-esteem for both patients and caregivers, which can strain their relationship. Several studies conducted in India indicate that family members of individuals with severe mental disorders encounter significant stigma and experience a reduced quality of life due to their association with a person with a mental disorder (Thara & Srinivasan, 2000), (Singh et al., 2016), (Raguram et al., 2004). Given these factors, the quality of life of individuals with schizophrenia can be significantly impacted. Unfortunately, there is a scarcity of studies from India that have examined the influence of caregiver stigma on the quality of life of patients with schizophrenia. Against this backdrop, the study aimed to investigate the stigma experienced by caregivers and its effects on the quality of life of individuals with schizophrenia.

METHODOLOGY

The cross-sectional study was conducted at the Outpatient Department of Psychiatry, Pt. B.D. Sharma University of Health Sciences, Rohtak, from February 2023 to June 2023. All patients and their respective caregivers were recruited after obtaining written informed consent. The study was approved from Institutional Ethics Committee.

The samples were selected through purposive sampling and consisted of 160 caregivers and patients diagnosed with schizophrenia according to the International Classification of Disease-10 (ICD-10) by the treating psychiatrist, in remission aged between 18-50 years of any gender, and able to read, write, and understand Hindi language. Exclusion criteria included individuals with organic brain syndrome, mental retardation, co-morbid psychiatric and physical illnesses, and co-morbid drug dependence. Caregivers, aged between 18-60 years, of any gender, who could read, write, and understand Hindi, were included. Caregivers with acute physical or mental illnesses, or substance use, were excluded from the study.

Patients and their caregivers were evaluated using the following instruments:

A specially designed proforma was used for the evaluation of patients. It included the following:

- Socio-demographic data sheet.
- Clinical profile sheet.

Jaipur Stigma Questionnaire

The Jaipur Stigma Questionnaire, utilized in this study, was designed to gauge stigma related to mental illness. This tool is in the Hindi language and comprises 14 statements covering various aspects of stigma. Each statement offers four options for respondents to choose from (Gautam et al., 2011).

WHO-Quality of Life BREF Questionnair

The structured self-report interview utilized in this study was developed by the WHO Division of Mental Health. It comprises 26 items and is intended to evaluate the Quality of Life (QOL) of individuals. The assessment encompasses four domains: physical, psychological, social, and environmental. Its psychometric properties are deemed comparable to those of the full version of WHO QOL-100. (Saxena, S., Chandramani, K., & Bhargava, 1998).

Statistical analysis was carried out using the IBM Statistical Package for the Social Sciences (SPSS) trial version 29 (IBM Corp, 2023).

RESULTS

Sociodemographic profile of patients

Most of the patients belong to the age group of 26 to 35 years (42.5%). Males (77.5%) outnumbered females (22.5%) in the study sample. The majority of the participants were unmarried (55%), Hindu (97.5%) by religion, belonging to nuclear families (67.5%), rural locality (60%), unemployed (65%), and their family income ranging between 9-15 thousand (35%) monthly. Most of the patients (30%) were educated till the secondary level. (Table 1)

Clinical profile of the patient

The age of onset of the illness in the majority of the participants (59.4%) was 15 to 25 years with the total duration of illness of 6 to 10 years (30%), on treatment for the last 2 to 4 years (60%). (Table 1)

Quality of Life of Patients with schizophrenia

The mean score of physical quality of life of patients with schizophrenia was 11.35 (1.37). In the psychological domain, the score was 9.32 (1.51), and the mean scores for social relationship and environmental domain were 8.05(2.1) and 12.42(1.72) respectively. (Table 2).

Socio-demographic profile of caregivers

The majority of the caregivers belonged to the age group of 26 to 35 and 56 to 65 years (30%), 57.5% were males, belonged to the Hindu religion (97.5%), and were married (90%). The maximum number of caregivers were educated till secondary class (32.5%), and most of them were homemakers by occupation (32.5%). (Table 3)

Stigma faced by caregivers of patients with schizophrenia

Table 4 shows the stigma among patients with schizophrenia. The majority of the participants faced social distance/segregation in the form of prejudice (42.5%), followed by stereotypy (32.5%). Rejection in employment was a bit high in the form of stereotypy (57.5%), 27.5% in the form of prejudice, and 5% of patients faced discrimination in this area. 25% consider heredity as stereotypy, 22.5% consider it as prejudice and 17.5% face it in the form of

Table 1: Socio-demographic profile of patients with schizophrenia

Socio-demographic parameters		N=160	%
Age Group	18 to 25 years	20	12.5
	26 to 35	68	42.5
	36 to 45	32	20.0
	46 to 50	40	25.0
Gender	Male	124	77.5
	Female	36	22.5
Religion	Hindu	156	97.5
	Muslim	4	2.5
Marital Status	Unmarried	88	55.0
	Married	64	40.0
	Separated	8	5.0
Educational Qualification	Primary	32	20.0
	Middle	20	12.5
	Secondary	48	30.0
	Senior Secondary	28	17.5
	Diploma	16	10.0
	Graduate	16	10.0
Occupation	Unemployed	104	65.0
	Homemaker	24	15.0
	Farmer	4	2.5
	Labourer	8	5.0
	Self-employed	20	12.5
Current living arrangement	Joint family	52	32.5
	Nuclear family	108	67.5
Age of onset	15 to 25 years	95	59.4
	26 to 35	37	23.1
	36 to 45	23	14.4
	46 to 50	5	3.1
Total duration of illness	<5 years	44	27.5
	6-10 years	48	30.0
	11-15 years	40	25.0
	16-20 years	20	12.5
	More than 20 years	8	5.0
The total duration of treatment	6 months- 1 year	32	20.0
	2-4 years	60	37.5
	5-8 years	40	25.0
	9-15 years	24	15.0
	>16 years	4	2.5
Family Income (Monthly)	1-5 thousand	4	2.5
	6-8 thousand	28	17.5
	9-15 thousand	56	35.0
	16-20 thousand	32	20.0
	Above 20 thousand	40	25.0
Locality	Rural	96	60.0
	Urban	60	37.5
	Semi-urban	4	2.5

discrimination. Presentation of mental illness in media was considered prejudiced by 90% of participants, 5% stereotypy, and 2.5% of participants considered it as discrimination, 55% were facing stereotypy and 27.5% were facing prejudice regarding the responsibility of illness. In chronicity of illness (shame for care) 47.5% considered it as prejudice, 30% as stereotypy, and 10% faced discrimination. Regarding violence, 50% stereotypy and 2.5% prejudice were reported by participants, 25% of the participants reported stereotypy, and prejudice equally, and 2.5% faced discrimination in the area of false belief. Marriage was another area where 70% of the participants reported prejudice, 22.5% stereotypy, and 7.5% reported possible discrimination. In coercive treatment 50% of the participants faced prejudice, 10% stereotypy and 37.5% faced discrimination. 87.5% of the participants reported stereotypy, 10% prejudice, and 2.5% faced discrimination in the area of shame for consultation. Concerning discrimination and labeling 12.5% of participants did not face any difficulty, 57.5% faced stereotypy, 17.5% prejudice and 12.5% reported discrimination in either form. 92.5% of the participants reported guilt. In the area of shame, 57.5% of the participants reported prejudice, 17.5% prejudice and 7.5% of the participants faced possible discrimination.

Relationship between Stigma faced by caregivers and quality of life of patients with schizophrenia

Table 5 reveals that the social distance domain of Stigma was significantly negatively correlated with psychological, physical, and environmental QoL, and Heredity was negatively associated with psychological and social QoL. There was a significant negative correlation found between Marriage, coercive treatment, and physical and psychological QoL. Shame for consultation domain was positively correlated with the psychological domain of QoL. The shame domain of stigma was significantly negatively correlated with the physical, psychological, and social domains of QoL.

Relationship between Stigma faced by caregivers and their socio-demographic profile

Table 6 shows a significant positive and negative relationship between social distance of domain of stigma and religion and educational qualification. Presentation in Media had a significantly negative correlation with living arrangements and gender. It was positively correlated with educational qualification. The guilt and shame domain of stigma was negatively correlated with marital status as participants reported that due to the patient's condition, they felt shame and avoided treatment consultation.

Table 2: Quality of life of patients with schizophrenia.

QOL Domains	Mean (SD)
Physical	11.35 (1.37)
Psychological	9.32 (1.51)
Social relationship	8.05 (2.1)
Environment	12.42 (1.72)
Overall Quality of life	2.70 (.56)
Overall Health	2.65 (.57)

Table 3: Socio-demographic profile of caregivers of patients with schizophrenia

Socio-demographic Parameters		N=160	%
Age	18 to 25 years	4	2.5
	26 to 35	48	30.0
	36 to 45	20	12.5
	46 to 55	40	25.0
	56 to 65	48	30.0
Gender	Male	92	57.5
	Female	68	42.5
Religion	Hindu	156	97.5
	Muslim	4	2.5
Marital status	Unmarried	12	7.5
	Married	144	90.0
	Separated	4	2.5
Educational Qualification	Primary	20	12.5
	Middle	52	32.5
	Secondary	52	32.5
	Senior Secondary	20	12.5
	Diploma	4	2.5
	Graduate	8	5.0
	Postgraduate	4	2.5
Occupation	Unemployed	4	2.5
	Teacher	8	5.0
	Homemaker	52	32.5
	Farmer	28	17.5
	Labourer	20	12.5
	Student	4	2.5
	Self-employed	36	22.5
	Government Job	8	5.0
Relation with Patient	Father	40	25.0
	Mother	44	27.5
	Husband	16	10.0
	Wife	24	15.0
	Son	16	10.0
	Brother	20	12.5

Table 4: Stigma experienced by caregivers of patients with schizophreniaVariables

	No impact N (%)	Stereotypy N (%)	Prejudice N (%)	Possible Discrimination N (%)
Social distance/ Segregation	40 (25.0%)	52 (32.5%)	68 (42.5%)	0
Rejection/Employment	16 (10.0%)	92 (57.5%)	44 (27.5%)	8 (5.0%)
Heredity	56 (35.0%)	40 (25.0%)	36 (22.5%)	28 (17.5%)
Presentation in Media	4 (2.5%)	8 (5.0%)	144 (90.0 %)	4 (2.5%)
Responsibility for illness	28 (17.5%)	88 (55.0)	44 (27.5%)	0
Chronicity of illness	20 (12.5%)	48 (30.0%)	76 (47.5%)	16 (10.0%)
Violence	76 (47.5%)	80 (50.0%)	4 (2.5%)	0
False belief	72 (45.0%)	40 (25.0%)	40 (25.0%)	8 (5.0%)
Marriage	0	36 (22.5%)	112 (70.0%)	12 (7.5%)
Coercive treatment	4 (2.5%)	16 (10.0%)	80 (50.0%)	60 (37.5%)
Shame for consultation	0	140 (87.5%)	16 (10.0%)	4 (2.5%)
Discrimination/Labeling	20 (12.5%)	140 (87.5%)	0	0
Guilt	12 (7.5%)	40 (25.0%)	100 (62.5%)	8 (5.0%)
Shame	112 (70%)	20 (12.5%)	28 (17.5%)	0

Table 5: Relationship between Stigma faced by caregivers and quality of life of patients with schizophrenia

	Physical QoL	Psych.	Social	Env.	Overall Qol	Overall Health
Social Distance	-.264*	-.295*	-.171*	-.490**	-.218**	-.248**
Rejection/Employment	.056	.127	-.180*	-.241*	-.299**	.114
Heredity	-.119	-.314**	-.234**	-.090	.069	-.152
Presentation in media	.137	-.001	-.025	-.203*	.011	.101
Responsibility for illness	-.234*	.118	.033	-.015	.217*	.092
Chronicity of illness	-.038	.037	-.059	.011	-.290*	-.225*
Violence	-.159*	-.309**	-.245**	-.036	-.033	-.024
False belief	-.384*	-.241*	-.330*	-.066	-.152	-.250*
Marriage	-.488**	-.569**	-.062	-.206*	-.068	-.423*
Coercive treatment	-.336**	-.480**	-.007	-.178	-.329**	-.413**
Shame for consultation	-.092	.199*	-.037	-.123	-.021	-.093
Discrimination	.042	-.119	.009	.006	.204*	.165*
Guilt	-.190	-.011	-.058	-.170	-.143	-.120
Shame	-.326*	-.240*	-.373**	-.152	.157*	.037

Table 6: Relationship between Stigma faced by caregivers and their socio-demographic profile

	Age	Gender	Religion	Marital Status	Educational Qualification	Occupation	Living Arrangement	Locality
Social Distance	.012	-.124	.165*	-.057	-.272**	.136	.018	.001
Rejection/Employment	.014	.095	-.062	-.129	.094	.113	.152	.043
Heredity	348**	-.038	.112	.330**	.121	-.011	.141	.132
Presentation in media	.072	-.212**	.029	.000	.202*	.021	-.256**	.031
Responsibility for illness	-.209**	.023	.217**	-.275**	-.094	-.004	.024	.090
Chronicity of illness	-.166*	-.142	-.105	-.273**	.050	.142	-.054	.091
Violence	.181*	-.125	.132	.167*	.311**	-.174*	-.181*	-.030
False belief	.251**	-.177*	-.153	.242**	.046	.102	.209**	-.063
Marriage	.113	-.235**	.046	.347**	.073	.008	-.198*	-.127
Coercive treatment	-.096	-.058	-.050	.063	-.042	.075	-.006	-.243
Shame for consultation	.000	-.066	-.057	-.325**	-.048	.086	.120	-.060
Discrimination	.090	.019	.061	.000	.069	-.091	.222**	.157*
Guilt	-.114	-.296**	.081	-.264**	.024	.284**	-.042	-.003
Shame	.089	-.266**	-.098	-.236**	.256**	.009	.012	-.183*

DISCUSSION

The culmination of the results from this exploratory study highlights the complex relationship between caregiver stigma and the quality of life of patients with a diagnosis of schizophrenia. More specifically, the levels of stigma in the facet of caregivers tested for the correlation with multiple QoL aspects in patients depicted a significant correlation. Socio-demographic characteristics of both patients and caregivers should be acknowledged, as they may impact stigma perceptions and experiences and overall quality of life. Accordingly, patients in the current study were mainly in the age group of 26-35 years, male, unmarried, from rural backgrounds, and unemployed. The majority of caregivers were middle-aged, married, and most commonly homemakers (Bhutia et al., 2023) also have similar findings in their study. These demographic profiles offer a broader scope to evaluate how societal norms and cultural beliefs surrounding the stigma experienced by the caregivers correlate and, in turn, affect the patient's QoL. As detailed in the results above, stigma experienced by the caregivers covers multiple domains, including social distance/segregation, rejection in employment, heredity, presentation in media, shame, and violence, false belief, coercive treatment and guilt, and labeling. These domains depict the complex nature of stigma encircling mental illness and its impact on the individuals living with this condition and their caregivers similar findings were observed in a study conducted by (Manesh et al., 2023). Findings also indicated a negative direct association between multiple stigma factors, including marriage, coercive treatment, and shame for consultation, with the physical and psychological dimensions of the QoL. This result demonstrates how society's overall perceptions and predispositions can significantly affect the well-being of people with schizophrenia. Last but not least, the correlation between stigma and QoL demonstrates an existing link between social perceptions, self-esteem, and mental health outcomes. High stigma perceptions of caregivers might imply a hostile environment for the patient these findings coincide with the studies conducted by (G. et al., 2021), (Grover et al., 2012). Decreased self-esteem leads to reduced social activity and, eventually, more severe symptoms. An inverse correlation between domains of stigma and different QoL components confirms worsening symptoms and quality of life manifestation (Nigussie et al., 2023). The findings also shed light on the required targeted interventions aimed at reducing stigma in caregivers and improving the QoL of patients diagnosed with schizophrenia. These might include educational programs, community activities and events, and psychological support for caregivers and patients. To summarize, stigma can be reduced, and the well-being of those affected by schizophrenia can be improved by addressing misconceptions, promoting empathy, and creating a supportive environment. On the other hand, this study has several limitations to consider, including a cross-sectional design and self-report measures. Future studies may consider using longitudinal designs and more objective measures to deepen the knowledge of the caregiver stigma-patient QoL relationships. Furthermore, studying the effectiveness of stigma-reduction treatments in practice may provide useful information to guide evidence-based practice decisions on the support for people affected by schizophrenia and their caregivers.

CONCLUSION

In conclusion, this study contributes to the growing body of literature on caregiver stigma and its implications in the QoL of patients with schizophrenia. Identifying specific domains of stigma that impact patient outcomes, provides a foundation for targeted interventions to address stigma and improve overall well-being in this vulnerable population.

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Conflict of interest

None of the authors have any conflict of interest with the information presented in the manuscript.

Ethical Approval and Consent to Participate

Ethical clearance was taken from the Institutional Ethics Committee vide letter no. BREC/22/TH/Psychiatry-011. Written informed consent was obtained from the study participants themselves before the interview. For illiterates, the written consent was signed in the presence of a witness. Privacy and confidentiality of all data were assured by ensuring the anonymity of the questionnaire, interviewing the participants separately in a closed room, and keeping data files in a safe place.

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