Research Report

PERCEIVED SOCIAL SUPPORT AMONG PEOPLE WITH LIVED EXPERIENCE OF SERIOUS MENTAL ILLNESS IN REMISSION AND THEIR DISABILITY: A CROSS-SECTIONAL STUDY

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ABSTRACT

Background: Disability associated with mental illness is a major contributor to the global burden of disease. There are only limited studies assessing perceived social support and disability among patients who are in remission. This study helps us understand whether the perceived social support among people with lived experience (PWLE) is associated with disability. Aim: To determine the association between perceived social support and disability among people with lived experience of serious mental illness. **Material and Methods:** This cross-sectional analytic study was conducted over 6 months among 125 patients diagnosed with Schizophrenia spectrum disorders, Depressive disorders, and Bipolar and related disorders who are in complete or partial remission according to DSM-5 criteria. Socio-demographic data was collected using a semi-structured proforma. Multidimensional Scale of Perceived Social Support (MSPSS), and World Health Organization Disability Assessment Schedule 2.0. (WHODAS II) were used to study perceived social support and disability. An association between perceived social support and disability among people with lived experience of serious mental illness was done using the Chi-square test. **Results:** Among 125 patients, 13.6% perceived high social support, 48% perceived moderate social support, and 38.4% perceived low social support. The majority of the PWLE of serious mental illness in remission had no disability. **Conclusion:** This study shows that there is no significant association between disability and perceived social support. There may be other factors that determine disability among people with lived experience of serious mental illness.

Keywords: Perceived social support, People with lived experience, Serious Mental Illness, Disability.

INTRODUCTION

Serious mental illness (SMI) can be defined as a mental, emotional, or behavioral disorder (excluding developmental and substance use disorders) that results in marked functional impairment and substantially interferes with or limits one or more major life activities.[1] It mainly includes schizophrenia spectrum disorders, depressive disorders, and bipolar and related disorders.[2] It is a chronic or recurring illness that negatively affects an individual's life, family, and community.

People with lived experience of SMI are those who have personally faced the disabling effects of mental illness. This includes emotional isolation, financial burdens, job denial, marital problems, and poor psychological well-being, apart from social stigma. [3] Disability can be defined as any condition of the body or mind that interferes with the activities of the whole person concerning the immediate environment,

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resulting in activity limitation and restriction in participation. [4] The magnitude of disability caused by SMI is severe and reflected in every sphere of life of PWLE and is equally shared by caregivers, especially in a developing country like India. [5] According to a recent study on the Global Burden of Diseases (GBD), psychiatric illness accounts for 32.4% of years lived with disability (YLDs) and 13% of the disability-adjusted life-years (DALYs). The contribution of mental disorders to the total DALYs in India has doubled since 1990 and reached 4.7%. [6]

Social support is commonly divided into perceived and received support. In perceived support, the individual subjectively believes that their network will provide adequate help when needed, whereas in received support, the individual is actually provided with help when needed. [7] Of the two variables, perceived support is most frequently assessed and more consistently reduces stress and improves physical and mental health. [8,9]

Many measures have been taken in the last few decades to improve social support for people with a lived experience of SMI. However, there were only a few studies examining the impact of perceived social support on their disability.[10] Hence, this study aims to find out the association between perceived social support and disability among people with lived experience of serious mental illness

MATERIALS AND METHODS

This is a cross-sectional study conducted among patients diagnosed with schizophrenia spectrum and other psychotic disorders, bipolar and related disorders, and depressive disorders in complete or partial remission according to DSM-5[11] criteria by a treating psychiatrist attending psychiatry OPD of a tertiary care center from Kerala. The study was conducted over a period of 6 months, following clearance from the Institutional Ethics Committee. The sample size required for the study was calculated using GPower version 3.2.9.6, with inputs based on the survey conducted by Prabhakaran et al.[12] The minimum sample size needed for this study was 124.

After describing the nature of the study, written informed consent was obtained from study participants who were recruited consecutively, and patients without capacity were excluded. Sociodemographic details were also collected using a semi-structured proforma prepared for the study, and available medical records were used to obtain the clinical information of the patients. A semi-structured proforma comprising past medical, psychiatric, and personal history was used to exclude patients with intellectual disability, patients with substance use disorder other than nicotine, chronic medical illness, and other physical illness, such as locomotor, visual, and hearing impairment. Participants from both genders in the age group of 20 to 65 years were included in the study. The principal investigator then administered the following tools depending on the diagnosis.

1. The Hamilton Depression Rating Scale (HAM-D-17) is a clinician-administered scale for depression that is used most frequently. A score of 0-7 is within the normal limit and indicates remission. [13]

2. The Young Mania Rating Scale (YMRS) is the most widely used clinician-administered scale for assessing symptoms of mania. It has 11 items, and a total score of $\leq$ 12 out of 60 indicates remission. [14]

4. The Brief Psychiatric Rating Scale (BPRS) is an instrument used for assessing the severity of illness in an individual with psychosis. There are a total of 18 items, and the total score is obtained by adding each item. A score of $\leq$ 8 indicates remission. [15]

5. Multidimensional Scale of Perceived Social Support (MSPSS) is the self-rated most extensively used scale to assess perceived social support. This is a 12-item scale designed to measure the perception of support from 3 sources: family, friends, and significant others, which includes special partners, service staff, organizations, neighbors, or close relatives such as an uncle or aunt. The total score of 12-48 is taken as poor perceived social support, 49-68 as moderate, and 69-84 as high perceived social support. [16] The tool was translated into the vernacular language using the translation and back-translation method.

6. World Health Organization Disability Assessment Schedule 2.0. (WHODAS II) – This is a 12-item questionnaire to assess the disability. It captures the level of functioning in six domains of life, namely cognition, mobility, self-care, getting along, life activities, and participation, by asking about difficulties over the past 30 days.[17] It can be administered by a lay interviewer, self, or by a proxy (family member, friend, or carer). Each question was graded as none, mild, moderate, severe, or extreme disability based on the Likert scale. The total score is calculated, and scores of 24 or more are considered to indicate a relevant disability. [18]

Categorical variables were recorded as frequencies and percentages, and the continuous variables as mean and standard deviation. To find out the association, Fisher's exact and Chi-square tests were used. $P < 0.05$ was considered statistically significant. Statistical analysis was done using Statistical Package for the Social Sciences (SPSS) version 27.

RESULTS

Among 125 participants, 32 (25.6%) had schizophrenia spectrum disorder, 51 (40.8%) had bipolar and related disorder, and 42 (33.6%) had depressive disorder in partial or complete remission. The mean age of the study population was 43.88 years (SD $\pm$12.8). The mean age of participants with schizophrenia spectrum disorder was 41.96 (SD $\pm$ 4.8); depressive disorder was 43.23(SD $\pm$ 5.6); and bipolar and related disorder was 45.62 years (SD $\pm$ 6.8). More than half (77) of the participants were female (61.6%); among them, 34 (44.1%) had depressive disorder, 30(38.96%) had bipolar and related disorders, and 13 (16.8%) had schizophrenia spectrum disorder. Depressive disorder is found to be more common in females. Among 125 participants, 70 (56%) belong to the Christian community, which may be due to the specific geographic area. Out of 125 participants, 41 (32.8%) were housewives and 27(21.6%) were unemployed. Only 47(37.6%) were employed, and 10 (8%) were students. Duration of illness was more than twenty years for 34 participants (27.2%), 10 to 20 years for 45 participants (36%), and less than 10 years for 46 participants (36.8%). Seventy-six (60.8%) participants had a family history of psychiatric illness. Fifteen (12%) participants had a self-harm attempt in the past. (Table 1)

Perceived social support was high in 17 (13.6%) participants, moderate in 60 (48%), and low in 48 (38.4%) participants. One hundred thirteen participants (90.4%) did not have any disability that affected their day-to-day activities and could fulfill their responsibilities.

Table 1. Distribution of Socio-demographic and Clinical Variables

Variables	Total sample 125	Schizophrenia spectrum disorder Total=32	Bipolar and Related Disorder Total =51	Depressive Disorder Total=42
Age (Years)				
20-35	32(25.6%)	6(18.7%)	12(23.5%)	14(33.3%)
36-50	49(39.2%)	17(53.1%)	20(39.2%)	13(30.9%)
51-65	44(35.5%)	9(28.1%)	19(37.2%)	15(35.7%)
Gender				
Male	48(38.4%)	19(59.3%)	21(41.1%)	8(19.04%)
Female	77(61.6%)	13(40.6%)	30(58.8%)	34(80.9%)
Marital Status				
Single	37(29.6%)	18(56.2%)	10(19.6%)	9(21.4%)
Married	77(61.6%)	13(40.6%)	35(68.6%)	29(69.04%)
Separated/Divorce	8(6.4%)	1(3.1%)	5(9.8%)	2(4.7%)
Widow	3(2.4%)	0	1(1.9%)	2(4.7%)
Education				
Primary	32(25.6%)	6(18.7%)	13(25.4%)	13(30.9%)
Secondary	33(26.4%)	11(34.3%)	16(31.3%)	6(14.2%)
Undergraduate	43(34.4%)	8(25%)	17(33.3%)	18(42.8%)
Postgraduate	17(13.6%)	7(21.8%)	5(9.8%)	5(11.9%)
Residency				
Urban	23(18.4%)	7(21.8%)	6(11.7%)	10(23.8%)
Rural	102(81.6%)	25(78.1%)	45(88.2%)	32(76.1%)
Occupation				
Farmer/Laborer	6(4.8%)	3(9.3%)	1(1.9%)	2(4.7%)
Student	10(8%)	2(6.2%)	2(3.9%)	6(14.2%)
House wife	41(32.8%)	5(15.6%)	19(37.2%)	17(40.4%)
Unemployed	27(21.6%)	15(46.8%)	8(15.6%)	4(9.5%)
Non-Professional	20(16%)	4(12.5%)	11(21.5%)	5(11.9%)
Professional	14(11.2%)	1(3.1%)	8(15.6%)	5(11.9%)
Retired	7(4%)	2(6.2%)	2(3.9%)	3(7.1%)
Type of family				
Nuclear	120(96%)	31(96.8%)	51(100%)	38(90.4%)
Extended	5(4%)	1(3.1%)	0	4(9.5%)
Medical Co-morbidity				
Asthma	2(1.6%)	1(3.1%)	-	1(2.3%)
Hypertension	23(18.4%)	4(12.5%)	13(25.4%)	6(14.2%)
Diabetes	28(22.4%)	6(18.7%)	16(31.3%)	6(14.2%)
Hypothyroidism	25(20%)	2(6.2%)	17(33.3%)	6(14.2%)
Dyslipidemia	9(7.2%)	2(6.2%)	5(9.8%)	2(4.7%)
Others	6(4.8%)	1(3.1%)	3(5.8%)	2(4.7%)
Nil	67(53.6%)	21(65.6%)	22(43.1%)	23(54.7%)
Duration of illness				
1-5 years	25(20%)	4(12.5%)	4(7.8%)	17(40%)
5-10 years	21(16.8%)	5(15.6%)	7(13.7%)	9(21.4%)
10-20 years	45(36%)	14(43.7%)	23(45.0%)	8(19.0%)
>20 years	34(27.2%)	9(28.1%)	17(33.3%)	8(19.0%)

Table 2: Association between Perceived Social Support and Illness

Disability	Low social support	Moderate social support	High social support	p-value*
Mild	7(14.6%)	5(8.3%)	0	0.19
None	41(85.4%)	55(91.7%)	17(100%)	
Total (125)	48	60	17	

Table 3. Association between disability and serious mental illness

		Schizophrenia spectrum disorder Total=32	Bipolar and Related Disorder Total =51	Depressive Disorder Total=42	p-value $
Family support	Low	0(0%)	1(1.9%)	3(7.1%)	0.36
	Moderate	14(43.7%)	20(39.2%)	14(33.3%)	
	High	18(56.2%)	30(58.8%)	25(59.5%)	
Support from significant others	Low	0(0%)	0(0%)	2(4.7%)	0.33
	Moderate	18(56.2%)	22(43%)	15(35.7%)	
	High	14(43.7%)	29(56.8%)	25(59.5%)	
Support from friends	Low	22(68.7%)	26(50%)	21(50%)	0.97
	Moderate	9(28.1%)	22(43.1%)	16(38%)	
	High	1(3.1%)	3(5.8%)	5(11.9%)	

Table 4. Association between disability and perceived social support.

Disability	Schizophrenia spectrum disorder	Bipolar and Related Disorder	Depressive Disorder	p-value
Mild (12)	7(58.3%)	2(16.7%)	3(25%)	**0.021 ***
None (113)	25(22.1%)	49 (43.4%)	39(34.5 %)	
Total (125)	32(25.6%)	51(40.8 %)	42(33.6 %)	

Patients who perceived high social support have no disabilities. (Table 4) And there is no statistically significant association found between perceived social support and disability. (p-value= 0.193)

DISCUSSION

Disability associated with SMI is a major contributor to the global burden of disease. The people with lived experience are set apart from society due to restrictions on participation in the community. They need a sense of security and emotional assistance to address their mental health challenges more effectively. Social support can accelerate healing, prevent relapse, and help recovery. This study was conducted to find out the association between perceived social support and disability among people with lived experience of serious mental illness in South Kerala, and it highlights that people with lived experience of serious mental illness have high support from family members and have less disability.

The mean age of the study population was 43.88(SD 12.8) years, which is higher than the mean age of a similar study conducted in JIPMER, India in 2021 where the mean age of Schizophrenia spectrum disorder and the Bipolar and related disorder group was 35.86 years (SD 11.40) and 38.34 years (SD 11.10) respectively. [12] This may be due to the selection of a sample with patients who are in remission in this study.

Interestingly, we found that females perceive more support than males, which is not statistically significant. This may be explained by the fact that there were more female participants in this study. Previous studies conducted in our department also point towards a greater number of female participants compared to male participants. [19,20] This may also be due to the better compliance and follow-up in female patients, which needs further research.

The majority of participants (61.6%) were married, and they reported having better social support from their family compared to the unmarried. This is in accordance with the study conducted by Prabhakaran and others. [12] This further highlights the importance of family support in Indian culture compared to Western culture.

All the participants in the sample were literate, and three-fourths (73.6%) of the patients had completed their secondary education, which is similar to the study conducted in Mumbai.[21] This could be attributed to Kerala's high level of literacy.[22]

Disability among People with Lived Experience

Disability attributed to psychiatric illness were mainly associated with social and cognitive difficulties, whereas those attributed to medical illness were physical limitations. [23] The significant finding of the study is that the majority (90%) of the patients with serious mental illness who are in remission have less disability, which is similar to the findings of the study conducted in South India in 2021. [12] As in other studies, patients with schizophrenia had more disability compared to those with other serious mental illnesses.[24] Earlier studies conducted in Western countries have reported that serious mental illness (SMI) significantly interferes with various aspects of daily life and is strongly associated with disability. [25, 26] Interestingly, this study observed that participants in remission exhibited no or only mild disability.

Perceived Social Support among People with Lived Experience

Perceived social support has a significant role in socio-occupational functioning and prevents relapse, thus prolonging remission.[27] This study shows 61.6% of PWLE perceive moderate to high support, and support perceived from family is higher than from friends. These results are similar to those found in studies conducted in Iran in 2014 and Nigeria in 2022. They report that perceived social support, especially from family, is a strong protective factor against depression. [28,3] Whereas a study conducted in Egypt in 2022 states that the majority of psychiatric patients perceived a low level of social support and only 8.9% perceived a high level of social support, [29,] they also mentioned that support from friends is more than from family and significant others. Another study conducted in

India among symptomatic patients reports more perceived social support from friends, followed by family, and significant others. As this study was conducted among patients with active symptoms, other factors may have contributed to this finding.

The present study shows there is no difference in social support perceived by people with lived experience of serious mental illness, whereas the study conducted in Malaysia shows social support perceived by PWLE of schizophrenia spectrum disorder was poor. [30] Another study conducted in India at JIPMER, in 2020, reports that PWLE of schizophrenia spectrum disorder had significantly better perceived support when compared to bipolar and related disorder patients, especially from family and friends.[7] As per the Indian studies, support perceived by PWLE of serious mental illness is more, which emphasizes the importance of family involvement in their treatment and recovery.[31,32]

There are only a few studies that have explored the association between disability and social support. In this study, participants with lower levels of social support experienced greater disability, even though all individuals with disability had only mild disability. No statistically significant association was found between disability and perceived social support.

Most people with serious mental illness were happy to share their insights. Many do so without compensation. People with lived experience of serious mental illness have a desire for a normal life in the community, a desire for an active social life, to be involved in meaningful activities, to have stable and healthy relationships, to be recognized as an individual, and to be treated with respect, desire to involve in treatment decision. Many of the study participants reported that they were able to lead a normal life; however, a few reported the painful experience of isolation from society, labelling them as having a serious mental illness.

Strengths and limitations

The strength of our study was that we conducted our study among the patients who are in remission and partial remission, so that the affective symptoms or psychotic symptoms do not influence the reporting of disability and perceived social support. We assessed both social support and disability among people with lived experience of all three major psychiatric illnesses, which was not done in South Kerala.

There were several limitations to our study. There are mainly four types of social support: i) emotional support- perceived love and empathy, ii) instrumental support- tangible goods and services, iii) informational support- available environmental resources, and iv) appraisal support- self-evaluation. [33] The measures used to evaluate social support do not assess all types of support. Our sample consists of outpatients in a tertiary care hospital who were undergoing regular follow-up, which does not represent the general population of patients. This affects the study's generalizability. We did not study factors that influence social support and disability among people with severe mental illness (SMI); this may be explored in future research. Our study is based on an observational study design using self-reported measures, which may be subject to recall and social desirability bias. A qualitative or mixed study design would be a better method for studying perceived social support among PWLE in remission.

CONCLUSION

The majority of the people with lived experience had no disability, which is contrary to the general public's assumption about them, and 63% had moderate to high perceived social support. Psychosocial interventions should be promoted in routine patient care, which aims to improve social support and destigmatize mental illness.

To enhance the mental health of patients with Serious mental illness, mental health professionals should ensure supporting

networks from family, significant others, and friends to strengthen their quality of life. Stigma related to serious mental illness persists; in this background, the lived experience of people with serious mental illness plays a great role, which further helps to destigmatize mental health.

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