Internalised stigma and self-esteem in patients with remitted schizophrenia and their spouses

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Abstract

There are plenty of studies on stigma and self-esteem in patients with schizophrenia. Patients with remitted schizophrenia and particularly their spouses had not been studied sufficiently to explore the association between stigma and self-esteem. Keeping this in view, the current study was initiated. This study was aimed at exploring the association between internalised stigma and self esteem in patients with remitted schizophrenia and their spouses. This study was carried out in 100 participants (50 patients with remitted schizophrenia and their spouses) at the outpatient Department Post Graduate Institute of Behavioural and Medical Sciences, India. Patients and spouses, who fulfilled the inclusion criteria of the study, were interviewed and data were collected by Positive and Negative Symptoms Scale, Brief Psychiatric Rating Scale, Rosenberg Self-Esteem Scale and Internalized Stigma of Mental Illness Inventory (ISMI). Patients with remitted schizophrenia were observed with a significant negative correlation (r=-.80, p<0.01) between internalized stigma and self-esteem. Similarly, also in spouses there was a significant negative correlation (r=-.39, p<0.01) between these two variables. The current study is concluded with the comment that in patients with remitted Schizophrenia and their spouses, high internalized stigma and its relation with low self-esteem require the attention of clinicians for better functional outcomes in patients and enhanced well-being in their spouses.

Keywords: Internalized stigma, self-esteem, remitted Schizophrenia, spouses

Self-esteem is a crucial aspect of mental health. High self-esteem has a positive association with healthy social relations, greater well-being and job satisfaction (Henriksen, Ranoyen, Indredavik, & Stenseng, 2017; Orth, Robins, & Widaman, 2012), whereas, low self-esteem is associated with emotional disturbance and psychiatric conditions (Leary, Schreindorfer, & Haupt, 1995). Internalized stigma refers to how people with mental illness apply negative stereotypes to themselves, perceive rejection from others, and feel isolated from society (Park, Bennet, Couture, & Blanchard, 2013).

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Schizophrenia is a chronic and severe mental disorder that affects how a person thinks, feels and behaves. It affects 1% of the population worldwide (Perälä et al., 2007). Lifetime prevalence of Schizophrenia is reported around 1.4% (Murthy, 2017).

During recovery phase, stigma plays a significant role in the lives of schizophrenia patients. Particularly when patients begin to attend follow-up appointment, work, and engage in other activities of daily living that require social interaction. Internalized stigma is common in schizophrenia patients, and it has been linked to lower levels of functioning, depression, social anxiety, secrecy, lower social functioning, and less mastery (Singh, Matto, & Grover, 2016; Gerlinger et al., 2013). Self-esteem plays an important role in the development in various areas of adjustment in one's life. As a result, there appears to be a need to investigate the connection between internalized stigma and self-esteem in remitted schizophrenia patients.

Furthermore, not only do patients face stigma, but so do their caregivers, especially spouses, because of their loved ones' illness. A multicentre research in India discovered that caregivers of schizophrenia patients face more stigma than caregivers of other disorders (Grover et al., 2017). Spouses are also the main caregivers for these patients. If stigma has an effect on a spouses' thinking, behaviour and their interaction with patients after the onset of illness, it is likely to have a negative or positive impact. By contrast, spouses' self-esteem is just as critical for their mental health as it is for providing good care to their patient

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partners. It is assumed that if self-esteem is influenced by or associated with internalized stigma because of illness to their loved ones, it would have a negative impact on their adjustment in various areas of life. In light of the above, the current study was planned. The first objective of the study was to check the difference in internalized stigma and self-esteem between patients with remitted schizophrenia and their spouses. Moreover, literature is dubious about the kind of association between internalized stigma (perceived by spouses) and the self-esteem of spouses. Hence, the second and third objectives were to see the association of internalized stigma with self-esteem in both patients and their spouses separately.

Research design

This study was conducted using cross-sectional correlational research design. In this study patients with schizophrenia and their spouses were recruited. They were compared for self-esteem and internalized stigma in order to know if any difference between them. This comparison was intended to explore whether being diagnosed and living with schizophrenia bring similar stigma in both the groups. Both the groups then were assessed for the association between internalized stigma and self-esteem.

Sample: The sample for the present study consisted of 100 participants (50 patients with schizophrenia, who were in remission phase as per Andreasen et al.'s criteria (Andreasen et al., 2005) and their 50 respective spouses). Criterion sampling method was used to select the participants from the Out-Patient Department of Post Graduate Institute of Behavioural and Medical Sciences (PGIBAMS), Raipur, C.G. In the patient group 36% were males and 64% were females and in the spouse group 64% were males and 36% were females. The mean age of patients was 39.14 (7.89) and the mean age of the spouses were 42.2 (8.92). Most of the patients and spouses had at least a primary and secondary level of education. Maximum (60%) of the sample were from the rural background and were married (68%) for more than 10 years. Fifty percent of patients were with a treatment history of more than 5 years, 28% with 2-5 years and 12% were with of treatment history 1 year or less.

Inclusion criteria

- Follow up patients diagnosed with schizophrenia as per ICD-10 (DCR)
 - Fulfilling the criteria of remission on PANSS
 - Aged between 18- 60 years

- Both male and female patients and spouses who could read and comprehend Hindi
- The spouse has been living with and providing care to the patient during illness
- Patients and/or spouses, who agreed to give formal informed consent for the study

Exclusion criteria

- Patients who had co-morbid conditions i.e., substance dependence, organic illnesses etc. (as per the history)
- Spouses with a history of schizophrenia, mood disorder, substance abuse/dependence, anxiety spectrum disorders and organic illness (as per the history and BPRS)

Tools

Positive and Negative Symptoms Scale involves 30-items is a seven-point rating instrument. Out of the 30 parameters assessed, seven were chosen to constitute a Positive Scale (score range 7–49), seven a Negative Scale (7–49), and the remaining 16 a General Psychopathology Scale (16–112). This scale has sound psychometrics and is widely used in clinical setting and in researches (Kay, Fiszbein, & Opler, 1987).

Brief Psychiatric Rating Scale is designed to assess the severity of psychotic illness. It consists of 18 items. Five of the items (tension, emotional withdrawal, mannerisms and posturing, motor retardation and uncooperativeness) are based on observations of the patient. The remaining 13 items are based on the patient's verbal report. Items are rated on a 7-point Likert scale, from 1 = "not present" to 7 = "extremely severe", with scores ranging from 18 to 126 (achieved through summing the item scores). Interrater reliability for the scales: range from 0.56 (tension) to 0.87 (guilt feelings and hallucinatory behaviour) Inter-rater reliability for overall scores: range from 0.67 to 0.95 (Overall & Gorham, 1962).

Rosenberg Self-Esteem Scale is a 10-item scale that measures global self-worth by measuring both positive and negative feelings about the self. The scale is believed to be one-dimensional. All items are answered using a 4-point Likert scale format ranging from strongly agree to strongly disagree. This scale is valid and reliable one (Gray-Little, Williams, & Hancock, 1997).

Internalized Stigma of Mental Illness Inventory (ISMI) scale has been developed by Ritsher, Otilingam, and Grajiales (2003) to measure the subjective experiences of self-stigma. The ISMI

consists of 29 items. Each item is rated on a 4-point Likert-type scale with 1 representing strongly disagree and 4 representing strongly agree. A higher total score indicates a higher level of internalized stigma. The ISMI consists of five subscales that measure alienation, stereotype endorsement, perceived discrimination, social withdrawal, and stigma resistance (SR). This scale had adequate psychometric properties and is widely used in researches worldwide (Ritsher, Otilingam, & Grajales, 2003).

Procedure

After receiving approval from the institutional ethical committee of PGIBAMS, Raipur, CG, the study began. Measures to be used in the study were translated into Hindi using the back translation method recommended by WHO (the translation was done for Rosenberg self-esteem scale and internalized stigma of mental illness inventory). Adult patients who were male or female (visited OPD of PGIBAMS) accompanying by their spouses, who were remitted on PANSS, patients and their spouses who could comprehend the Hindi were included in the study using criterion sampling. All the participants were requested to give formal consent after being briefed about the

study. Study measures were used in couples individually and separately. If any participant had difficulty understanding any item in the tools were explained keeping the integrity of content intact. After the completion of data collection, they all were thanked for their participation in the study and data was processed for statistical analysis.

Data analysis

IBM Statistical Package for Social Sciences, version 21.0 was used to analyze the data. Descriptive statistics were used for demographic (for patients and spouses) and clinical data (for patients). To check the major assumption of the parametric test, normality of data was assessed by Shapiro-Wilk, which revealed that data on internalized stigma (W= .93, p<0.05) among patients and data on self-esteem (W= .95, p<0.05) among spouses were violating the normality assumption, therefore, spearman's correlation was used to assess the association between internalized stigma and self-esteem and Mann-Whitney U test was used to compare study variables between patients and spouses.

Results

Results revealed (Table 1) that there was no significant difference (p_s <.05) between patients and spouses for self-esteem and internalized stigma.

Table 1: Comparison of self-esteem and internalised stigma between patients and their spouses

	Patient (n=50)		Spouse (n=50)		Mann-		
Variables	Mean (SD)	Mean	Mean (SD)	Mean	Whitney	Sig.	
		Rank		Rank	U		
Self Esteem	19.50(4.50)	49.95	19.44(3.64)	51.05	1222.5	.84	
Internalized stigma							
Alienation	2.18 (.88)	50.34	2.16 (.77)	50.66	1242	.95	
Stereotype	2.12 (.85)	48.68	2.17 (.77)	52.32	1159	.53	
Discrimination	2.19 (1.03)	48.77	2.18 (.73)	52.23	1163.5	.55	
Withdrawal	2.23 (.92)	51.18	2.16 (.82)	49.82	1216	.81	
Resistance	2.02 (.66)	45.90	2.36 (2.90)	55.10	1020	.11	
Total	2.15 (.68)	49.95	2.17 (.60)	51.05	1222.5	.85	

Table 2 Correlation of self-esteem with internalized stigma among patients with remitted Schizophrenia (n=50)

Variable	SelfEsteem			
Internalized stigma				
Alienation	75 **			
Stereotype	77 **			
Discrimination	74 **			
Withdrawal	76 **			
Resistance	0.07			
Total	80**			

^{**} p<0.01

There was a significant strong negative correlation between internalized stigma and self-esteem (r= -.80, p>.01) in the patients with schizophrenia suggesting that with increasing levels of stigma, self-esteem decreases (Table 2).

There was a significant negative correlation between internalized stigma and self-esteem in the spouses of patients with schizophrenia (r=-.39, p>.01) indicating that higher internalized stigma (due to illness to their partners) is associated with lower self-esteem in the spouses (Table 3).

Table 3 Correlation of self-esteem with internalized stigma among spouses (n=50)

SelfEsteem				
Internalized stigma				
43 **				
26				
26				
38**				
.17				
39**				

^{**} p<0.01

There were differences in spearman's correlation coefficients (for domains of internalized stigma and self-esteem) of patients and spouses. For the spouses, only alienation (r = -.43, p > .01) and withdrawal (r = -.38, p > .01) are significantly inversely associated with self-esteem. Whereas among patients almost all domains of internalized stigma i.e., alienation (r = -.75, p > .01), stereotype (r = -.77, p > .01) discrimination (r = -.74, p > .01) and withdrawal (r = -.76, p > .01) had strong significant negative association with self-esteem. These findings imply that the association between internalized stigma and self-esteem for patient and spouse varies in domain wise analysis.

Discussion

The current study was aimed to explore the association between internalised stigma and self-esteem for the patients with schizophrenia and their spouses. Self-esteem is well known to play an important role in an individual's growth and development. Because patients with schizophrenia go through remarkable turmoil during the course of illness because of the nature of symptomatology and its impacts in functional impairment in them, hence their self-esteem is vulnerable to change. Meanwhile, the presence of schizophrenia in patients is assumed to influence the self-esteem of their spouses living with them and providing care. In the current study, self-esteem in both groups was hypothesized to be related to their perception of being stigmatized due to the diagnosis of schizophrenia.

The first objective of the study was to compare internalized stigma and self-esteem between the patients with schizophrenia and their spouses. Results (table 1) demonstrated that there was no significant difference (p<0.05) observed in self-esteem and internalised stigma between both groups. It indicates that patients and caregiver spouses, who are sharing for their hardships, are forming similar perceptions about their reduced ability to meet role expectations due to illness (Park, Bennet, Couture, & Blanchard, 2013) and sharing perception of being stigmatised by others. This finding demonstrated that although in the phase of symptomatic remission, their (both patients and spouses) self-esteem appears to be reduced in an approximately similar amount. More research is required to explore the self-esteem and internalized stigma of patients and their spouses before, during and after the remission of illness in a longitudinal study to see the kind of changes that occur in these variables across the phases of illness and other factors associated with it.

The second objective of the study was to explore the relationship between internalized stigma and self-esteem in patients with schizophrenia. The findings (table 2) revealed that there was a significantly strong negative correlation between almost all the domains of internalized stigma and global internalized stigma with self-esteem. Other studies also suggested that higher levels of stigma, perceived discrimination and devaluation are associated with low self-esteem and moreover undermines self-efficacy and illness related empowerment (Berge, & Ranney, 2005; Vauth, Kleim, Wirtz, & Corrigan, 2007; Ow & Lee, 2015)

The crucial impact of stigma among these patients is found in form of negative reaction from others, negative views and feelings about self and reduced ability to meet role expectations (Ow & Lee, 2015). These impacts might be the underpinning of strong association between internalized stigma and self-esteem which our study noticed. Koschorke et al. (2014) in an Indian study recruited the patients with moderate severity of schizophrenia to explore these variables whereas our study included the patients with symptomatic remission. Our study indicated that even in symptomatic remission patients with schizophrenia felt stigmatized and decreased self-esteem, and there is a strong association between these two variables.

The third objective of the study was to explore the relationship between internalized stigma and selfesteem among the spouses of patients with schizophrenia. The findings (table 3) revealed that there was a significant moderate negative correlation in two domains viz, alienation and withdrawal and global internalized stigma with self-esteem. Although compared with the patient group, the strength of the relationship is weak, but it is significant. However, in larger sample studies the strength of the relationship is more likely to be closer. An Indian study indicated that caregivers' emotional reactions and feelings about themselves depend upon patients' and their reduced ability to meet role expectation, negative reactions of people toward patients and caregivers and so on (Koschorke et al., 2017), can be the fundamental reasons behind the moderate association between reduced self-esteem of caregivers and high perceived internalized stigma among these spouses. Thus, our study indicate that spouses, who are the closest caregivers of patients, experience both reduced selfesteem and high internal stigma when their partners are diagnosed and living with schizophrenia even in the symptomatic remission phase.

Moreover, internalized stigma is an important psychological mechanism in recovery (Vass, Sitko, West, & Bentall, 2017), especially when it is negatively associated with the self-esteem of both patient and care giving spouse. These findings have a major direction for the clinicians to work toward the reduction of internalized stigma in remitted patients with schizophrenia and their spouses to boost up their self-esteem. It is found that adequate self-esteem would not only help them to be more functional in meeting their role expectations but also would be a protective factor in the relapse of illness (Holding, Tarrier, Gregg, & Barrowclough, 2013).

In the current study, there are bound limitations. This research was unable to involve randomly selected participants, which may have resulted in deviated data on variables, limiting the use of parametric statistics. The generalizability of the results is restricted due to this limitation and the small sample size. We were unable to include patients in functional remission, which would have been a better fit for investigating the connection between internalised stigma and selfesteem, and potentially providing crucial information to researchers and clinicians working to improve functional remission. Based on these shortcomings, the authors recommend that future research should focus on internalised stigma and self-esteem in a random sample of schizophrenia patients achieving functional remission and their partners.

Conclusion

There was no significant difference in internalized stigma and self-esteem between patients with remitted (symptomatic remission) schizophrenia and their care giving spouses. Moreover, the study found that there was a significant association of high internalized stigma with low self-esteem not only in patients with remitted schizophrenia but also in spouses. This research, despite the limitations listed above, shows that clinicians must strive to minimize stigma and improve self-esteem in patients with schizophrenia, as well as their spouses who provide care, even after symptomatic remission. If clinicians focus on these areas, it is expected that patients can recover more quickly and prevent relapse.

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