Comparing Stigma and Wellbeing among Offspring of Patients with Schizophrenia and Bipolar Affective Disorder - A Pilot Study

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ABSTRACT

Introduction: Needs of the children often get disregarded, if parent develops mental illness. During early adulthood, while striving for establishing their identity and fulfilling responsibilities, mental illness of parents could make them vulnerable in the society due to stigma, associated stress and other negative experiences. This study aims to assess and compare stigma and well-being between the offspring, caring for their parent diagnosed with Schizophrenia or Bipolar affective disorder (BPAD). **Methodology:** It was cross-sectional pilot study, including 15 offspring of patients diagnosed with schizophrenia and 15 of BPAD, using purposive sampling. Participants were 18-30 years of age and residing with parent having psychiatric illness, since past at least 1 year. They were assessed on Affiliate Stigma Scale (ASS) and PGI General Well-being Scale (PGIGWBS). Descriptive analysis included frequency estimation and inferential statistics included Pearson's correlation and Mann-Whitney U test. **Result:** Majority participants were male (83.3%); all were literate; 76.7% were single; 50% were financially independent. Mean scores of ASS was higher in schizophrenia (16.47) than BPAD (14.53), and of PGIGWBS higher in BPAD (18) than schizophrenia (13); however difference was not significant. Scores of PGIGWBS had negative correlation with ASS scores, but did not reach statistical significance. Behavior domain of ASS had significant correlation with sex of the patient (p=0.045); cognitive domain of ASS is significantly related to financial dependency of the patient on other family members; and PGIGWBS related to sex of the patient. **Conclusion:** Offspring of patients with schizophrenia or BPAD experience nearly similar form of stigma, affecting their well-being. Sex and financial dependency of patient appears to have a role in offspring's experience of stigma. Appropriate steps by mental health professionals and policy makers required to create awareness and mitigate stigma prevailing around mental illnesses.

Keywords: Stigma, Well-being, offspring, parental mental illness, schizophrenia, bipolar affective disorder

INTRODUCTION

The impact of psychiatric illness is multifarious which ranges from the patient to the significant others related to them. Usually, needs of the children often get disregarded, when their parent(s) develops any psychiatric illness. Moreover, during their early adulthood when they are full of ambitions, striving for making their own identity and adapting to new roles, psychiatric illness of their parents makes them vulnerable in the society due to the stigma, associated stress and other related negative experiences.

When any patient with psychiatric illness experience stigma is known as *internalized stigma* and when experienced by their relatives is called *stigma-by-association* which include associative stigma and affiliate stigma. Associative stigma is prejudice and discrimination against people who do not have a mental illness because they have a social relationship with a person living with a mental illness (Corrigan, Watson, & Miller, 2006). When family members internalise associate stigma, it is termed as Affiliate Stigma (Mak & Cheung, 2008). They feel unhappy and helpless about their affiliation with the stigmatized individual and

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also feel a negative influence on them. Due to these negative experiences, associated people usually tend to conceal their status from others, withdraw themselves from social relations and alienate themselves from the patients in order to avoid association (Mak & Cheung, 2008).

A narrative study found adults who experienced parental mental illness highlight common childhood narratives including stigma, uncertainty, and feeling unsafe, all of which are known to hinder protective factors, such as conversations about parental mental illness and help-seeking behaviours (Foster, 2010). In another narrative study on thirteen adult children with parental mental illness revealed the awareness of societal stigma and fear of disclosure regarding their parent's mental illness (Murphy, Peters, Wilkes & Jackson, 2015).

Among the various psychiatric disorders, schizophrenia is considered to be associated with high level of stigma (Grover, Aakansha & Mattoo, 2016), effecting the 3.5 million Indian population with 9.8% DALY (Sagar et.al. 2020). Although, the use of psychopharmacological drugs, the open-door policies in hospitals, the deinstitutionalization in hospitals, and the emphasis on rehabilitation and community- based care for patients have all led to an increase in the marriage and fertility rates among persons with schizophrenia. Consequently, the number of children born to patients with schizophrenia is continually increasing. (Kaplan & Saddock, 2015)

A comparative cross-sectional study on 431 adult offspring of parents with schizophrenia concluded that offspring had more poor social adjustment along with less frequency of being married and poorer employment as compared with off-springs of general population (Terzian, Andreoli, de Oliveira, de Jesus Mari & McGrath, 2007).

BPAD, on the other hand, effected 7.6 million Indians with 6.9% DALY (Sagar et.al. 2020). In a cross-sectional observational study consisting 71.1% caregivers of BPAD within age range of 16-30years showed experiences of affiliate stigma (Kumar, Jha & Sinha, 2020). Greater stigma was associated with being a caregiver who is the adult child of a parent with bipolar affective disorder, who has a college education having fewer social interactions, and caring for a female bipolar patient (Gonzalez et al., 2007).

Impact of parental mental illness on offspring has brought into the need to focus on well-being of their dependent offspring as stigma is a serious impediment to the well-being of those who experience it. General wellbeing may be defined as the subjective feeling of contentment, happiness, satisfaction with life's experiences and of one's role in the world of work, sense of achievement, utility and no distress, dissatisfaction or worry etc. (Verma and Verma, 1989)

In comparison to adults in the general population, adult children of parents with mental illness were found to have lower self-esteem, increased psychosocial problems (Abraham & Stein, 2010). Even in the absence of any diagnosable psychological problems, children of patients with schizophrenia experience stigma and they have poor psychological well-being compared to children of parents without psychiatric illness (Chan & Heidi 2010).

There are many studies focussing on the effects of parental mental illness over psychopathology of their children especially but very scant information about experience of stigma and well-being of the offspring of patients with schizophrenia and bipolar affective disorders. Mostly available are narrative interviews and qualitative design. Keeping in view the dearth of research about this subject, more so in Indian context, this pilot study is planned with the aim to assess and compare the stigma and well-being of the offspring living with their parent having schizophrenia or BPAD.

METHODOLOGY

This pilot study was carried out at Vidyasagar psychiatry block under the Institute of Mental Health, Pt. B. D. Sharma University of Mental Health Sciences, Rohtak, Haryana. It was the cross- sectional design. Using the purposive sampling technique, total of 30 offspring of patients diagnosed with Schizophrenia or BPAD who gave written consent for the participation in study were selected. For making comparison, 15 offspring from each group were selected. Study was conducted after the ethical approval of Institutional Ethics Committee and written informed consent was sought from the study participants.

The inclusion criteria of participants were: age between 18-30 years, any sex, able to read, write and understand Hindi, only one parent diagnosed with schizophrenia or BPAD as per ICD-10 with total duration of illness of 2 years at least and participants currently living with diagnosed parent since past 1 year minimum. In case, there was presence of psychiatric illness in participant or any family member other than patient, he/she was excluded from the study. The participants were assessed on the following tools:

a. **Socio-demographic data sheet-** The data sheet developed for the purpose of present study to collect socio demographic details of the participant and illness variables of the patient.
b. **The Affiliate Stigma Scale (Hindi)-** The Affiliate Stigma Scale assesses the level of internalized stigma among caregivers or relatives of person with mental illness. It consists of a total of 22 items. All the items are rated on a 4-point Likert scale coded from 1 (strongly disagree) to 4 (strongly agree). It measures the three major domains of the stigma - Cognitive, Affective, and Behavioural. It has a Cronbach's alpha value of 0.93. The higher the score, higher the level of stigma. The scale originally was developed by Mak and Cheung, 2008. Its Hindi version was developed and validated by Rajbala Kumari et al. 2020 (Kumari, Ranjan, Verma & Asthana, 2020).
c. **PGI General Well Being Scale** - The PGI General Well-being Scale assesses the general well-being of the participants. The scale was developed by Verma and Verma (1989), it consists of 20 items, and the participants had to respond to tick (✓) the items applicable to them. Numbers of ticks are counted and constitute the well-being score of the particular participants ranging from 0-20. Higher scores on the PGI general well-being scale are indicative of higher levels of general well-being. The reliability of the PGI General Well-being scale was determined to be 0.91.

Statistical analysis was carried out using the Statistical Package for the Social Science Version 16 (SPSS for Windows, Version 16.0. Chicago, SPSS Inc., USA). Descriptive analysis was computed in terms of mean and standard deviation and frequency with percentage for ordinal and nominal variables. For correlation between variables the Pearson's correlation coefficient was used. Comparisons were made using Mann–Whitney U-test.

RESULT

Socio- demographics

Mean age of the patients was 49.8 (SD: 7.0). Majority of the patients (46.7%) were educated up to higher secondary and there was equal distribution of the patients among male and female. 86.7% of the patients were living with their spouses while remaining were widow(er). 66.7% of the patients were financially dependent upon their family members. More than half of the patients (60%) residing in nuclear family in rural area (76.7%). [Table 1]

Mean of total duration of illness was 20.3 years (SD: 6.5). Among all the patients, 43.3% had history of previous hospitalization for once or twice in their total duration of illness. [Table 1]

Mean age of participants was 23.6 (SD: 4.3). All were literate and 70% had completed their higher secondary education; 83.3% were male and about three fourth (76.7%) were unmarried. Half of them were financially dependent on other family members. [Table 1]

Table 1- Socio-demographic and clinical profile of the patients and the participants

Variables	Mean (SD)/Frequency (%)	
	Patient	Participants
Age (years)	49.8 (7.0)	23.6 (4.3)
Education (Degree wise)		
Illiterate	8 (26.7%)	-
Middle	8 (26.6%)	1(3.3%)
Higher Secondary	14 (46.7%)	21 (70.0%)
UG	-	6 (20.0%)
PG	-	2 (6.7%)
Sex		
Male	15 (50.0%)	25 (83.3%)
Female	15 (50.0%)	5 (16.7%)
Marital Status		
Unmarried	-	23 (76.7%)
Married	26 (86.7%)	7 (23.3%)
Widow/widower	4 (13.3%)	-
Occupation		
Unemployed	12 (40.0%)	11 (36.7%)
Professional	-	3 (10.0%)
Skilled	2 (6.7%)	5 (16.7%)
Unskilled	2 (6.7%)	7 (23.3%)
Others	14 (46.7%)	4 (13.3%)
Financial Dependency		
Dependent	20 (66.7%)	15 (50.0%)
Independent	10 (33.3%)	15 (50.0%)
Type of family		
Nuclear	18 (60.0%)	
Joint	12 (40.0%)	
Locality		
Rural	23 (76.7%)	
Urban	7 (23.3%)	
Relationship with patient		
Daughter	5 (16.7%)	
Son	25 (83.3%)	
Clinical Profile		
Duration of illness(years)	20.3(6.5)	
Previous hospitalizations		
No previous admission	10 (33.3%)	
1-2	13 (43.3%)	
3-4	6 (20%)	
>4	1 (3.3)	
Diagnosis		
BPAD	15 (50.0%)	
Schizophrenia	15 (50.0%)	

On assessing the level of well-being and stigma in participants, it was found that mean score for PGIWB scale was 31.57 (SD: 6.8) and of ASS was 48.53 (SD: 10.5). Concerning about domains of ASS, the highest mean score was of the Affect. When the stigma and well-being of the participants of the patients with schizophrenia and bipolar affective disorder were compared, mean scores of ASS was higher in schizophrenia (16.47) than BPAD (14.53), and of PGIGWBS higher in BPAD (18) than schizophrenia (13); however, using Mann Whitney U-test, it was found that difference of the two was not statistically significant. [Table 2]

Table 2 Comparison of stigma and well-being between both groups

Variables	Clinical Diagnosis	N	Mean Rank	Man-Whitney U test	Sig. (1-tailed)
PGIGWB	F 20	15	13.00	75.0	0.126
	F 31	15	18.00		
Domains of ASS					
Affect	F 20	15	15.20	108.0	0.870
	F 31	15	15.80		
Behaviour	F 20	15	16.30	100.0	0.624
	F 31	15	14.70		
Cognition	F 20	15	17.43	83.5	0.233
	F 31	15	13.57		
Total Score of ASS	F 20	15	16.47	98.0	0.567
	F 31	15	14.53		

PGIGWB: PGI General Well-being Scale, ASS: Affiliate Stigma Scale,
F20: Schizophrenia, F31: Bipolar affective disorder

Relationship between stigma and well-being

On evaluating the scores of ASS and PGIGWB scale, finding shows the negative correlation exist between affiliate stigma and well-being of the participants. The negative correlation between the 'behavior' domains of stigma with well-being was higher compared to 'affect' and 'cognition' domains. [Table 3]

Table 3: Correlation of score of ASS with PGIGWB (stigma with well-being)

Variables	**Pearson Correlation (*r*)**	**Sig. value**
Affiliate Stigma Scale		
Affect	**-0.166**	**0.380**
Behaviour	-0.355	0.054
Cognitive	-0.258	0.169
Total score of ASS	-0.264	0.159

ASS: Affiliate Stigma Scale
PGIGWB- PGI General Well-being Scale

Relationship of stigma and well-being with socio-demographic factors

When the relationship of stigma and well-being was assessed with socio demographic factors it showed that neither well-being nor stigma depended on duration of illness or number of hospitalizations of the patient, and age or order of birth of the participant, i.e., the offspring.

[Table 4] However, female sex of the patient showed significantly higher wellbeing in the participant, when compared to those having male mentally ill parent (mean PGIWBS score in male=32.71 and females=50.57, df=11, p=0.049).

Table 4 – Correlation of Stigma and well-being with Demographic factors

Variables	Score of PGIGWB *r (sig.)*	Affiliate Stigma Scale			
		Affect *r(sig.)*	Behaviour *r(sig.)*	Cognitive *r(sig.)*	Total score
Illness duration	0.050(0.795)	0.189(0.326)	0.129(0.507)	0.076(0.689)	0.143(0.452)
Hospitalization	0.052(0.786)	-0.144(0.449)	-0.055(0.771)	-0.186(0.325)	-0.146(0.441)
Participants' Age	0.298(0.109)	-0.242(0.197)	-0.170(0.369)	-0.092(0.628)	-0.185(0.327)
Birth Order	-0.269(0.150)	-0.141(0.459)	-0.094(0.621)	-0.037(0.847)	-0.100(0.599)

ASS-Affiliate Stigma Scale PGIGWB- PGI General Well-being Scale

DISCUSSION

A core component of stigma is the mark of otherness, which is then followed by negative evaluation (Link & Phelan, 2001). Children of parents with mental illness seem to internalize this otherness by feeling a sense of being "abnormal" or "wrong" (Dobener et al., 2022). The present pilot study, thus, focused on similar experiences of the offspring of the patients with schizophrenia and BPAD.

In present study, most of the offspring were unmarried which was similar to the previous study conducted on the caregivers of the BPAD (Grover, Aneja, Hazari, Chakrabarti & Avasthi, 2019) and more than half of the participants were male belonging to nuclear families similar to study conducted to compare the stigma between schizophrenia and BPAD caregivers (Yannawar et al, 2015).

In current study, the affiliate Stigma was reflected to be higher in the domain of the Affect followed by the cognitive and behavioural which was similar to the findings of the study conducted in North India on the caregivers of the schizophrenia with similar inclusion and exclusion criteria as our study.

In any given population, psychiatric illness is likely to be associated with poorer mental and physical well-being, impaired functioning, lower economic productivity and marked decrements in an individual's health-related Quality of life (Atkinson, Zibin & Chuang, 1997). When parents experience SMI, these extends far beyond the individual concerned, with potential for multiple adverse outcomes in successive generations (Berg-Nielsen, Vikan & Dahl, 2022). In present study also, the negative correlation was found between the stigma and well-being of the participants irrespective of the diagnosis of their parents.

On comparing the stigma between offspring of the schizophrenia and BPAD, higher stigma was reflected in the schizophrenia similar to the finding of the other studies (Grover et al., 2017; Grover, Mehra, Kumar, Chakrabarti & Avasthi, 2020).

CONCLUSION

It is well-known that mental illnesses are associated with stigma. It is sometimes assumed that certain illness is more stigmatising than others. This study conferred that when compared, the stigma associated with schizophrenia and BPAD did not differ significantly.

Stigma affects the well-being of an individual in many aspects, and thus it is prudent to take steps at all possible levels to mitigate stigma towards mental illnesses, e.g., psychoeducation of the family members, awareness camps for general population and increasing knowledge about mental illness among health professionals, in addition to mental health professionals.

This study however has certain limitations. It is a cross-sectional, hospital-based study including the participants who are in contact with health care services, and also with small sample size. A longitudinal community-based study with a larger sample size, would yield more generalizable results.

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