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Original Research Article

Stigma and mental health awareness among caregivers of patients with bipolar affective disorder

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ABSTRACT

Background: Stigma and poor mental health literacy in caregivers of patients with bipolar affective disorder lead to loss of social support and occupational and financial burden reduced functioning, poor compliance and poorer quality of life for both the patient and the caregiver. With this study we aim to find out stigma and mental health awareness in caregivers of patients with bipolar affective disorder.
Methods: 90 caregivers of patients diagnosed with bipolar affective disorder according to International statistical classification of diseases and related health problems (ICD-10) criteria were included in our study. Affiliate stigma scale on caregivers of people with mental illness and Public perception of mental illness questionnaire were applied on them after informed consent and acquiring socio-demographic details.
Result: Analysis of the affective dimension of affiliate stigma scale on caregivers showed significant value for emotional disturbance and pressure due to care of Bipolar Affective Disorder diagnosed patient. Domains and the overall score in patients with mania was significantly more than in the patients with depression. The most significant difference ($p<0.001$) in the opinion of respondents was found with regards to the questions that the mental illness is caused by heredity, substance abuse, personal weakness or by God's decree.
Conclusions: Stigma towards mental disorders worsens the prognosis and compliance towards treatment, therefore, it needs to be assessed in all patients and their caregivers to improve overall well-being and improve acceptance of the patient and the caregiver in the society.

Keywords: Stigma, Mental health awareness, Caregivers

INTRODUCTION

Bipolar affective disorder, previously known as manic depression, is a mental disorder that causes periods of depression and periods of abnormally elevated mood. The elevated mood is significant and is known as mania or hypomania, depending on its severity, or whether symptoms of psychosis are present.[1] Bipolar affective disorder is the sixth leading cause of disability worldwide and has a lifetime prevalence of about 1 to 3 percent in the general population.[2]

Stigma is defined as negative appreciation of an individual based on some derogatory attributes from which other negative characteristics are inferred.[3] Stigma is a serious concern for individuals with bipolar affective disorder and their families. Stigma occurs within affected individuals, families, social environments, work and school environments, and the healthcare industry. Stigma often leads to a loss of social support and occupational success, reduced functioning, higher symptom levels and lower quality of life. There is considerable evidence indicating that bipolar patients and their families are shunned by

society at all levels which further deteriorates the quality of life as well as social functioning.[4]

Having a patient with mental illness in the family often lead to caregivers either hiding the affected individual or avoiding any interaction with people, thereby leading to isolation and further development of mood symptoms in them. Taking care of affected patients is a full-time task which is physically, emotionally and financially draining for the caregivers. This may further lead to development of psychiatric conditions in the caregivers further deteriorating the family functioning as a whole.

Usually stigma is based on a lack of information and understanding about the illness. Being well informed about bipolar affective disorder can help to recognize some of the misconceptions involved in stigma.[5] Information about bipolar affective disorder should be dispersed in the community by educating them that bipolar affective disorder is a health condition like any other disease example, diabetes, hypertension etc., and not a flaw in personality. Also, while certain illness-related behaviors might be socially unacceptable, these behaviors are symptoms of a treatable illness.[6]

There have been limited number of studies on bipolar affective disorder in India due to low prevalence of disease in the country. Moreover, the poor awareness and stigma regarding psychiatric illnesses have further reduced the number of individuals and their families seeking treatment for their symptoms. This has led to even more scarcity in the studies conducted on the awareness of bipolar affective disorder as well as stigma faced by the patients and their caregivers in general.

METHODS

This cross-sectional observational study titled "Stigma and mental health awareness among caregivers of patients with bipolar affective disorder" was conducted in the Department of Psychiatry, Era's Lucknow Medical College and Hospital, Lucknow, Uttar Pradesh, India for a period of 18 months from January 2018 to June 2019 after obtaining approval from the Institute's ethical committee.

90 caregivers of patients with bipolar affective disorder according to the International Classification of Diseases 10th revision (ICD-10) were recruited in this study. Study subjects were also assessed for socio-demographic details and related variables. The selected tools for this study were applied on the study subject on the same day or on some other mutually consented day by the investigator.

The following were tools of assessment for bipolar disorder used in the study: consent form; socio-demographic data sheet and; specific tools of assessment-which included affiliate stigma scale on caregivers of people with mental illness and public perception of mental illness questionnaire.

Affiliate stigma scale on caregivers of people with mental illness

A 22 item scale to measure caregivers internalized stigma. The scale items measure the cognitive, affective and behavioral component of affiliated stigma. Participant related to extent to which they endorsed each item on a 4-point scale from strongly disagree to strongly agree.[1,4,7,8]

Public perception of mental illness questionnaire

This instrument had 33 items that measured mental health literacy of the participants regarding etiology of mental illness, knowledge of people with mental illness, attitude toward the people with mental health problem and management of people with mental health problem. Answer are coded on 5-point scale from agree to disagree.[9]

Inclusion criteria

The inclusion criteria for the study was as follows: age 16-60 year, caregivers of patients confirming to bipolar affective disorder according to guidelines laid down by ICD-10 and caregiver giving informed consent.

Exclusion criteria

The exclusion criteria for the study was as follows: caregivers with co-morbid psychiatric illness, caregivers not in contact with the patient on a daily basis and caregivers with mental and behavioral disorder due to psychoactive. substance use.

Statistical analysis

Data entry was made in Microsoft office excel software in codes and analysis was done by Statistical package for social sciences (SPSS) software® version 18.0. Descriptive statistical analysis, which included frequency, percentages, mean and standard deviation was used to characterize the data. Student's unpaired t-test, Mann Whitney test and chi square tests was applied to check association and difference.

RESULTS

In the study, it was observed that the maximum number of caregivers (71.1%.) belonged to the age group 16-30 years. 23 (25.6%) were aged 31-50 year and 3 (3.3%) were above 50 years. 55 caregivers (61.1%) were females and rest 35 (38.9%) were males.

13 caregivers (14.4%) were uneducated, while 20 (22.2%) had High school level education and only 5 (5.6%) had education of graduation level or above. Majority of the caregivers (51.1%) had income more than 10000 (Table 1).

Analysis of the affective dimension of affiliate stigma scale on caregivers with the help of chi square test shows significant value for (1) of the 7 items given in the table

above. The difference between the number of people agreeing and disagreeing in their opinion was significant for item number 1 (p<0.001) (Table 2).

Analysis of the cognitive dimension of affiliate stigma scale on caregivers with the help of chi square test shows no significant inference regarding any of the items on the list (items 8-14) (Table 3).

Analysis of the behavioural dimension of affiliate stigma scale on caregivers with the help of chi square test shows significant difference between the number of respondents who agreed and those who strongly agreed regarding item 19 and 21 on the list above (p=0.007 in both cases) (Table 4). An application of Mann Whitney test to analyse the association of various domains of caregiver's stigma suggests significant difference between mania and depression subjects regarding alienation (p<0.001), stereotype endorsement (p<0.001) and discrimination experience (p<0.001). In all the domains and the overall score in patients with mania was significantly more than in the patients with depression (Table 5).

An application of Mann Whitney test to analyse the association of various domains of caregiver's stigma suggests significant difference between mania and depression subjects regarding alienation (p<0.001), stereotype endorsement (p<0.001) and discrimination experience (p<0.001). In all the domains and the overall score in patients with mania was significantly more than in the patients with depression (Table 5).

Table 1: Distribution of caregivers according to bio-social characteristics.

Variables		Number	%
Age (in years)	16-30	64	71.1
	31-50	23	25.6
	>50	3	3.3
Gender	Female	55	61.1
	Male	35	38.9
Education	12th standard	10	11.1
	Graduate and above	5	5.6
	Junior	24	26.7
	Primary	18	20.0
	Upto High school	20	22.2
	Uneducated	13	14.4
Income	<10000	44	48.9
	≥10000	46	51.1

Table 2: Affiliate stigma scale on caregivers- affective domain.

Dimension	Items of affiliate stigma scale	Disagree		Agree		Chi-square	P value
		No.	%	No.	%		
Affective	I feel inferior because one of my family members is a mental health consumer/child with intellectual disability	64	71.1	26	28.9	16.04	<0.001
	I feel emotionally disturbed because I have a family member with mental illness/intellectual disability	52	57.8	38	42.2	2.18	0.337
	The behaviour name of family member with mental illness/intellectual disability makes me feel embarrassed.	58	64.4	32	35.6	7.51	0.023
	I feel helpless for having a family member with mental illness/intellectual disability.	47	52.2	43	47.8	0.18	0.915
	I feel sad because I have a family member with mental illness/intellectual disability.	40	44.4	42	46.7	0.05	0.976
	I worry if other people would know I have a family member with mental illness/intellectual disability.	45	50.0	45	50.0	0.00	1.000
	I am under great pressure as I have a family member with mental illness/intellectual disability.	45	50.0	45	50.0	0.00	1.000

Table 3: Affiliate stigma scale on caregivers- cognitive domain.

Dimension	Items of affiliate stigma scale	Disagree		Agree		Chi-square	P value
		No.	%	No.	%		
Cognitive	Other people would discriminate against me if I am with (name of family member with mental illness/intellectual disability)	42	46.7	48	53.3	0.40	0.819
	My reputation is damaged because I have a family member with mental illness/child with intellectual disability at home.	52	57.8	38	42.2	2.18	0.337
	People's attitude towards me turns sour when I am with… (name of family member with mental illness/intellectual disability)	47	52.2	43	47.8	0.18	0.915
	Having a family member with mental illness/intellectual disability imposes a negative impact one me.	39	43.3	51	56.7	1.60	0.449
	Having a family member with mental illness/intellectual disability makes me think that I am incompetent compared to other people.	54	60.0	36	40.0	3.60	0.165
	Having a family member with mental illness/intellectual disability makes me think that I am lesser to others.	40	44.4	50	55.6	1.11	0.573
	Having a family member with mental illness/intellectual disability makes me lose face.	44	48.9	46	51.1	0.04	0.978

Table 4: Affiliate stigma scale on caregivers- behavioral domain.

Dimension	Items of affiliate stigma scale	Agree		Strongly agree		Chi-square	P value
		No.	%	No.	%		
Behavioural	I avoid communicating with … (name of family member with mental illness/intellectual disability)	55	61.1	35	38.9	4.44	0.108
	I dare not to tell others that I have a family member with mental illness/intellectual disability	42	46.7	48	53.3	0.40	0.819
	I reduce going out with… (name of family member with mental illness/intellectual disability)	37	41.1	53	58.9	2.84	0.241
	Given that I have a … (Name of family member with mental illness/intellectual disability I've cut down the contacts with my friends and relatives.	33	36.7	57	63.3	6.40	0.041
	When I am with… (name of family member with mental illness/intellectual disability), I would keep an especially low profile	30	33.3	60	66.7	10.00	0.007
	I've cut down the contacts … (name of family member with mental illness/intellectual disability)	35	38.9	55	61.1	4.44	0.108
	I dare not to participate in activities related to … (Name of family member with mental illness/intellectual disability lest other people would suspect that I have a … (name of family member with mental illness/intellectual disability)	30	33.3	60	66.7	10.00	0.007
	Given that I have … (Name of family member with mental illness/intellectual disability, I've cut down the contacts with my neighbours.	37	41.1	53	58.9	2.84	0.241

Table 5: Comparison of caregiver stigma scores between mania and depression cases.

Mania/depression	Mania		Depression		Mann-Whitney test	
	Mean	SD	Mean	SD	U–value	P value
Alienation	14.32	0.82	11.50	1.28	21.00	<0.001
Stereotype endorsement	19.89	1.66	16.31	2.08	28.00	<0.001
Discrimination experience	15.86	2.21	11.92	2.56	16.00	<0.001
Overall	50.07	4.83	39.73	6.01	17.00	<0.001

Table 6: Overall stigma score of caregivers.

Domain	Mean ISMI score	SD
Affective	18.50	1.75
Cognitive	17.63	2.57
Behavioural	23.44	3.05
Overall	59.57	7.54

Table 7: Public perceptions of mental illness.

Variables	Agree		Neutral		Disagree		Chi square	P value
	No.	%	No.	%	No.	%		
Cause of mental illness								
Mental illness is caused by genetic inheritance.	18	20.0	61	67.8	11	12.2	48.87	<0.001
Mental illness is caused by substance abuse.	28	31.1	48	53.3	14	15.6	19.47	<0.001
Mental illness is caused by bad things happening to you	28	31.1	41	45.6	21	23.3	6.87	0.032
Mental illness is God's punishment	36	40.0	49	54.4	5	5.6	34.07	<0.001
Mental illness is caused by brain disease.	30	33.3	43	47.8	19	21.1	9.41	0.009
Mental illness is caused by a personal weakness.	25	27.8	49	54.4	16	17.8	19.40	<0.001
Knowledge of people with mental illness								
People with mental health problems are largely to blame for their own condition.	19	21.1	44	48.9	27	30.0	10.87	0.004
One can always tell a mentally ill person by his or her physical appearance.	22	24.4	38	42.2	28	31.1	4.46	0.108
Mentally ill persons are not capable of true friendships.	20	22.2	36	40.0	24	26.7	5.20	0.074
Mentally ill persons can work.	21	23.3	49	54.4	20	22.2	18.07	<0.001
Mentally ill persons are usually dangerous.	27	30.0	44	48.9	19	21.1	10.87	0.004
Anyone can suffer from a mental illness.	16	17.8	41	45.6	31	34.4	10.80	0.005
Attitude toward people with mental illness								
The mentally ill should be prevented from having children	13	14.4	43	47.8	34	37.8	15.80	<0.001
The mentally ill should not get married.	8	8.9	54	60.0	28	31.1	35.47	<0.001
One should avoid all contact with the mentally ill.	5	5.6	63	70.0	22	24.4	59.27	<0.001
The mentally ill should not be all wed to make decisions, even those concerning routine events.	16	17.8	46	51.1	28	31.1	15.20	<0.001
I could maintain a friendship with someone with a mental illness.	21	23.3	40	44.4	29	32.2	6.07	0.048
I could marry someone with a mental illness.	15	16.7	34	37.8	41	45.6	12.07	0.002
I would be afraid to have a conversation with a mentally ill person.	26	28.9	36	40.0	28	31.1	1.87	0.393
People with mental health illnesses should have the same rights as anyone else.	12	13.3	34	37.8	44	48.9	17.87	<0.001
I would be upset or disturbed about working on the same job as a mentally ill person.	15	16.7	31	34.4	44	48.9	14.07	<0.001
I would be ashamed if people knew that someone in my family had been diagnosed with a mental illness	13	14.4	50	55.6	27	30.0	23.27	<0.001
If I was suffering from a mental health illness, I wouldn't want people to know about it.	15	16.7	51	56.7	24	26.7	23.40	<0.001
People are generally caring and sympathetic towards people with mental illness.	25	27.8	34	37.8	31	34.4	1.40	0.497

The overall stigma score of caregivers was found to be 18.50±1.75 for affective domain, 17.63±2.57 for cognitive domain, 23.44±3.05 for behavioural domain and the total score was 59.57±7.54. The maximum score was found for Behavioural domain (Table 6).

Statistical analysis of public perception of mental illness using chi square test suggests a significant difference of opinion regarding its causes. The most significant difference ($p<0.001$) in the opinion of respondents was found with regards to the questions that the mental illness

is caused by heredity, substance abuse, personal weakness or by God's decree (Table 7).

Pointers pertaining to the understanding of people with mental illness were analyzed by chi square test. A significantly high ($p<0.001$) variation in the opinion existed regarding the question that mentally ill people can work. Opinion also varied significantly ($p<0.05$) over the queries entered in the first, fifth and sixth row of the Table 7.

A chi square analysis of the data about general attitude toward mentally ill people showed a highly significant variation ($p<0.05$) in 10 of the 12 questions put before the subjects (Table 7).

DISCUSSION

Stigma is a serious impediment to the well-being of those who experience it. Many family-caregivers are challenged by the stereotypes and prejudice that result from misconceptions about bipolar affective disorder.

In our study, the analysis of the affective dimension of affiliate stigma scale on caregivers showed significant value for emotional disturbance and pressure due to care of bipolar affective disorder diagnosed patient. The difference between the number of people agreeing and disagreeing in their opinion was significant towards the feeling of inferiority and behavior changes.

Similar results were observed by Marimbe et al (and Zhou et al in regard to the caregivers of bipolar affective disorder patients.[10,11] All these studies observed significant results in emotional disturbance, inferiority complex and mental pressure in taking care of bipolar patient.

However, Grover et al in their study gave contrasting observations to our study by hypothesizing that caregivers in bipolar affective disorder have lesser disruption of routine family activities and lower impact on the mental health of others.[12]

In our study we observed that majority of caregivers were female and association of various domains of caregiver' stigma suggested significant difference between mania and depression subjects regarding alienation ($p<0.001$), stereotype endorsement ($p<0.001$) and discrimination experience ($p<0.001$).

Though most of the caregivers were females as observed in the studies of Chatzidamianos et al, Ellison et al, Imran et al, there was no association between alienation, stereotype association seen in the studies.[13-15] However, discrimination was seen to be having a significant association among the caregivers of the mentally ill patients as in most of the studies observed.

Our study analyzed public perception of mental illness and it suggested a significant difference of opinion regarding its causes. The most significant difference ($p<0.001$) in the opinion of respondents was found with regards to the questions that the mental illness is caused by heredity, substance abuse, personal weakness or by God's decree. A significantly high ($p<0.001$) variation in the opinion existed regarding the question that mentally ill people can work. Opinion also varied significantly ($p<0.05$) towards the factors whether the mentally ill person is dangerous, can a mentally ill person be friended and whether the illness is contagious or not. Analysis of the data about general attitude toward mentally ill people showed a highly significant variation ($p<0.05$) in regard to family, friendship, marriage and job.

Sessions et al, Chatzidamianos et al and Brohan et al have demonstrated in their studies about the social problems and public perception toward patient of mental illness and their caregivers.[13,16,17] Community stakeholders expressed concerns regarding the idea of individuals with mental health issues being treated in the community. They also frequently expressed their belief that the hospital was the appropriate place for those with mental illness to receive treatment before returning to their communities. There were three factors identified that influenced accessibility namely: pre-existing worldviews, the quality of relationships and of communication between those involved, and specific structural impediments. In a reduced multivariate model, 71.6% moderate or high perceived discrimination was seen among people with a diagnosis of bipolar affective disorder or depression, accounted for by levels of empowerment, perceived discrimination, number of areas of social contact, education and employment.

There was significantly high relationship towards the view whether mentally ill person should marry and have families. In our study, there was a significant association between people who agreed to the fact that mentally ill patient should have family vs. those who opposed it. A significant number responded that the mentally ill patients should avoid marrying and starting family.

Similar to our study, Aljedaani, Bassirnia A et al also observed a negative attitude towards mentally ill patients marrying and starting a family.[18,19] While in study of Aljedaani et al there was significant association between mental illness and danger to society, in study Bassirnia et al, caregivers and family members were indirectly affected with mental illness while taking care of the patient.

CONCLUSION

Our study not only aims at raising the possible questions regarding stigma associated with mental illness but also gives us a larger picture about how prevalent it is in our society due to lack of awareness. As physicians, it is our duty to ensure awareness in public and provide assistance to such patients and their caregivers. This would not only improve the prognosis of patients but will also ensure their

well-being, their acceptance in the society and compliance towards long-term treatment strategies.

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