Experiences and Impact of Stigma increases with increase in severity of Obsessive Compulsive Disorder but not with increase in severity of Depression---A Cross-Sectional Study in a Tertiary Care Hospital

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Abstract:

Background: *Most research on stigma revolves around the attitude of general public towards the mentally ill. Assessment of stigma perceived by the persons with mental illness is equally relevant. The present study was intended to assess whether the experiences and impact of stigma increases with increase in disease severity in persons suffering from Obsessive Compulsive Disorder and Depression.*

Methods: *60 patients diagnosed to have Obsessive Compulsive Disorder and 60 patients diagnosed to have Depression were assessed cross-sectional using Y-BOCS and HAM-D to assess severity. Stigma Experiences Scale (SES) and Stigma Impact Scale (SIS) were administered to assess the relationship between severity of illness and stigma. Appropriate tests were applied for statistical analysis.*

Results: *Significant positive correlation was noted between severity of Obsessive Compulsive Disorder (as measured by Y-BOCS) with SES (Pearson's correlation coefficient 0.302 and significant p-value 0.019) and SIS (Pearson's correlation coefficient 0.437 and significant p-value 0.000). It denotes that with increasing severity of obsessive-compulsive symptoms stigma experienced by the patient and impact of stigma on the patient both escalated.*
No significant correlation could be demonstrated between severity of Depression (as measured by HAM-D) with SES (Pearson's correlation co-efficient 0.206 and insignificant p-value 0.114) and SIS (Pearson's correlation co-efficient 0.186 and insignificant p-value 0.156). It denotes that stigma experienced by the patient and impact of stigma on the patient both remained unchanged with increasing severity of Depression.

Conclusion: *Stigma experienced by the patient and impact of stigma on the patient both increased with increase in disease severity in case of Obsessive Compulsive Disorder but not in case of Depression.*

Key Words: Stigma severity, Impact, Experiences, Discrimination, Obsessive Compulsive Disorder, Depression, Disease severity

1. Introduction:

Stigma is a social construct that has been defined by Goffman as 'an attribute that is deeply discrediting'. Recognition of such attribute leads the stigmatized person to be reduced…'from a whole and unusual person to a tainted or discounted one'. Research on mental illness stigma has been conceptually driven mainly by two leading concepts, one by Link and Phelan (Link, B.G., Phelan, J.C., 2001) and the other by Corrigan and colleagues (Corrigan,P.W., 2000). Link and Phelan conceptualized stigma as the co-occurence of it's components: 'labelling, stereotyping, separation, status loss and discrimination'. Corrigan and colleagues proposed that stigma can be broken down into three elements: stereotypes, prejudice and discriminations.

In the literature mental illness stigma has been mainly categorized into public stigma, perceived stigma, experienced stigma and self-stigma.

Public stigma refers to the reactions of the general public towards a group based on stigma about the group (Rusch, N., Angermeyer, M. C., & Corrigan, P. W., 2005). Perceived stigma has been defined by Van Brakel and colleagues as 'people with a (potentially) stigmatized health are interviewed about stigma and discrimination they fear or perceive to be present in the community or society' (Van Brakel, W.H., Anderson, A.M., Mutatkar, R.K., Bakirtzief, Z., Nicholls, P.G., Raju, M.S., 2006).

Perceived stigma can include both what an individual thinks most people believe about the stigmatized group and how the individual thinks society views him or her personally as a member of the stigmatized group (Le Bel, T., 2008). Experienced stigma has been defined by Van Brakel and colleagues as 'experience of actual discrimination and/or participation restrictions' (Van Brakel, W.H., Anderson, A.M., Mutatkar, R.K., Bakirtzief, Z., Nicholls, P.G., Raju, M.S., 2006). Self-stigma refers to the reactions of individuals who belong to the stigmatized group and internalization of public stigma (Corrigan, P.W., Watson, A.C., 2002). Self-stigma has been further defined as 'product of internalization of shame, blame, hopelessness, guilt and fear of discrimination' (Corrigan, P.W., 1998). The persons who turn the prejudice against themselves may agree with the stereotype and have emotional reactions such as low self-esteem (Rusch, N., Angermeyer, M. C., & Corrigan, P. W., 2005). Such self-prejudices then may lead to behavioral responses such as failing to pursue work or seeking treatment options (Rusch, N., Angermeyer, M. C., & Corrigan, P. W., 2005).

Although it is important to understand that the process of self-stigmatizing thoughts unfold in the everyday lives of people with mental illness, to date only limited research has been conducted to conceptualize and distinguish the habitual process of self-stigma from it's cognitive content (Chan, K.K.S., Mak, W.W.S., 2014).

Stigma is one of the key barriers to mental health and mental health reform. Public stigma can negatively affect life opportunities such as employment, suitable accommodation and interpersonal relationships (Stuart, H., 2006). Moreover self and internalized stigma can prevent some from seeking professional help and contribute to decreased adherence to treatment (Stuart, H., 2006). Furthermore stigma may contribute to symptoms of anxiety, depression, paranoia and other conditions that may hinder recovery (Stone, L., & Finlay, W. M. L., 2008). The stigma of receiving a psychiatric 'label' may act as stressor, thus worsening of psychiatric symptoms or obstructing recovery (Stone, L., & Finlay, W. M. L., 2008).

Depression and Obsessive Compulsive Disorder are common debilitating mental illnesses with significant burden of stigma. Both of them are among the top ten leading causes of disability worldwide. This study is intended to look into whether the severity of stigma increases with increase in severity of Obsessive Compulsive Disorder or Depression.

2. Materials and Methods:

Total 120 patients (60 patients primarily diagnosed with Depression as per ICD-10 DCR and another 60 patients primarily diagnosed with Obsessive Compulsive Disorder as per ICD-10 DCR) were studied at Burdwan Medical College and Hospital, Burdwan, West Bengal, India from February 2015 to January 2016 (Period of 1 year). Both male and female patients aged between 18-65 years who could understand and speak in Bengali and who provided valid and informed consent were the study subjects. Exclusion criterias were: Age <18 years and >65 years, any significant co-morbid medical illness, Organic psychiatric illness, Substance dependence disorder as the primary diagnosis except nicotine dependence, and patients who fulfilled syndromal criteria for both Depression and Obsessive Compulsive Disorder. Their socio-demographic and clinical variables were assessed by semi-structured proforma. Severity of Obsessive Compulsive Disorder was assessed by Yale-Brown Obsessive Compulsive Scale (Y-BOCS) and severity of Depression was assessed by Hamilton Depression Rating Scale (HAM-D). Thereafter the questionnaire of Stigma Experiences Scale (SES) and Stigma Impact Scale (SIS) were administered to each of these groups as a semi-structured interview and scored accordingly. Appropriate statistical methods were applied to analyze the results.

2.1 Study Tools:

1.Semi-structured socio-demographic and clinical proforma.

2.Diagnostic guidelines for Depression and Obsessive Compulsive Disorder from the 10th Revision of the International Classification of Diseases and Related Health Problems - Diagnostic Criteria for Research (ICD-10 DCR) [World Health Organization, Geneva (1993) The ICD-10 Classification of Mental and Behavioural Disorders - Diagnostic Criteria for Research]

3.Hamilton Depression Rating Scale (HAM-D): It is the most widely used 17-item clinician administered Depression assessment scale. Each item is calculated as 0-2 to 0-4 and the total score ranges from 0-50. The scale takes 15-20 minutes to administer. It is a clinician rated scale with good reliability and validity. Severity of Depression, assessed by this scale can be scored as follows:

Very severe: >23
Severe: 19-22
Moderate: 14-18
Mild: 8-13
No Depression: 0-7
[Hamilton, M.A. (1960) Rating Scale for Depression. J Neurol Neurosurg Psychiatry, 23, 56-62.]

4. Yale-Brown Obsessive Compulsive Scale (Y-BOCS): It is a 10-item clinician administered Obsessive Compulsive Disorder Rating Scale. Each item has 0-4 scores. Scores of first 10 items of which 5 are for obsessions and 5 are for compulsions are added to get total Y-BOCS score. The total score ranges from 0-40. This scale is available in the form of semi-structured interview and it takes 15 minutes or less to administer. It has good reliability and validity. Severity for patients who have both obsessions and compulsions can be scored as follows:

0-7 ---- Subclinical
8-15 ----- Mild
16-23 ---- Moderate
24-31---- Severe
32-40---- Extreme
[Goodman, W.K., Price, L.H., Rasmussen, S.A., et al. (1989) "The Yale-Brown Obsessive Compulsive Scale." Arch Gen Psychiatry, 46, 1006-1011.]

5. Inventory of Stigmatizing Experiences (ISE): This questionnaire consists of two sub-scales: Stigma Experiences Scale (measuring frequency and prevalence) and Stigma Impact Scale (measuring the intensity of psychosocial impact). The Stigma Experiences Scale consists of 10 questions. The first 2 questions refer to expectations of stigma and are scored on a 5- point Likert type scale using the response categories of never, rarely, sometimes, often and always. These responses were recoded into a binary variable with (1) reflecting a high expectation of stigma (often and always) and (0) reflecting no or low expectation (never, rarely, sometimes). The remaining 8 questions used 3 response categories: no, unsure, yes. These were also recoded into binary categories reflecting the presence (yes) or absence (no and unsure) to each experience. To create the index, scores were summed across all questions. The Stigma Impact Scale consists of 7 questions, 4 of which rate the degree to which stigma negatively impacted their individual quality of life, social contacts, family relations and self-esteem. The other 3 questions rate the degree to which stigma has impacted their family's quality of life, social contacts and family relations. Each question is rated on a scale 0 (lowest possible amount) to 10 (highest possible amount). Items were summed to give the scale score.

The inventory of stigmatizing experiences had been tested for reliability in a heterogeneous sample of psychiatric outpatients. Reliability coefficients were high for both the scales: 0.83 for the Stigma Experiences Scale and 0.91 for the Stigma Impact Scale.

[Stuart, H., Milev, R., Koller, M. (2005) "The inventory of stigmatizing experiences: its development and reliability". World Psychiatry, Vol-4, Supplement-1, 35-39.]

6. Prasad's Socio Economic Status classification: Prasad's classification (1961) based on the per capita monthly income has been widely in use in India. It is computed as: Per capita monthly income = Total monthly income of the family/Total members of the family.

Income limits thus obtained, are far more practical and realistic. For example, to compute a socio economic status classification for May 2014, the multiplication factor will be = 1130 x 4.93/100 = 55.71.
Multiplication factor so derived has to be multiplied with BG Prasad's value of 1961 and rounded off to the nearest rupee. (Rs100*55.71= Rs 5571).
Revised Prasad's classification of Socio Economic Scale (May 2014):

CLASS-I	Rs-5571 and above
CLASS-II	Rs-2786-5570
CLASS-III	Rs-1671-2785
CLASS-IV	Rs-836-1670
CLASS-V	Below Rs-836

(Dudala, S.R., Reddy, K.A.K., Prabhu, G.R. Prasad's socio economic status classification- An update for 2014. Int J Res Health Sci [Internet]. 2014 Jul 31; 2 (3):875-8. Available from http://www.ijrhs.com/issues.php?val=Volume2&iss=Issue3)

2.2 Statistical Analysis:

The data was pooled and statistical analysis was done by using SPSS for Windows version 20. Discrete variables were compared by using Chi-Square test and continuous variables by using independent samples t-test. Categorical variables between groups were analyzed using Pearson's Chi-Square test. Data had been summarized as mean and standard deviation for numerical variables and count and percentages for categorical variables.
All tests were two tailed. A p-value of <0.05 was considered statistically significant (95% confidence interval). Correlation analysis between total scores of Stigma Experiences Scale (SES), Stigma Impact Scale (SIS), Y-BOCS and HAM-D were conducted by Pearson's correlation analysis.

The results and analysis have been described under the headings as follows:

1. Correlation between Y-BOCS and Stigma Experiences Scale
2. Correlation between Y-BOCS and Stigma Impact Scale
3. Correlation between HAM-D and Stigma Experiences Scale
4. Correlation between HAM-D and Stigma Impact Scale
5. Comparison between stigma in Obsessive Compulsive Disorder group and Depression group with the increase in their severity.

3. Ethical Aspects:

Ethical clearance was obtained from the Institutional Ethics Committee. Informed consent was obtained from the individuals before inclusion into the study.

4. Results:

Socio-demograpic and clinical variables: Among the Socio-demographic variables, marital status (p value-0.0344) and type of family (p value-0.0443) were found statistically significant.

Among the Clinical Variables: Mental health now compared to a year ago (p value-0.0013), age at which symptoms first noticed (p value-0.0012), age at first treatment (p value-0.0001), previous consultation for Psychiatric illness, whether hospitalized as a voluntary (p value-0.0328) or involuntary (p value-0.0328) patient and frequency of OPD treatment (p value-0.0489) were found statistically significant.

CORRELATION BETWEEN Y-BOCS AND STIGMA EXPERIENCES SCALE:

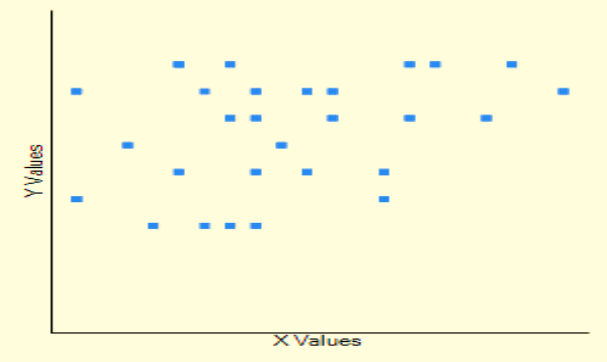
Table 1-a Descriptive Statistics

	Mean	Std. Deviation	N
YBOCS	29.0667	4.99446	60
STIGMA EXPERIENCES SCALE	7.3833	2.08377	60

Table 1-b Correlations[b]

		YBOCS	STIGMA EXPERIENCES SCALE
YBOCS	Pearson Correlation	1	.302*
	Sig. (2-tailed)		.019
STIGMA EXPERIENCES SCALE	Pearson Correlation	.302*	1
	Sig. (2-tailed)	.019	

*. Correlation is significant at the 0.05 level (2-tailed).
b. Listwise N=60



X values- Y-BOCS Y values- Stigma Experiences Scale

Chart 1: Scatterplot depicting statistically significant correlation between Y-BOCS and Stigma Experiences Scale

CORRELATION BETWEEN Y-BOCS AND STIGMA IMPACT SCALE:

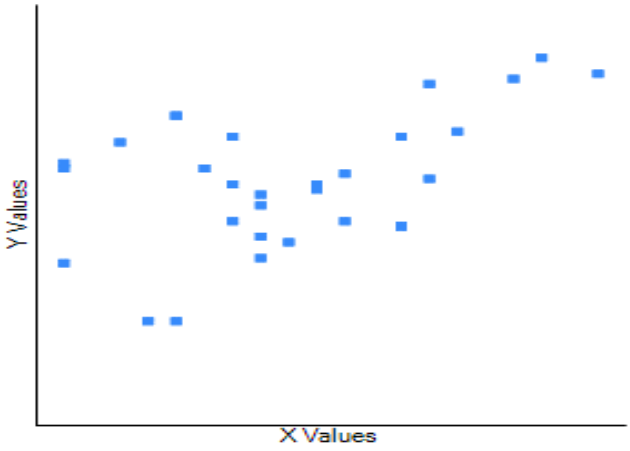
Table 2–a Descriptive Statistics

	Mean	Std. Deviation	N
YBOCS	29.0667	4.99446	60
STIGMA IMPACT SCALE	44.7833	12.51452	60

Table 2–b Correlations[b]

		YBOCS	STIGMA IMPACT SCALE
YBOCS	Pearson Correlation	1	.437**
	Sig. (2-tailed)		.000
STIGMA IMPACT SCALE	Pearson Correlation	.437**	1
	Sig. (2-tailed)	.000	

**. Correlation is significant at the 0.01 level (2-tailed).
b. Listwise N=60



X values- Y-BOCS Y values- Stigma Impact Scale

Chart 2: Scatterplot depicting statistically significant correlation between Y-BOCS and Stigma Impact Scale

CORRELATION BETWEEN HAM-D AND STIGMA EXPERIENCES SCALE:

Table 3–a Descriptive Statistics

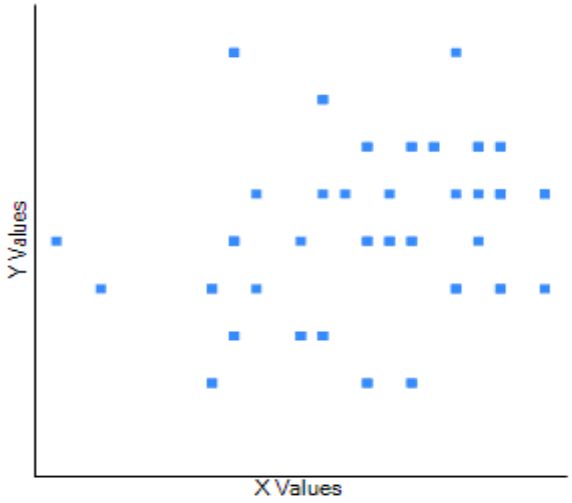
	Mean	Std. Deviation	N
HAMD	29.0333	5.14853	60
STIGMA EXPERIENCES SCALE	5.0833	1.88024	60

Table 3-b Correlations[a]

Table 4-b Correlations[a]

		HAMD	STIGMA IMPACT SCALE
STIGMA EXPERIENCES SCALE	Sig. (2-tailed)		.114
	Pearson Correlation	.206	1
	Sig. (2-tailed)	.114	

a. Listwise N=60 Statistically insignificant



X values- HAM-D Y values- Stigma Experiences Scale

Chart 3: Scatterplot depicting statistically insignificant correlation between HAM-D and Stigma Experiences Scale

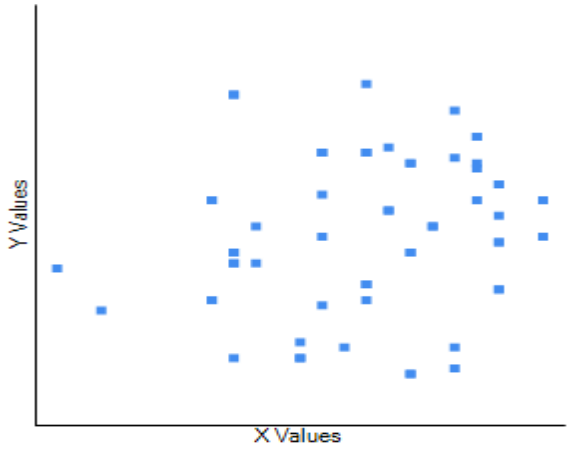
CORRELATION BETWEEN HAM-D AND STIGMA IMPACT SCALE:

Table 4-a Descriptive Statistics

	Mean	Std. Deviation	N
HAMD	29.0333	5.14853	60
STIGMA IMPACT SCALE	33.4667	14.19413	60

HAMD	Pearson Correlation	1	.186
	Sig. (2-tailed)		.156
STIGMA IMPACT SCALE	Pearson Correlation	.186	1
	Sig. (2-tailed)	.156	

a. Listwise N=60 Statistically insignificant



X values- HAM-D Y values- Stigma Impact Scale

Chart 4: Scatterplot depicting statistically insignificant correlation between HAM-D and Stigma Impact Scale

5. Discussion:

Both Obsessive Compulsive Disorder and Depression are debilitating psychiatric illnesses and significant stigma is adherent to both of them. In our study significant positive correlation has been noted between severity of Obsessive Compulsive Disorder (as measured by Y-BOCS) and SES with Pearson's correlation coefficient 0.302 and significant p-value at 0.019 level (Vide Table–1a, 1b and Chart-1). It denotes that with increasing severity of obsessive-compulsive symptoms stigma experienced by the patient escalated.

Significant positive correlation also noted between severity of Obsessive Compulsive Disorder (as measured by Y-BOCS) and SIS with Pearson's correlation coefficient 0.437 and significant p-value at 0.000 level (Vide Table–2a, 2b and Chart-2). It denotes that with increasing severity of obsessive- compulsive symptoms impact of stigma on the patient escalated.

In our study no significant correlation could be demonstrated between severity of Depression (as measured by HAM-D) and SES with Pearson's correlation co-efficient 0.206 and insignificant p-value 0.114 (Vide Table–3a, 3b and Chart-3). It denotes that stigma experienced by the patient remained unchanged with increasing severity of Depression.

No significant correlation could also be demonstrated between severity of Depression (as measured by HAM-D) and SIS with Pearson's correlation co-efficient 0.186 and insignificant p-value 0.156 (Vide Table–4a, 4b and Chart-4). It denotes that impact of stigma on the patient remained unchanged with increasing severity of Depression.

In individuals with Obsessive Compulsive Disorder, emotions such as shame, guilt and fear emerge during the first appearance of the disease. The first reaction is usually a tendency to reject. Individuals try to cope with the symptoms alone. They start to live with the disease by trying to hide their symptoms. Stigma slows down the process and causes them to have negative emotions. The treatment phase can be long-lasting, sometimes challenging and painful. While this process is difficult enough to cope with, the stigma makes this process even harder. The self-perception can be changed and his belief that he is a successful cure is shaken. The negative effect of stigmatization on patience and perseverance prevents the steady maintenance of treatment. These affect the prognosis of the disease negatively (Corrigan, P.W., Miller, F.E., 2004; Hayward, P., Bright, J.A., 1997)

Individuals with Obsessive Compulsive Disorder experience feelings of shame, guilt, fear, and anxiety when they are diagnosed with the disease and prefer to fight alone in the treatment process. Fear of exposure to stigmatization prevents individuals from giving information about their illness to their relatives. In general, individuals tend to keep it confidential from the family and those close to them. This situation causes environmental support to fail. As with all other illnesses, it is important that environmental support is available to deal with the disease during the treatment process (Fennell, D., Boyd, M., 2014). Concerns about accusations and exclusion by those who are close to the family in relation to other people cause problems and distances away from others (Ociskova, M., Prasko, J.,Sedlackova, Z., 2013; Glazier, K., Wetterneck, C., Singh, S., Williams, M., 2015)

Studies show that violence and sexual obsessions are not shared in particular and that it is more difficult to seek help in this regard. Because of the feeling of embarrassment in these obsessions, it is delaying the search for treatment that cannot be shared with health personnel (Glazier, K., Wetterneck, C., Singh, S., Williams, M.,2015). In another study, 738 adults were asked about pollution, symmetry, damage, and taboo obsessions. While symmetry obsessions were defined as Obsessive Compulsive Disorder, subjects with taboo obsessions were exposed to stigma. Failure to have sufficient knowledge of Obsessive Compulsive Disorder leads to the exposure of people with certain obsessions to stigma, such as in this study (McCarty, R.J., Guzick, A.G., Swan, L.K., McNamara, J.P., 2017)

Exposure to stigma, prejudice and degrading attitudes, and discriminatory behavior of the community negatively affect the self-esteem of individuals. The stigma applied by the community is internalized by the individual and starts negative attitudes toward themselves. Individuals are self-stigmatizing and are beginning to label themselves. Self-stigma prevents the individual from making efforts on behalf of the formation of the social environment necessary to participate in social life. It leads to problems in the functionality of individuals (Corrigan, P.W., Watson, A.C., Barr, L., 2006; Link, B.G., Phelan, J.C., 2001). In sum, both the stigma created by other people and the stigma they apply to themselves are affecting negatively the quality of life of the individual with Obsessive Compulsive Disorder.

Stigma also negatively affects the relationship of individuals with their parents. An individual may be exposed to stigma by his or her family. Having inadequate knowledge about Obsessive Compulsive Disorder or having a false belief due to a mental illness leads the families to exclude them. The fact that the parents do not see the symptoms of the disease as illness causes accusations of individuals with Obsessive Compulsive Disorder (Ociskova, M., Prasko, J., Sedlackova, Z., 2013; Corrigan, P., 2004; Glazier, K., Wetterneck, C., Singh, S., Williams, M., 2015). During this period, the individual continues to internalize his self-labeling. The treatment of the individual with Obsessive Compulsive Disorder is badly affected by his/her family and self-stigma of the individual. Stigma thus leads to lack of family support and poor prognosis of the disease.

Stigma affects the relationship of individuals with Obsessive Compulsive Disorder to their friends. Individuals tend to conceal their illness from time to time, even from friends. They try to hide the symptoms of their illness by their anxiety, anger, mockery, exclusion, and stigma exposure by their friends. For this reason, they prefer to stay away from their friends in this period, to be alone. The tendency to go away, the desire to be alone, and the closure causes the individual to be left alone with this disease. In the course of treatment, environmental support is reduced in this way. This causes the individual's self-esteem to be impaired and the prognosis of the treatment to deteriorate (Corrigan, P., 2004; McCarty, R.J., Guzick, A.G., Swan, L.K., McNamara, J.P., 2017)

Stigma also negatively affects children's friendship relationship. Playing games take an important place in a child's life. Friends are needed to play games. Exposure to stigma among friends causes them to move away. The game environment of a child who is away from friends get disappeaed.
Moreover, friendship relationship improves the level of stress and loneliness in a child. The exposure of the child to stigma causes nervous, angry, and anxious behaviors. The family of the child, whose stress level is increasing, is also negatively affected by this situation (Piacentini, J., Langley, A.K., 2004; Futh, A., Simonds, L.M., Micali, N., 2012).

The family that is exposed to the child's stigma is also exposed to stigmatization. Family stigma causes family relations to be influenced, family members to be affected by the friendship relationship, and the level of family stress to be increased. The fact that the parents try to cope with these stress factors negatively affect their participation in the long treatment process of the child. Such problems caused by stigma are adversely affecting the treatment process in children, as well as in adults. Because of stigma, diminished supportive mechanisms, increased stress, emotional impact of the child, and problem of participation in the game are problematic in the progress of the treatment process (Abedi, M.R., Vostanis, P., 2010).

Research findings in different literatures as mentioned above clearly delineate that Obsessive Compulsive Disorder is associated with significant burden of stigma and our research findings corroborate with that.

6. Limitations:

The study was principally cross-sectional in design, hence prevented from coming to the conclusion of cause and effect relationships among the variables. The sample size was limited and it was a hospital based study, not community based.

7. Conclusion:

Stigma is one of the key barriers to mental health and mental health reform. It has been reported that mental illness stigma can have a detrimental impact on the patient's quality of life and also have adverse clinical impacts by interfering with help-seeking behaviour and adherence to treatment, thereby hindering the goals to recovery. Despite the growing efforts to develop anti-stigma programs, little research has been conducted on quantifying experiences of stigma and their psychosocial impacts not only in the western world but also in India. This study has revealed that stigma experiences and stigma impact both increase with increase in disease severity in case of Obsessive Compulsive Disorder but not in case of Depression. These findings suggest that there is a need to develop various tailor-made interventions which may prove more successful than broad and unspecific approaches particularly in case of Obsessive Compulsive Disorder. Our study seems to be unique in it's class because even after exhaustive internet search we have seen that no study has ever been carried out till date that has enquired about whether stigma increases with increase in disease severity either in case of Obsessive Compulsive Disorder or Depression. Nonetheless more research is needed regarding empirical use of various psychosocial interventions including psychoeducation and mindfulness based approaches, precisely targeting both the patients and their caregivers along with widespread anti-stigma campaigning that may usher in a new era in bringing down stigma particularly in the case of Obsessive Compulsive Disorder where stigma increases with increase in disease severity.

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