ORIGINAL ARTICLE

Stigma Causing Delay in Help Seeking Behavior in Patients With Mental Illness

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Abstract

Introduction: *Stigma is a sign of disgrace or discredit that sets a person apart from others. Stigma has detrimental effect on stigmatized persons' life which may even hamper or delay the help seeking behavior, which ultimately increases the duration of untreated mental illness.*

Material And Method: *A cross sectional survey was conducted among 90 psychiatry outpatients attending Manipal Teaching Hospital, Pokhara, Nepal. Discrimination and disclosure sub-scale of the Stigma scale and ISMI-10 was administered to measure the extent of stigma. Help seeking delay was assessed using pre- structured questionnaire. Prediction of help seeking delay due to stigma was identified using logistic regression.*

Results: *Low mean value on the subscales of the Stigma scale indicated low public stigma in the participants. 34% of the study population exhibited moderate to high self stigma. The full model for initial help seeking delay using logistic regression explained 21.8% (Cox and Snell R square) and 31.5% (Nagelkerke R square) of the variance in initial help seeking delay while the model for the recent help seeking delay explained 13.6% (Cox and Snell R square) and 20.8 % (Nagelkerke R square) of the variance in recent help seeking delay. The strongest predictor of both initial and recent help seeking delay was discrimination subscale (OR= 1.11; 95% CI= 1.033- 1.195).*

Conclusion: *Discrimination experienced due to stigmatization leads to delay in help seeking behavior. Public stigma experienced by stigmatized individual acts as a stronger predictor for help seeking delay than self stigma.*

Keywords: Discrimination; disclosure; help seeking delay; stigma

INTRODUCTION

Stigma is a sign of disgrace or discredit, that sets a person apart from others[(1)]. It is seen that people are stigmatized on the basis of physical disability, visible deformity, race, medical disease/disorder as well as mental illness [(2-9)]. Mentally ill patients are discriminated which affects their self confidence, thereby, abstaining them from behaviors that are stigmatized in the community such as seeking help for mental health problem[(10)]. Therefore, among the various barriers that causes help seeking delay, stigma of mental illness is also one of them[(11)].

The aim of this study is to identify extent of stigma associated with mental illness and to see whether stigma associated with mental illness causes delay in help-seeking behavior.

Moreover, no study has been conducted so far in Nepal, regarding delay in help seeking behavior in patients with psychiatric illness due to stigmatization, which accounts to making this study an important one.

MATERIAL AND METHOD

A hospital based, cross sectional, observational study was conducted in the out- patient department of Psychiatry, after obtaining approval from Institutional Ethical Board of Manipal Teaching Hospital, Pokhara, Nepal. Inclusion criteria were: 1)Age: >18 years and <60 years, 2)patient with mental illness for a minimum duration of one year, 3)patient with neither acute symptoms of mental illness nor gross cognitive impairment, 4)absence any other medical conditions. Sample size of 90 was calculated using the formula of sample size for regression, where the number of predictors was assumed to be 5. Data was collected after getting informed written consent by the first author. A pre-structured proforma was used to gather information regarding socio-demographic profile which was followed by scales that measured stigma and help seeking delay.

Measures of stigma

Stigma scale: Public stigma was measured using a self report scale developed in United Kingdom (U.K) by King et al. which has 3 factor structure:- discrimination, disclosure and positive aspects of mental illness. The scales' psychometric properties have been demonstrated to be good[12]. Items in these subscales were rated on a 5- point Likert scale. In this study, positive aspects subscale was omitted to reduce the assessment time. 2 items on Discrimination and 3 items on Disclosure subscales are reverse coded. Higher mean value indicated higher level of public stigma.

Internalized stigma of mental illness-10 (ISMI-10): ISMI- 10 is a brief version of the original ISMI-29 scale. It retains the necessary components of ISMI-29 making it a reliable alternative with an acceptable internal consistency[13,14]. Two items on this scale are reverse coded. Each item was rated on a 4- point Likert scale. Higher mean value indicated higher level of self stigma.

Scales to assess help seeking delay: Using the initial and recent help seeking subscale, which was adopted from a Srilankan study, delay in help seeking behavior due to stigma of mental illness was assessed. The internal consistency of these additional subscales was good, as reported in Srilankan study[15].

RESULT

Mean age of the participants was 35.87 (SD-11.02: min= 18 and max= 58) years, with slightly more males (49) than females (41). Most of the participants (33) were educated up to higher secondary level. Almost half of the participants belonged to upper lower socioeconomic class. Twenty eight participants had schizophrenia followed by anxiety (27), bipolar affective disorder (14), somatoform disorder (11) and psychosis not otherwise specified (10). Half of the participants had consulted a psychiatrist first, after feeling that they have a mental health problem. Median number of days taken to seek help after the onset of mental illness was 2 months (60 days) with inter-quartile range of 12 month (350 days).

Stigma experienced by patients:

Higher mean value on discrimination and disclosure subscales of the Stigma Scale and ISMI-10 indicates higher degree of stigmatization. Mean and SD of the stigma experienced by patients are illustrated in Table 1 given below.

Table 1: Showing descriptive statistics of stigma experienced by the participants

	N	Minimum	Maximum	Mean	SD
Discrimination subscale	90	0	44	16.32	11.38
Disclosure subscale	90	4	44	31.96	8.9
Stigma scale total	90	8	80	48.28	16.64
ISMI-10	90	10	40	21.98	8.83

Severity of internalized stigma:

34% of the participants felt moderate to severe internalized stigma. The frequency and percentage of self stigma experienced is given in Table 2 below.

Table 2: Showing severity of self stigma experienced by the participants

	Frequency	Percent (%)
Minimal	47	52.2
Mild	12	13.3
Moderate	12	13.3
Severe	19	21.1
Total	90	100.0

Help seeking delay in relation to stigma of mental illness

In this study, less than one third participants agreed to have delayed in seeking professional help due to stigma of mental illness, the frequency and percentage of which is shown in Table 3.

Table 3: Showing help seeking delay in relation to stigma of mental illness

Initial delay scale:		**Frequency**	**Percent (%)**
When I first realized I had a mental health problem I was reluctant to seek professional help.	Disagree	65	72.2
	Agree	25	27.8
When I first realized I had a mental health problem I delayed seeking professional help.	Disagree	64	71.1
	Agree	26	28.9
Recent delay scale:		**Frequency**	**Percent (%)**
During the last year have you avoided seeking professional help due to the concerns about being labeled as a mentally ill patient?	Disagree	71	78.9
	Agree	19	21.1
During the last year have you delayed seeking professional help due to the concerns about being labeled as a mentally ill patient?	Disagree	70	77.8
	Agree	20	22.2

Relation of stigma with delay

Means of Stigma scale and ISMI-10 in those having initial or recent delay was compared with those not having initial or recent delay by using Independent Sample T-test, the results of which are presented in Table 4.

Prediction of initial and recent help seeking delay:

Direct logistic regression was preformed to assess the impact of a number of factors, on the likelihood that respondents would report that they initially or recently delayed in help seeking due to stigma. Both the models contained 3 independent variables: discrimination subscale, disclosure subscale and ISMI-10 scale. For initial delay, the full model containing all predictors was statistically significant x^2 (3, N=90) =22.16, P<0.001 indicating that model was able to distinguish between respondents who reported or didn't report initial delay in help seeking. The model as a whole explained between 21.8% (Cox and Snell R square) and 31.5% (Nagelkerke R square) of the variance in initial help seeking delay and correctly classified 82.2% of cases.

For recent delay, the full model containing all predictors was also statistically significant x^2 (3, N=90) =13.14, P= 0.004. The model as a whole explained between 13.6% (Cox and Snell R square) and 20.8 % (Nagelkerke R square) of the variance in the recent help seeking delay and correctly classified 81.1% of cases. As shown in Table 5 and 6 below, only 2 of the independent variable made statistically significant contribution to the model (Discrimination, Disclosure). The result of the logistic regression predicting the initial and recent delay in seeking help is given in Table 5 and Table 6 below.

DISCUSSION:

In this study, the median help seeking delay prior to first visit to a psychiatrist was 2 months (60 days) with inter-quartile range of 12 month (350 days). However, longer delays have been reported in other studies. A study conducted in UK in 1999 reported a median delay of 22 months which included patients with depression, anxiety and sexual disorders[16]. Likewise, a delay of 17 months was reported in a study conducted in Asian American population by Okazaki in 2000 which used the medical records to assess the delay[17]. Another study reported a mean delay of 7 months which was conducted in 2001 by Czuctha and McCay in patients with first episode schizophrenia[18]. A study conducted in Hongkong in 2007 which also included first episode psychosis patients reported a mean delay of 5 months[19].

Table 4: Comparison of stigma experienced by patients with and without initial or recent delay

1) When I first realized I had a mental health problem I was reluctant to seek professional help due to the concerns about being labeled as a mentally ill patient.			
	Disagree (N=65)	Agree (N= 25)	
	Mean (SD)	Mean (SD)	P- value
Discrimination subscale	14.06 (9.62)	22.20(13.54)	0.010
Disclosure subscale	32.69 (8.48)	30.04 (9.88)	0.208
Stigma Scale (total)	46.75 (15.26)	52.24 (19.58)	0.162
ISMI-10	20.65 (8.62)	25.44 (8.63)	0.02
2) When I first realized I had a mental health problem I delayed seeking professional help due to the concerns about being labeled as a mentally ill patient.			
	Disagree (N=64)	Agree (N= 26)	
	Mean (SD)	Mean (SD)	P- value
Discrimination subscale	14.16 (9.66)	21.65 (13.56)	0.015
Disclosure subscale	32.83 (8.48)	29.81(9.75)	0.146
Stigma Scale (total)	46.98 (15.27)	51.46 (19.59)	0.250
ISMI-10	20.81 (8.58)	24.85 (8.98)	0.049
3) During the last year have you avoided seeking professional help due to the concerns about being labeled as a mentally ill patient?			
	Disagree (N=71)	Agree (N= 19)	
	Mean (SD)	Mean (SD)	P- value
Discrimination subscale	14.68 (10.67)	22.47 (12.11)	0.007
Disclosure subscale	32.20 (8.76)	8.76(9.66)	0.622
Stigma Scale (total)	46.87 (16.04)	53.53 (18.21)	0.122
ISMI-10	21.25 (8.75)	24.68 (8.89)	0.134
4) During the last year have you delayed seeking professional help due to the concerns about being labeled as a mentally ill patient?			
	Disagree (N=70)	Agree (N= 20)	
	Mean (SD)	Mean (SD)	P- value
Discrimination subscale	14.83 (10.73)	21.55 (12.28)	0.019
Disclosure subscale	32.16 (8.67)	31.25 (9.93)	0.691
Stigma Scale (total)	46.99 (16.00)	52.80 (18.42)	0.169
ISMI-10	21.30 (8.72)	24.35 (9.06)	0.175

Table 5: Showing logistic regression predicting the initial delay in seeking help

	B	S.E.	Wald	df	P-value	OR	95% CI for OR	
							Lower	Upper
Discrimination subscale	.105	.037	8.001	1	.005	1.111	1.033	1.195
Disclosure subscale	-.114	.035	10.422	1	.001	.892	.833	.956
ISMI- 10	.001	.044	.000	1	.986	1.001	.918	1.092
Constant	-.464	.926	.251	1	.617	.629		

Table 6: Showing logistic regression predicting the recent delay in seeking help

	B	S.E.	Wald	df	P-value	OR	95% CI for OR	
							Lower	Upper
Discrimination subscale	.105	.037	8.042	1	.005	1.111	1.033	1.195
Disclosure subscale	-.069	.035	4.030	1	.045	.933	.872	.998
ISMI- 10	-.039	.045	.728	1	.394	.962	.881	1.051
Constant	-1.048	.960	1.192	1	.275	.351		

Stigma experienced by patients:

Participants reported low mean value on the various measures of stigma used in this study. Comparing the mean score of the discrimination subscale of this study with UK[12] and Sri Lankan sample[15], it is evident that discrimination is felt highest in UK followed by in Sri Lanka then finally in the participants of this study. Possible reason maybe because participants in UK study were recruited from mental health user groups which might have lead them to speak more freely about their prejudiced experience. In Sri Lankan study, 32.2% of the participants were diagnosed with mild to moderate depression[15]. A study in South India showed that patients with moderate to severe depression scored high on stigma scales[20]. In our study, there were no cases of depression, which could explain why our study population scored lower on the discrimination subscale than the Sri Lankan sample.

Comparing the means of the disclosure subscale with the UK and Sri Lankan sample, it was seen that mean score of our study (31.96) was similar to that of Sri Lankan study (29.1) [15] but the mean score in UK population (24.7)[12] was lower indicating that UK sample were more open to disclosing their mental health problems.

Disclosure of mental illness posed greater problem than feeling discriminated, which is reflected by higher mean scores on disclosure subscale than discrimination subscale in this study, which is similar to UK[12] and Srilankan study[15]. In our study, moderate to severe self stigma was reported by 34% of the participants, which is quite close to the findings of the European study conducted across 14 European countries by Brohan et al, which revealed that slightly over 40% participants reported moderate to severe self stigma[21].

Stigma and help seeking delay:

The various factors influencing the help seeking delay maybe the lack of availability/accessibility of the health care services, lack of awareness, cultural beliefs and reluctance to seek help due to stigma[22-26]. Our study focused on whether stigma associated with mental illness caused delay in help seeking behavior. Here, 26 participants accepted that they delayed initially and 20 participants agreed to have delayed follow up visits in the past one year due stigma of mental illness. However, statistically significant difference was only seen in discrimination subscale of the Stigma Scale in both cases. This denotes that patients who accepted to delaying help seeking felt discriminated as compared to those who didn't delay in help seeking.

Relationship between help seeking delay and stigma:

The relationship between help seeking delay and stigma associated with mental illness was assessed to see whether stigma could predict the help seeking delay. The predictor of reporting an initial help seeking delay was discrimination felt, recording an OR of 1.11 (95% CI: 1.033-1.195). This indicates that respondents who felt discriminated were 1.1 times more likely to report initial delay in seeking help than those who didn't feel discriminated. However, it was seen that initial help seeking delay was less with higher score on disclosure subscale recording as OR of 0.89 (95% CI: 0.833- 0.956). Similar finding was seen for help seeking delay in last 1 year. It can be pointed out that as discriminatory experience increases, the delay in help seeking also increases. Moreover, those who avoided disclosing information regarding their mental illness were found not to delay in both initial and recent help seeking behavior. The presumable cause being that people in the patients' immediate vicinity not being aware of the patients' mental health problem as they didn't disclose it, thereby, shielding the patients from being subjected to stigmatization. Moreover, a study by Compton and Easterberg on African- American patients with first episode psychosis, didn't report any association between help seeking delay and stigma[27]. This is possibly because their study included only patients with acute psychosis which might have prompted recognition and necessitated early alleviation of the symptoms.

In our study, there was no statistically significant correlation between self stigma and help seeking delay. However, a study conducted by Eisenberg et al showed that self stigma was significantly but negatively associated with help seeking where as perceived public stigma was not significantly associated with help seeking[28]. Moreover, a study by Hsiu-Lan Cheng and colleagues reported that higher levels of self-

stigma predicted delay in help seeking [29]. Possibly because people with high internalized stigma may worry about what others think of them which—may result in restraining from stigmatized behaviors, such as seeking help for mental health problems.

CONCLUSION:

The strongest predictor for delay in help seeking was discrimination experienced. Disclosure of information regarding one's mental illness was significantly but negatively associated with delay in help seeking. Self stigma didn't predict help seeking delay.

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CONFLICT OF INTEREST: None

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