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Original Article

Experiencing stigma: Nepalese perspectives

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Abstract

Background: Experiencing stigma by patients with mental illness in their day to day lives has substantial importance in treatment, compliance and quality of life. There is dearth of information and researches in experiences/ perceptions and coping of stigma in Nepal.

Aims: The objective of this study was to find out experiences/ perceptions and coping of stigma and stigmatizations among patients with mental illness.

Materials and methods: This is a retrospective, cross sectional study of patients admitted in psychiatry ward. Patients were assessed using self-report questionnaire which focused on beliefs about discrimination against mental illness, rejection experiences, and ways of coping with stigma. Patient's socio demographic profiles were also assessed.

Results: Fifty three patients completed questionnaire concerning various constructs of stigma. There were 29 male patients and 24 female patients. Majority (N=45; 84.9%) were of Hindu religion but there were mixed numbers regarding caste. Most of the patients were aware of the stigma associated with mental illness. There were experiences of rejection by family members and colleagues (N=23; 43.4%) and health care professional (N=16; 30.2%). There were strong perceptions of stigmatization felt by patients in different social circumstances. Though maintaining secrecy and avoidance/withdrawal of stigma provoking scenario were not experienced much, there was a strong sense of advocacy whenever there was any negative view of mental illness. Some of the questionnaire items in "perception", "rejection" and "coping" showed statistical significance (p=0.001).

Conclusion: People with mental illness experience stigma during their course of illness and treatment and it is an important determinant for the relapse of symptoms and non-compliance to treatment. Despite experiencing stigma, patients were generally treated fairly by other people. Patients develop various mechanisms to cope with stigma, mostly secrecy and avoidance. Advocacy and anti-stigma campaign along with positive attitudes of health professionals play important role in decreasing stigmatizing experiences in patients.

Key Words: Stigma, stigmatization, mental illness, coping, perception.

Stigma marks someone different from others, leading to devaluation of that person. Goffman[1] defines stigma as "an attribute that is deeply discrediting", where a person is diminished "from a whole and usual person to a tainted and discounted one". Stigma has become a marker for adverse experiences. There are numerous personal accounts of psychiatric illness, where shame overrides even the most extreme of symptoms[2]. In two identical UK public opinion surveys, little change was recorded over ten years, with over 80% endorsing the statement that "most people are embarrassed by mentally ill people", and about 30% agreeing "I am embarrassed by mentally ill persons"[3]. Stigma obstructs social integration and recovery as a consequence of certain psychosocial processes leading to stigmatization. These psychosocial constructs include labeling, stereotyping, status loss and discrimination in context of power imbalance[4].

Box 1 The experience of STIGMA [2]
Shame
Blame
Secrecy
The "black sheep of the family" role
Isolation
Social exclusion
Stereotypes
Discrimination

Prejudice and discrimination related to mental illness lead to poor treatment compliance, increased social

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isolation, difficulty in finding housing, education and employment and increased probability of alcohol and drug abuse.

Stigma in mental illness is of three types (a) public stigma, (b) self stigma, (c) courtesy stigma (stigma endured by family and care givers). Apart from public stigma and courtesy stigma, self stigma is the most detrimental one. It leads to worsen individuals' recovery[5] and prevent him/her from seeking professional assistance[6].

As described in figure 1, negative public opinion about mental illness leading to self stigmatization becomes a stumbling block for the recovery in patients with mental illness. This starts the vicious cycle of stigmatization, leading to struggle to recovery/exaggeration of illness which further leads to isolation from the mainstream culture. These lead to increased burden on patients and their families[8].

Experiences and perceptions of stigma among patients are important to know so that patients can be given adequate counseling and direction to prevent vicious cycles described before. Though stigma related researches and articles are coming in voluminous amount, most of them are attitude surveys of community and patients' family members and care givers. Very few studies have been done regarding experiences and a concept of stigma among sufferers of mental illness. This study was done in this context and it is the first study of its kind in Nepal, which tries to find out experiences/perceptions and coping of stigma.

Materials and methods

This is a retrospective cross sectional study done at Kathmandu Medical College Teaching Hospital (KMCTH). Department of Psychiatry at KMCTH has in-patients, outpatient services along with clinical psychology facility. It has three psychiatrists, one clinical psychologist, one qualified medical doctor and one psychiatry nurse along with other nursing and non-technical staffs. The department has 12 inpatient beds along with psychotherapy room and recreational facility. The current study was done at the in-patient unit of the department. Patients who were admitted from January 2007 to June 2007 in the hospital were considered for study. All the patients who were admitted in psychiatry ward were assessed.

Following inclusion criteria were used:

1. Patients giving consent for the study
2. Patients aged 18-60 years
3. Based on assessment by the researchers, the patient was in remission or not severely ill

After patients' assessment, a day or two before discharge, they were given self-report questionnaire assessing beliefs about discrimination against individuals with mental illness, rejection experiences and ways of coping with stigma.

During six months of periods, 114 patients were admitted in the psychiatry ward. Eighty seven patients were found to be fit to answer the questionnaire. Twenty two patients refused to give consent. Sixty five patients were recruited. The questionnaire was modified and derived from versions previously used in other studies [9,10,11]. English to Nepali and Nepali to English translation was done with the help of language faculties of university. Wording and sentences were made easier to understand. Participants rated the section on perception of stigmatization and experience of rejection using five point response scales ["Strongly Disagree", "Slightly Disagree", "Can't say/Don't know", and "Slightly Agree", "Strongly Agree"]. Items assessing rejection experiences and coping strategies used three point response scales ["Yes", "Don't Know", "No"]. Participants were advised to answer "Don't Know" if they had not encountered the relevant situation, to avoid overestimating negative responses.

All socio demographic and questionnaire data were recorded on pre-designed proforma. The collected data were checked and coded manually and entered in the computer. Statistical analysis was performed with SPSS program (version 12). Data interpretation was done along with mean, standard deviation. Chi-Square Test was used to assess the statistical significance of the associations between the variables.

Results

There were 53 patients, 29 of them were females and 24 were males. Forty five (84.9%) patients were of Hindu whereas rest followed other religions. Brahmin (N=11; 20.8%), Chettri (N=17; 32.1%) and Newar (N=13; 24.5%) were the predominant casts. Most of the patients were either students (N=19; 35.8%) or worked in agriculture sector (N=11; 20.8%). Majority of patients were secondary passed (N=21; 39.6%) or certificate passed (N=14; 26.4%) (Table 1).

Mean age of patients were 26.7 years and 41 patients gave no evidence of mental illness in the family (Table2). Twenty five patients had been ill for less than six months whereas five had been ill for six months to one year. Twenty three patients had duration of illness for more than one year (Table 2).

Majority of patients strongly perceived stigmatization against mental illness as shown in Table 3. Stigma perception items where patients "Slightly Agree" and

“Strongly Agree” were more than 50 percentage of response were SP1 (Untrustworthy), SP2 (Not Marry), SP4 (Opinion taken less seriously), SP5 (Looked down by people), SP6 ((Less intelligent), SP9 (Not accepted as close friend) and SP10 (Treatment as a personal failure). This shows strong perceptual responses considering stigma. As shown in Table 5, few patients experienced “rejection” as signs of stigma - “Slightly Agree” and “Strongly Agree” having more than 50 percentage of responses in RE2 (Avoided by other people), RE9 (Asked to resign due to mental illness), RE10 (Neglected by health professional).

Patients in this study gave strong opinion regarding advocacy and confrontation of stigma in social circumstances - Advocacy 1 (Correcting friends holding negative view; Yes[N=38(75.5%)]), Advocacy3 (Complain if treated unfairly; Yes[N=38(71.7%)]), Advocacy4 (Participate in social activities; Yes[N=42(79.2%)]), Advocacy5 (Refuse to resign if asked for; Yes[N=34(64.2%)]) as shown in Table 7. There were few “Yes” responses regarding other items of coping against mental illness - “Secrecy” and “Avoidance” and “Withdrawal”. Most of the responses were either “No” or “Don’t know/can’t say” in these items as given in Table 7.

Five items of questionnaire for “stigma perception” [SP2, SP4, SP6, SP9, SP10] had shown statistical significance as given in Table 4. Only two items of “rejection experience” [RE1, RE2] showed statistical significance, as given in Table 6. As described in Table 8, there were many items of “coping” showing statistical significance. Three items of “secrecy” [secrecy2, secrecy3, secrecy 6] showed significance out of seven items. Out of seven items of “avoidance”, only two showed statistical significance [avoidance 5, avoidance 6]. Regarding “advocacy”, out of five items, four items showed statistical significance [advocacy 1, advocacy 3, advocacy 4, advocacy 5]. This implies strong sense of advocacy in patients whenever they are facing stigma and discrimination.

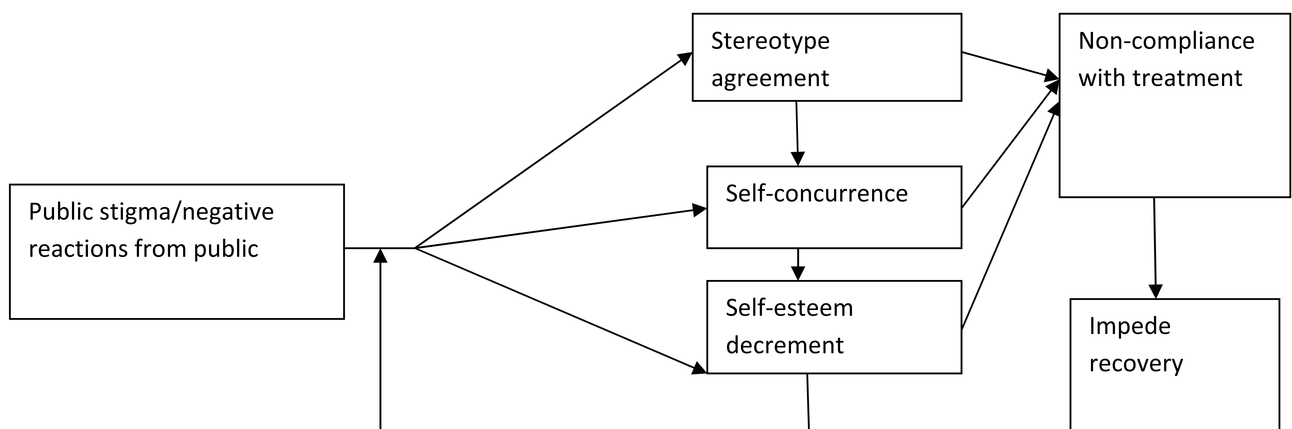

Fig 1: Simplified process of self-stigmatization on recovery [7]

Table 1: Socio-demographic Characteristics of Patients (N=53)

GENDER	Male Female	29 (54.7%) 24(45.3%)
RELIGION	Hindu Buddhist Muslim Christian	45(84.9%) 4(7.5%) 1(1.9%) 3(5.7%)
CASTE	Brahmin Chettri Newar Gurung Rai Magar Tamang Others	11(20.8%) 17(32.1%) 13(24.5%) 1(1.9%) 2(3.8%) 1(1.9%) 3(5.7%) 5(9.4%)
FAMILY TYPE	Joint Nuclear Others	20(37.7%) 29(54.7%) 4(7.5%)
OCCUPATION	Service Agriculture Business Unemployed Labor Student Others	6(11.3%) 11(20.8%) 5(9.4%) 5(9.4%) 1(1.9%) 19(35.8%) 6(11.3%)
EDUCATION	Illiterate Primary Lower Secondary Secondary Certificate Bachelor Others	3(5.7%) 6(11.3%) 6(11.3%) 21(39.6%) 14(26.4%) 2(3.8%) 1(1.9%)

Table 2: Socio-demographic Characteristics of Patients (Contd.)

	Mean	**Minimum**	**Maximum**	**Standard Deviation**
AGE (YEARS)	26.7	12	60	10.05
FAMILY INCOME (RUPEES)	8443	3000	20000	3155.67
FAMILY MEMBERS	5.55	2	16	2.52
DURATION OF ILLNESS	**Number (%)** (a) Less than six months 25 (47.2%) (b) 6 months to one year 5 (9.4%) (c) More than one year 23 (43.4%) **TOTAL** **100 (100%)**			
FAMILY HISTORY OF MENTAL ILLNESS	YES N=12 (22.6%) NO N=41 (77.4%)			

Table 3: Questionnaire of "PERCEPTION" of Stigmatization

ITEMS	Strongly Disagree	Slightly Disagree	Can't Say/ Don't Know	Slightly Agree	Strongly Agree
STIGMA PERCEPTION (SP)					
SP1	6(11.3%)	6(11.3%)	12(22.6%)	19(35.8%)	10(18.9%)
SP2	3(5.7%)	5(9.4%)	16(30.2%)	9(17%)	20(37.7%)
SP3	4(7.5%)	7(13.2%)	12(22.6%)	17(32.1%)	13(24.5%)
SP4	7(13.2%)	3(5.7%)	12(22.6%)	23(43.4%)	8(15.1%)
SP5	4(7.5%)	6(11.3%)	10(18.9%)	15(28.3%)	18(34%)
SP6	4(7.5%)	6(11.3%)	10(18.9%)	20(37.7%)	13(24.5%)
SP7	8(15.1%)	8(15.1%)	13(24.5%)	16(30.2%)	8(15.1%)
SP8	12(22.6%)	5(9.4%)	13(24.5%)	10(18.9%)	13(24.5%)
SP9	4(7.5%)	6(11.3%)	14(26.4%)	21(39.6%)	8(15.1%)
SP 10	9(17%)	4(7.5%)	12(22.6%)	22(41.5%)	6(11.3%)

Table 4: Statistical significance of questionnaire of "PERCEPTION" of Stigmatization

ITEMS	95% Confidence Interval of difference (C.I.) [Lower-Upper]	Statistical significance ["p" value]
STIGMA PERCEPTION (SP)		
SP1	3.05-3.74	0.028
SP2	3.38-4.06	0.001
SP3	3.19-3.86	0.042
SP4	3.08-3.75	0.001
SP5	3.35-4.05	0.011
SP6	3.27-3.93	0.005
SP7	2.79-3.51	0.267
SP8	2.72-3.54	0.371
SP9	3.13-3.74	0.001
SP 10	2.88-3.58	0.001

Table 5: Questionnaire of "EXPERIENCES OF REJECTION" due to stigma

ITEMS	Strongly Disagree	Slightly Disagree	Can't Say/ Don't Know	Slightly Agree	Strongly Agree
REJECTION EXPERIENCE (RE)					
RE1	3(5.7%)	7(13.2%)	21(39.6%)	14(26.4%)	8(15.1%)
RE2	2(3.8%)	9(17%)	12(22.6%)	7(13.2%)	23(43.4%)
RE3	7(13.2%)	11(20.8%)	10(18.9%)	12(22.6%)	13(24.5%)
RE4	11(20.8%)	7(13.2%)	16(30.2%)	14(26.4%)	5(9.4%)
RE5	13(24.5%)	8(15.1%)	17(32.1%)	5(9.4%)	10(18.9%)
RE6	13(24.5%)	7(13.2%)	14(26.4%)	11(20.8%)	8(15.1%)
RE7	11(20.8%)	2(3.8%)	13(24.5%)	14(26.4%)	13(24.5%)
RE8	9(17%)	6(11.3%)	11(20.8%)	12(22.6%)	15(28.3%)
RE9	4(7.5)	5(9.4%)	14(26.4%)	16(30.2%)	14(26.4%)
RE10	12(22.6%)	4(7.5%)	8(15.1%)	13(24.5%)	16(30.2%)

Table 6: Statistical significance of questionnaire of "EXPERIENCES OF REJECTION" due to stigma

ITEMS	95% Confidence Interval of difference C.I.) [Lower-Upper]	Statistical significance ["p" value]
REJECTION EXPERIENCE (RE)		
RE1	3.03-3.62	0.001
RE2	3.4-4.11	0.001
RE3	2.86-3.63	0.736
RE4	2.55-3.26	0.09
RE5	2.44-3.22	0.09
RE6	2.50-3.27	0.476
RE7	2.91-3.70	0.057
RE8	2.94-3.74	0.371
RE9	3.25-3.92	0.017
RE10	2.90-3.75	0.084

Table 7: Questionnaire of "COPING" strategies against stigma

ITEMS		YES	CAN'T SAY/DON'T KNOW	NO
SECRECY	Secrecy1	13(24.5%)	13(24.5%)	27(50.9)
	Secrecy2	14(26.4%)	9(17%)	30(56.6%)
	Secrecy3	12(22.6%)	10(18.9%)	31(58.5%)
	Secrecy4	23(43.4%)	14(26.4%)	16(30.2%)
	Secrecy5	21(39.6%)	9(17%)	23(43.4%)
	Secrecy6	11(20.8%)	5(9.4%)	37(69.8%)
	Secrecy7	25(47.2)	18(34%)	10(18.9%)
AVOIDANCE	Avoidance1	23(43.4%)	15(28.3%)	15(28.3%)
	Avoidance2	20(37.7%)	12(22.6%)	21(39.6%)
	Avoidance3	16(30.2%)	11(20.8%)	26(49.1%)
	Avoidance4	18(34%)	10(18.9%)	25(47.2%)
	Avoidance5	19(35.8%)	7(13.2%)	27(50.9%)
	Avoidance6	13(24.5%)	10(18.9%)	30(56.6%)
	Avoidance7	24(45.3%)	8(15.1%)	21(39.6%)
ADVOCACY	Advocacy1	40(75.5%)	6(11.3%)	7(13.2%)
	Advocacy2	26(49.1%)	13(24.5%)	14(26.4%)
	Advocacy3	38(71.7%)	12(22.6%)	3(5.7%)
	Advocacy4	42(79.2%)	8(15.1%)	3(5.7%)
	Advocacy5	34(64.2%)	14(26.4%)	5(9.4%)

Table 8: Statistical significance of questionnaire of "COPING" strategies against stigma

ITEMS		95% Confidence Interval of difference (C.I.) [Lower-Upper]	Statistical significance ["p" value]
SECRECY	Secrecy1	2.03-2.49	0.025
	Secrecy2	2.06-2.54	0.001
	Secrecy3	2.13-2.59	0.001
	Secrecy4	1.63-2.10	0.282
	Secrecy5	1.78-2.29	0.039
	Secrecy6	2.26-2.72	0.001
	Secrecy7	1.51-1.93	0.041
AVOIDANCE	Avoidance1	1.62-2.08	0.299
	Avoidance2	1.77-2.26	0.252
	Avoidance3	1.95-2.43	0.037
	Avoidance4	1.88-2.38	0.041
	Avoidance5	1.90-2.41	0.003
	Avoidance6	2.09-2.55	0.001
	Avoidance7	1.69-2.20	0.017
ADVOCACY	Advocacy1	1.18-1.57	0.001
	Advocacy2	1.54-2.01	0.052
	Advocacy3	1.18-1.50	0.001
	Advocacy4	1.11-1.42	0.001
	Advocacy5	1.27-1.64	0.001

Discussion

This study has important implications in relation to stigma and its relation to mental illness in Nepali context since this is the first of its type in Nepal. Our patients strongly perceived stigma and feel stigmatized in very social context in which they are residing and they have to cope these situations which has been also substantiated by other studies[11,12,13,14]. This study gives some glimpses about how difficult it is to live with mental illness and to face day to day activities. High agreement in items of sigma perception (marrying someone mental illness, opinion taken less seriously, looked down upon, less intelligent, not accepted as close friends, treatment as signs of failure in Table 3) show that patients could be discriminated in many ways.

A study conducted in the USA among patients with schizophrenia receiving out-patient treatment found that stigma experiences were common, but actual discrimination were less frequent[13]. Half of the samples replied "sometimes", "often" or "very often" on items treated less competent, turned down on job, difficulty in renting apartment, denial in educational opportunities and exclusion from voluntary activities. This response indicates that they were generally treated fairly by others. In one UK study, 56% experienced discriminations within family, 51% from friends, 47% in the workforce and 44% from general practitioners [15]. Another study was done in the USA about racial differences in stigmatizing attitudes toward individuals with mental illness[16] which highlighted the complexity of the stigma process and emphasized the need to consider racial differences in developing interventions targeted to improve public attitudes.

The stigma associated with mental illness also harms self-esteem as shown in this study ("Rejection" items in Table 5). An important consequence of reducing stigma would be to improve the self-esteem of people who have mental illness [17]. Stereotype of danger and desire for social distance persist despite much advancement in psychiatry etiology and management [18]. Studies conducted in China [19], Israel [20] and Fiji [21] gives similar finding that has been deducted in this study.

This study has limitations: (a) it is a non-random sampling. (b) Study was conducted in hospital in-patient set up and it's difficult to generalize these findings. (c) Being self-report questionnaire, it did not facilitate emotional expressions and stigma experiences as could have been done in an interview.

Conclusion

Box 2: Ways to reduce the stigma of mental illness[22]

i. Examine our own attitudes
ii. Update our knowledge of mental illness
iii. Listen to what our patients say about mental illness and its consequences
iv. Watch out for stigmatizing language
v. Advocate for those with mental illness
vi. Add political activism to our daily work
vii. Challenge stigma in the media

To improve the life quality of people with mental disorders, decrease the burden of mental illness on families, realize mental health reforms, and generate new knowledge that can be used to reduce psychiatric disability, stigma must be beaten[23]. Every mental health professional has a very critical role to play to reduce stigma on patients. Due to nature of stigma, it is unlikely that patients will tell "I am stigmatized or experiencing discriminations due to mental illness". Mental health professionals (importantly psychiatrists) should ask about nature of adverse experiences, discrimination, self image, extent of social networks and stereotyping behaviors/languages and incorporate these issues into the treatment plan. Inquiring patients about "stigma" and "prejudice" is as important as asking patients about "suicidal ideation" and "death wish". Strong anti-stigma campaign at the national level will have significant impact on reducing stigma against people with mental illness.

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