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Stigma in Patients Using Mental Health Services

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Abstract:
Background:
Mental illnesses are conspicuous by their universal presence in all geopolitical regions and cultures.[1] De-institutionalization has been the prevalent mental health policy. The success of this broad goal doesn't come easily, however, it has been shown that stigma plays a significant role in accessing treatment, continuing treatment, being compliant, and reaching favorable outcomes and level of functioning; which continues far beyond recovery of a patient.[2] Stigma is defined as a sign of disgrace or discredit, which sets a person apart from others. The stigma of mental illness, although more often related to context than to a person's appearance, remains a powerful negative attribute in all social relations.[3]
Aims and Objectives:
To study the subjective experiences of stigma and discrimination among patients. The purpose of this study was to determine whether stigma experienced by patients using mental health services is related to their age, gender, psychiatric diagnosis, and duration of illness.
Methodology:
Outpatients and inpatients attending Government Hospital for Mental Care, Visakhapatnam were invited to the study. After taking a written informed consent, sociodemographic data was collected. Then they were asked to complete the Discrimination and stigma scale (DISC). The purpose of the DISC is to collect information on how having a diagnosis of mental illness influences an individual's personal and social life. This instrument collects experiences of discrimination in key areas of everyday life and social participation, including work, marriage, parenting, housing, leisure, and religious activities.
Statistical analysis was done on the data, with ANOVA and student t-test, between demographic variables and scores obtained on the scale using SPSS software version 22.
Results:
Patients predominantly belonged to the age group 18 – 29 years (54.48%) and majority of the sample were males (70.9%). The sample consisted mostly Hindus (68.66%) and majority were employed (76.12%). Illiterates (58.21%) and married patients predominated the sample (62.69%).
This study shows that significant difference in the mean scores of subscale-2 (stopping self) were observed between the 4 groups of illnesses with patients with substance abuse having higher scores ($p<0.05$) indicating that they are stopping themselves due to stigma in various aspects such as stopping themselves at work and stopping themselves from being in a relationship. Significant difference in the total scores of subscales -2 (stopping self) were observed between males and females, with females having higher scores ($p<0.05$). Significant difference in the mean scores of subscale-3 (overcoming stigma) were observed between nuclear and joint families, with nuclear families having higher scores ($p<0.05$).
Significant difference in both total and mean scores was observed in all subscales of DISC ($p<0.05$) in relation to the duration of illness indicating that higher the duration of illness, higher is the stigma faced such as unfair treatment and also higher duration of illness is associated with lower positive treatment faced by the patients.
CONCLUSION:
From this study, it can be concluded that stigmatizing attitudes are prevalent in the community in these modern times and patients with mental illness are facing discrimination in various aspects of their life. This study has shown that patients with substance abuse experienced higher discriminatory attitudes than other disorders. This study also shows that with longer duration of illness, the stigmatizing attitudes experienced by the individuals was high. Further research is needed in investigating how best to intervene to prevent or minimize the discriminatory experiences.
Keywords:
Stigma, discrimination, quality of life

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I. Introduction

Mental illnesses are conspicuous by their universal presence in all geopolitical regions and cultures.[1] De-institutionalization has been the prevalent mental health policy. The success of this broad goal doesn't come easily, however, it has been shown that stigma plays a significant role in accessing treatment, continuing treatment, being compliant, and reaching favorable outcomes and level of functioning; which continues far beyond recovery of a patient.[2] Stigma is defined as a sign of disgrace or discredit, which sets a person apart from others. The stigma of mental illness, although more often related to context than to a person's appearance, remains a powerful negative attribute in all social relations.[3] Stigma results from a process whereby certain individuals and group are unjustifiably rendered shameful, excluded and discriminated against.[4]

The mentally ill, their families and relatives, as well as professionals providing specialized care, are still the object of marked stigmatization. These attitudes are deeply rooted in society. The concept of mental illness is often associated with fear of potential threat of patients with such illnesses. Fear, adverse attitude, and ignorance of mental illness can result in an insufficient focus on a patient's physical health needs. The belief that mental illness is incurable or self-inflicted can also be damaging, leading to patients not being referred for appropriate mental health care.[5]

Many factors contribute to such underutilization of services. The attitude of individual patient towards his or her mental disorders is important as far as health seeking is concerned. Adverse attitude towards psychiatry and psychiatrists has been observed among medical professionals, which could be another hindrance in providing adequate mental health services. It is pertinent to study the perceptions, myths, beliefs, and health-seeking behavior for mental health of population.[6] Research suggests that levels of discrimination against people using mental health services are high; however, reports of these people's experiences are rare.[7]

II. Aims And Objectives

To study the subjective experiences of stigma and discrimination among patients. The purpose of this study was to determine whether stigma experienced by patients using mental health services is related to their age, gender, psychiatric diagnosis, and duration of illness.

III. Methodology

STUDY DESIGN:

A cross sectional study was conducted to assess stigma and discrimination in patients using mental health services, with the study population being in-patients and out-patients attending Government Hospital for Mental Care, Visakhapatnam. Prior informed consent was taken from patients who were willing to participate in the study.

A total of 134 patients were involved in the study.

INCLUSION AND EXCLUSION CRITERIA:

In the sample, those patients were included who gave an informed consent and aged between 18 and 60 years and those who were diagnosed with a mental illness according to ICD – 10, chapter V (F) after excluding those with comorbid medical illness and other common stigmatizing illnesses (HIV, TB, leprosy, epilepsy, vitiligo).

TOOLS USED FOR THE COLLECTION OF DATA:

In the current study, following tools were used for collecting the required data:

1. Consent form.
2. General information sheet to collect socio-demographic details.
3. Discrimination and stigma scale (DISC).

DISCRIMINATION AND STIGMA SCALE (DISC)[8]:

The purpose of the DISC is to collect information on how having a diagnosis of mental illness influences an individual's personal and social life. This instrument collects experiences of discrimination in key areas of everyday life and social participation, including work, marriage, parenting, housing, leisure, and religious activities.

The scale underwent psychometric testing to establish the following properties: reliability; validity; precision; acceptability; and feasibility. The final DISC demonstrated good psychometric properties (n=86) including inter-rater reliability (weighted kappa range: 0.62-0.95), internal consistency (α=0.78) and test-retest reliability (n=46) (weighted kappa range: 0.56-0.89). Feasibility, validity and acceptability were also established. In conclusion, DISC is recommended for use in measuring experienced stigma and discrimination.

DISC-12 comprises 32 questions that are rated on a 4-point Likert scale: not at all; a little; moderately; a lot. It contains 4 subscales:

Subscale 1 – Unfair treatment (items 1 - 21)
Subscale 2 – Stopping self (items 22 - 25)

Subscale 3 – Overcoming stigma (items 26 and 27)
Subscale 4 – Positive treatment (items 28-32)

STATISTICAL ANALYSIS:

Both qualitative and quantitative variables were analyzed with the software SPSS statistics version 22. Various measures such as measures of central location (like mean and median) and measures of dispersion (like standard deviation, standard error) were calculated for the quantitative variables.

For the qualitative variables, independent t test and ANOVA were used to identify statistically significant differences between the groups. $p<0.05$ was considered statistically significant with a confidence interval of 95%.

IV. Results

DEMOGRAPHIC DATA:

Table 1: Characteristics of patients in the study (n, %):

Illness diagnosis	Schizophrenia 33 (24.63%)	Substance abuse 37 (27.61%)	Mood disorders 34 (25.37%)	Others 30 (22.39%)
Age	18 - 29 years 73 (54.48%)	30 - 45 years 43 (32.09%)	46 - 60 years 18 (13.43%)	
Gender	Male 95 (70.9%)	Female 39 (29.1%)		
Geographical area	Urban 69 (51.49%)	Rural 65 (48.51%)		
Religion	Hindu 92 (68.66%)	Muslim 24 (17.91%)	Christian 18 (13.43%)	
Employment status	Employed 102 (76.12%)	Unemployed 23 (17.16%)	Student/others 9 (6.72%)	
Marriage status	Unmarried 42 (31.34%)	Married 84 (62.69%)	Divorced /others 8 (5.97%)	
Socioeconomic class	Lower 69 (51.49%)	Middle 62 (46.27%)	Upper 3 (2.24%)	
Family type	Nuclear 117 (87.31%)	Joint 17 (12.69%)		
Literacy status	Literate 56 (41.79%)	Illiterate 78 (58.21%)		

The above table describes the characteristics of the patients in the study with schizophrenia patients being 24.63%, substance abuse 27.61%, mood disorders 25.37% and other disorders (anxiety, conversion and personality disorders) being 22.39%. Patients predominantly belonged to the age group 18 – 29 years (54.48%) and majority of the sample were males (70.9%). The sample consisted mostly Hindus (68.66%) and majority were employed (76.12%). Illiterates (58.21%) and married patients predominated the sample (62.69%).

DISCRIMINATION AND STIGMA SCALE (DISC):

Scoring patterns:

Table 2: Subscale 1 (unfair treatment) of DISC – response patterns:

Subscale 1	**Not at all** **N (%)**	**A little** **N (%)**	**Moderately** **N (%)**	**A lot** **N (%)**
D-1	11(8.21)	35(26.12)	54(40.3)	34(25.37)
D-2	9(6.72)	39(29.1)	57(42.54)	29(21.64)
D-3	22(16.42)	39(29.1)	43(32.09)	30(22.39)
D-4	14(10.45)	45(33.58)	40(29.85)	35(26.12)
D-5	16(11.94)	43(32.09)	33(24.63)	42(31.34)
D-6	20(14.93)	37(27.61)	39(29.1)	38(28.36)
D-7	18(13.43)	34(25.37)	54(40.3)	28(20.9)
D-8	20(14.93)	42(31.34)	42(31.34)	30(22.39)
D-9	20(14.93)	40(29.85)	51(38.06)	23(17.16)
D-10	14(10.45)	47(35.07)	43(32.09)	30(22.39)
D-11	25(18.66)	38(28.36)	45(33.58)	26(19.4)
D-12	23(17.16)	47(35.07)	40(29.85)	24(17.91)

D-13	18(13.43)	42(31.34)	50(37.31)	24(17.91)
D-14	15(11.19)	41(30.6)	48(35.82)	30(22.39)
D-15	18(13.43)	39(29.1)	44(32.84)	33(24.63)
D-16	22(16.42)	38(28.36)	38(28.36)	36(26.87)
D-17	22(16.42)	38(28.36)	37(27.61)	37(27.61)
D-18	11(8.21)	42(31.34)	49(36.57)	32(23.88)
D-19	15(11.19)	40(29.85)	48(35.82)	31(23.13)
D-20	17(12.69)	40(29.85)	48(35.82)	29(21.64)
D-21	16(11.94)	36(26.87)	51(38.06)	31(23.13)

This table shows that unfair treatment was reported moderately and a lot while making and keeping friends (65.67%) followed by unfair treatment by the people in their neighborhood (64.18%) in patients with mental illness.

Table 3: Subscale 2 (stopping self), Subscale 3 (overcoming stigma) and Subscale -4 (positive treatment) of DISC – response patterns:

Subscale 2	**Not at all N (%)**	**A little N (%)**	**Moderately N (%)**	**A lot N (%)**
D-22	20(14.93)	29(21.64)	53(39.55)	32(23.88)
D-23	16(11.94)	32(23.88)	42(31.34)	44(32.84)
D-24	13(9.7)	32(23.88)	58(43.28)	31(23.13)
D-25	10(7.46)	38(28.36)	54(40.3)	32(23.88)
Subscale 3	**Not at all N (%)**	**A little N (%)**	**Moderately N (%)**	**A lot N (%)**
D-26	27(20.15)	57(42.54)	31(23.13)	19(14.18)
D-27	24(17.91)	51(38.06)	39(29.1)	20(14.93)
Subscale 4	**Not at all N (%)**	**A little N (%)**	**Moderately N (%)**	**A lot N (%)**
D-28	21(15.67)	62(46.27)	34(25.37)	17(12.69)
D-29	24(17.91)	52(38.81)	33(24.63)	25(18.66)
D-30	21(15.67)	56(41.79)	29(21.64)	28(20.9)
D-31	20(14.93)	55(41.04)	38(28.36)	21(15.67)
D-32	16(11.94)	59(44.03)	43(32.09)	16(11.94)

This table shows that patients with mental illness have mostly stopped themselves from having a close personal relationship (66.41%) followed by trying to conceal their illness from others (65.18%).

This table also shows that majority of the sample (62.69%) had difficulty in overcoming stigma especially in making friends with people who don't use mental health services as they never made an attempt or made a little attempt in overcoming stigma.

The table also shows that positive treatment was not at all present of present a little only especially by their family members in up to 61.94% patients followed by low levels of positive treatment in work place in 55. 97% of the patient sample.

Table 4: Difference in response patterns of DISC in relation to various disorders:

Subscale-1 (unfair treatment)	**N**	**Mean**	**Std. Deviation**	**F**	**Sig.**
Schizophrenia	21	1.583	0.13344	5.512	**p<0.05**
Substance abuse	21	1.7658	0.13896		
Mood disorders	21	1.6653	0.18958		
Other disorders	21	1.6635	0.11101		
Subscale-2 (stopping self)	**N**	**Mean**	**Std. Deviation**	**F**	**Sig.**
Schizophrenia	4	1.6894	0.13859	13.634	**p<0.05**
Substance abuse	4	1.9797	0.12556		
Mood disorders	4	1.9338	0.11103		
Other disorders	4	1.525	0.07876		

Comparing individual disorders, substance abuse patients were treated with unfair treatment significantly higher than other disorders ($p<0.05$) in areas of unfair treatment by the police and being avoided by other people who knew they had the illness. Patients with a mood disorder have reported higher discrimination faced during situations of public transport and also being physically and verbally abused. The discrimination faced is low in getting welfare benefits or disability pensions and treatment in their religious practices especially in patients with a mood disorder.

When individual disorders are compared with the scoring patterns of subscale 2 (stopping self), significant difference was found ($p<0.05$) in patients with substance abuse who reported that they have stopped themselves from attending various work and training courses and also stopped themselves from having a close relationship with their partners more than other disorders. There is no significant difference in the scoring patterns between various disorders in subscale 3 and 4.

Association between scores and various demographic and illness variables:

Table 5: Difference in scores of DISC in relation to various demographic and illness variables:

		N	Mean	Std. Deviation	F	Sig.
Subscale 2 – Stopping self Total score	Schizophrenia	33	3.5455	0.75378	1.693	p>0.05
	Substance abuse	37	3.7027	0.57081		
	Mood disorders	34	3.6471	0.77391		
	Others	30	3.3	0.98786		
	Total	134	3.5597	0.78051		
Mean score	Schizophrenia	33	1.6894	0.65857	3.597	**p<0.05**
	Substance abuse	37	1.9797	0.56328		
	Mood disorders	34	1.9338	0.61023		
	Others	30	1.525	0.74957		
	Total	134	1.7948	0.6624		
Subscale 2 – Stopping self Total score	Male	95	3.4842	0.82337	7.967	**p<0.05**
	Female	39	3.7436	0.63734		
Mean score	Male	95	1.7368	0.68550	1.063	p>0.05
	Female	39	1.9359	0.58691		
Subscale 3 – Overcoming stigma Total score	Nuclear	117	1.6068	0.57171	2.239	p>0.05
	Joint	17	1.7059	0.46967		
Mean score	Nuclear	117	1.3803	0.77306	5.874	**p<0.05**
	Joint	17	1.2353	0.53379		

This table shows that significant difference in the mean scores of subscale-2 (stopping self) were observed between the 4 groups of illnesses with patients with substance abuse having higher scores ($p<0.05$) indicating that they are stopping themselves due to stigma in various aspects such as stopping themselves at work and stopping themselves from being in a relationship. Significant difference in the total scores of subscales -2 (stopping self) were observed between males and females, with females having higher scores ($p<0.05$) indicating that stigma is leading to a hindrance in their relationships. Significant difference in the mean scores of subscale-3 (overcoming stigma) were observed between nuclear and joint families, with nuclear families having higher scores ($p<0.05$) indicating that nuclear families play a better role in overcoming stigma than the joint families.

Table 6: Difference in scores of DISC in relation to the illness duration of the patient:

Illness duration		**N**	**Mean**	**Std. Deviation**	**F**	**Sig.**
Subscale 1 – Unfair treatment Total score	< 1year	42	14.1429	2.25855	223.453	**p<0.05** .
	1 – 5 years	40	19.4000	1.48151		
	>5 years	52	20.7308	.66023		
	Total	134	18.2687	3.24249		
Mean score	< 1year	42	1.0646	.28761	171.301	**p<0.05**
	1 – 5 years	40	1.7952	.29536		
	>5 years	52	2.0687	.22103		

	Total	134	1.6724	.50240		
Subscale 2 – Stopping self Total score	< 1year	42	3.0952	.98301	15.229	**p<0.05** .
	1 – 5 years	40	3.6000	.74421		
	>5 years	52	3.9038	.29768		
	Total	134	3.5597	.78051		
Mean score	< 1year	42	1.3333	.62143	20.902	**p<0.05** .
	1 – 5 years	40	1.8813	.65287		
	>5 years	52	2.1010	.48065		
	Total	134	1.7948	.66240		
Subscale 3 – Overcoming stigma Total score	< 1year	42	1.8571	.35417	7.709	**p<0.05** .
	1 – 5 years	40	1.6250	.49029		
	>5 years	52	1.4231	.66704		
	Total	134	1.6194	.55920		
Mean score	< 1year	42	1.8690	.69017	34.089	**p<0.05** .
	1 – 5 years	40	1.5000	.60975		
	>5 years	52	.8462	.53814		
	Total	134	1.3619	.74690		
Subscale 4 – Positive treatment Total score	< 1year	42	4.7143	.45723	10.646	**p<0.05**
	1 – 5 years	40	4.0750	.79703		
	>5 years	52	3.9808	1.01923		
	Total	134	4.2388	.86866		
Mean score	< 1year	42	1.9762	.40049	58.609	**p<0.05**
	1 – 5 years	40	1.4150	.47800		
	>5 years	52	1.0038	.42193		
	Total	134	1.4313	.59160		

This table shows that significant difference in both total and mean scores was observed in all subscales of DISC ($p<0.05$) in relation to the duration of illness indicating that higher the duration of illness, higher is the stigma faced such as unfair treatment and also higher duration of illness is associated with lower positive treatment faced by the patients.

V. Discussion

According to a study by E. Corker et al[9] (2013) most commonly reported sources of discrimination faced by the patient were a general report of being avoided or shunned (57%), discrimination by friends (53.3%) and also by family and social life contacts. These findings are similar to the present study which reported unfair treatment while making and keeping friends (65.67%) was highest followed by unfair treatment by the people in their neighborhood (64.18%).

Calum Thornicroft, Allan Wyllie[10] in 2014 reported that the most commonly experienced forms of discrimination were: by family members (30%), in making or keeping friends (28%) and being avoided (shunned) by people who know you have a mental health problem (26%). These findings from the literature and present study suggests that family members and friends have discriminatory attitudes towards the mentally ill persons. These results point out that the family members and friends are the primary contacts to a mentally ill person, and thus patients may have reported higher discrimination being faced from them. This study also reported higher discrimination from the neighbors and this may be explained by the fact that in Indian communities and villages, neighbors also play a role in providing care to the patient.

In a study by Calum Thornicroft, Allan Wyllie[10] in 2014, the majority (57%) of patients suffering from mental illness had concealed or hidden their mental health problems from others, while 37% had stopped themselves from trying to initiate a close relationship.

E. Corker et al[9], in a study in 2013, reported that 72% of participants felt that they had to conceal their mental health status to some extent. In 2008 the figure was 75%. The study also reported that 54% patients had stopped themselves from trying to initiate a close personal relationship. The present study, in line with the other studies, shows that patients with mental illness have mostly stopped themselves from having a close personal relationship (66.41%) followed by trying to conceal their illness from others (65.18%).

Gabbidon J. et al[11] (2013) reported that 55% had stopped themselves from looking for a close relationship and 72% felt the need to conceal their diagnosis. These findings suggest that concealing the mental illness is seen in majority of patients and this is mainly due to the stigma faced by the persons with mentally ill, either at the family level, or at the community level, or at the occupational level. These findings may also reflect

the anticipated discrimination where the patients with mental illness anticipate that they might be discriminated against and thus stop themselves at various areas of life and conceal their illness.

Calum Thornicroft, Allan Wyllie[10] in 2014 have reported that 58% of patients were not being able to use their personal skills or coping abilities to overcome stigma and discrimination. A similar proportion (57%) had difficulty in making friends with people who did not use mental health services. The present study showed similar results with majority of the sample (62.69%) having difficulty in overcoming stigma. The difficulty in using coping abilities and personal skills in overcoming stigma can be explained various factors such as the disease process itself, cognitive impairment, side effects of medication and also by stigma and discrimination faced by the patients.

In the present study, positive treatment was not at all present of present a little only especially by their family members in up to 61.94% patients followed by low levels of positive treatment in work place in 55. 97% of the patient sample. These findings are in accordance with the study by Calum Thornicroft[10] in 2014, where positive treatment was low at work i.e. up to 78% and low with family members up to 60%. Lower positive treatment scores imply higher discrimination faced by individuals, thus in turn affecting their quality of life. The lower levels of positive treatment may be due to the negative attitudes and stigma still prevalent among the community with regard to mental illnesses.

Comparing individual disorders, substance abuse patients were treated with unfair treatment significantly higher than other disorders ($p<0.05$) in areas of unfair treatment by the police and being avoided by other people who knew they had the illness. Patients with substance abuse also reported that they have stopped themselves from attending various work and training courses and also stopped themselves from having a close relationship with their partners. These findings implicate that substance abuse patients faced unfair treatment with police, mostly due to the various legislations against substance abuse and, their dependence pattern of substance abuse might be the cause for neglect of occupation or other activities leading to avoidance by the people they knew.

VI. Conclusion

From this study, it can be concluded that stigmatizing attitudes are prevalent in the community in these modern times and patients with mental illness are facing discrimination in various aspects of their life. These negative and discriminatory attitudes affect the quality of life and treatment compliance.

This study has shown that patients with substance abuse experienced higher discriminatory attitudes than other disorders. This study also shows that with longer duration of illness, the stigmatizing attitudes experienced by the individuals was high. Gender and family type also appear to play role in the stigma faced by patients. Other demographic variables had no significant effect. Further research is needed in investigating how best to intervene to prevent or minimize the discriminatory experiences. Prospective studies are needed to examine causal relationships.

Limitations:

This is a cross sectional study. Longitudinal studies with a control group to compare stigmatizing attitudes along with a study design to know the causal relationship can help in designing future strategies in overcoming stigma. Severity of illness and treatment details were not taken into account in this study which affect the stigmatizing attitudes. Study is conducted at a tertiary hospital. Community based studies with a larger sample size are needed to generalize the results.

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