People with Psychoses Experience

Arvind Kumar*

Abstract

Objectives: The relatively few studies including persons with a mental disorder in general and those with psychoses in particular indicate that they experience being stigmatized. This study assessed the nature and degree of stigma and examined its relationship with various demographic characteristics from the perspective of persons with a diagnosed psychotic disorder.

Methods: The sample comprised of 100 consecutive remitted adults with a psychotic disorder as per DCR, 1CD-10 attending out-patient services. Stigma was assessed using nine questions about people's interpersonal experiences. After computing a composite score, groups experiencing 'high' stigma were differentiated from those having 'low' stigma on the basis of the mean for tjie entire cohort. Data collected was analyzed with SPSS (11.0).

Results: Individuals tend to conceal their disorders for worry of being treated unfavorably and were also treated as less competent. Lower educational levels and family history of psychiatric illness predicted higher stigma.

Conclusions: These results still may be seen as a call for continued attention to stigma as a central and powerful experience of mental illness. Therefore, individuals with psychoses additionally with another family member having a psychiatric disorder and those with lower levels of educational attainment should be the one's who are particularly empowered.

Keywords: People with psychoses, stigma.

INTRODUCTION

Stigmatizing responses to people who have been identified as having a mental illness are seen as a major obstacle to recovery limiting opportunities and undermining self-esteem.[1] For example, research Tas shown that many people with severe mental illness experience discrimination at work,[2"4] when leasing apartments, and in the criminal justice svstem/ ^Moreover, studies have indicated that people with psychoses in general and schizophrenia in particular* experience being stigmatized primarily because of the visible nature of their symptoms.[10,11]

Studies on stigma of mental illness have chiefly studied public attitudes[8,12-14]may be because of the reasoning that one can accurately infer from the apparent conclusions of these studies what must be the experiences of those with mental illness. Stigma experienced by family members of persons with a psychiatric disorder has also been studied given the ‘‘associative” [n] or “courtesy”[10] effects of stigma.

Absent from the explorations of mental illness stigma is the person with the mental disorder who is presumably the recipient of stigma. However, the relatively few studies that have sought information directly from persons with a mental disorder provide evidence that they experience themselves as stigmatized[16-18]expect to be treated poorly by the public,[4,19]encounter rejection and discrimination.[1820] suffer demoralization and reduced life satisfaction connected to stigma, and employ specific strategies to protect themselves from expected rejection and discrimination.[18,22,23]These studies focused on general impressions and expectations of stigma rather than on specific experiences.

The concept of empowerment that is growing in importance in discussions of treatment of mental illness demands that people with mental disorder be included in research about their

* **M.Phil (Psychiatric Social Work) Central Institute of Psychiatry, Kanke, Ranchi, Jharkhand**

lives.' Rapp and colleagues,'[4] for example, have noted that "one of the reasons for the dominance of person-blaming interventions and research is that the people (whom clinicians) seek to help have not been judged to be important informants" (p. 729).

The current study, therefore, was undertaken to explore and expand knowledge of mental illness stigma particularly from the perspective of persons with a diagnosed psychotic disorder. This was done by assessing the nature and degree of stigma and examining its relationship with various demographic characteristics of this group

METHOD

Sample

The sample consisted of 100 consecutive persons attending routine follow-up services at the outpatient of Central Institute of Psychiatry. The inclusion criteria were as follows: age above 18 years: diagnosed having a psychotic disorder as per DCR. ICD-10;[25] absence of clear organic etiology for psychosis; currently in remission (i.e., asy mptomatic for two months); absence of mental retardation.

Measures

Stigma was assessed using nine questions about people's interpersonal experiences as mentally illpersons Questions addressed such topics as specific treatment by others (e.g., being shunned or rejected), negative things seen or heard about mental illness (e g., in mass media), and fears and behaviors relatedto disclosure of status having a mental illness. These items were adopted from a nation-wide surveyconducted by Wahl O.F .[9] and respondents were asked to rate the extent of each experiences on a fivepoint scale from 'never' to 'very often''. A composite stigma score was calculated by adding the scores ofthe nine items. Persons experiencing 'high' stigma were differentiated from those having 'low' stigma iftheir total stigma score was above the average for the cohort.

Analysis

Data collected was analyzed with SPSS (11.0). Descriptive statistics was employed to examine the nature and degree of stigma. Chi-square tests for categorical variables and /-tests for continuous variables were used to find out significant relationships among demographic variables, and low and high stigmagroups.

RESULTS

Demographic Characteristics

The age of the respondents ranged between 19-66 years, with the average age being 34.6 years. There was a preponderance of married respondents in comparison to unmarried respondents (64:36%), while there was a slight preponderance of males compared to female respondents (59:41%). Respondents belonging to the general category were 33%, whereas 46%, 14%, and 7% were from the other backward classes, schedule castes, and schedule tribes respectively. An almost equal number of respondents were from a rural and urban domicile (54:46 %). The educational level of the respondents ranged between 0-19 years, while the mean age was 8.8 years. Unemployed respondents comprised more than three-fourth of the sample (80%), while the rest (20%) were employed. Most of the respondents (63%) were living with their parents and other family members like elder siblings, uncle or aunts, and cousins, while 37% were living independently at home (table 1).

Exactly three-fourth of the sample (75%) comprised of respondents with a mood disorder and 25% had schizophrenia. The age of the respondents at the time of the onset of their illnesses ranged from 9-59 years, with the mean being 27.8 years, while the total duration of

illness ranged from six months to 21 years with the mean being 5.6 years. History of being hospitalized in the past was seen among 42% and the rest 58% were never hospitalized. Family history of a psychiatric illness was present in 43% and the rest (57%) had no such history (table 1).

Nature and Degree of Stigma

The most commonly reported experiences were avoiding telling others outside their immediate family about their mental illness, worrying others will view me unfavorably because I have a mental illness, being treated as less competent by others once their illness was known, and experiencing offensive media portrayals or depictions of mental illness, (table 2). (Note: Throughout the article, only events that occurred at least sometimes are considered to have a frequency worth noting). More than ninety percent (93%) of the respondents indicated that they had avoided telling others outside their immediate families about their mental illness; such experiences occurred often or very often to almost half (42%). Eighty' three percent (83%) worried that others would view them unfavorably if their status as a mental patient were disclosed, more than one-third (37%) said they worried about this often or very often, while almost eighty percent (78%) experienced being treated as less competent by others once their illness was known. Seventy five percent (75%) experienced stigmatizing media depictions of mental illness, such experiences were reported often or very' often by more than one-third (38%).

Seventy percent (70%) reported that they had had the experience of sometimes being shunned or avoided and being told to lower their expectations in life. More than half (55%) reported witnessing unfavorable or offensive comments about mental illness. One of five respondents (22%) never or seldom being treated fairly by others after coming to know- about their mental illness, while almost one-third (32%) never or seldom experienced support from friends who learned they were mentally ill.

Factors Associated with High and Low Stigma Groups

The total stigma score was computed for the entire sample. The median split stigma score was 27.50. hi-square and test indicate that educational level and family history significantly related with high andlow stigma groups.

DISCUSSION

Interpreting the results of this study may depend upon one's degree of optimism. It is possible, for example, to look at these reports as encouraging. Almost four in five experienced being treated fairly by others after coming to know about their mental illness, while almost seven in ten experienced support f rom friends who learned they were mentally ill. That many have been spared sijine of these stigma experiences may be seen as a positive result.

However, the most troubling result is that people with a psychotic illness avoided disclosure of their mental illness outside their immediate family. This however appeared to provide only some relief from stigma as more than one in three feared that others would view them unfavorably if their status as a mental patient was disclosed. Such experiences have led many people with a psychiatric disorder to maintain a secrecy that not only is uncomfortable but may also contribute to the very symptoms-anxiety, depression, paranoia-from which they are struggling to recover producing conditions antithetical to the goals of netovery. Additionally, results suggest that this group of people may still find themselves being shunned, avoided, and treated as less competent; may have witnessed themselves being the object of humor, intolerance, and insensitivity.

Results suggest furthermore, that the experiences of “indirect" i.e., negative remarks and

media portrayals of mental illness that arc not directed toward any particular individual or that do not directly express opinions about persons with psychiatric disorders-is the most common. The sources of such comments and depictions probably do not consider that their audiences might include people with mental illness who could be affected by such remarks. Results suggest that people with mental illness are sensitive to such remarks, which serve as constant reminders of the low esteem in which they are held.[9]

Another result that points to communications that people may not be aware are stigmatizing is the degree to which mentally ill individuals were sensitive to advice about lowering their expectations in life; one in two said this occurred at least sometimes. Moreover, more than three in five reported that they were sometimes treated as less competent The increasing success of consumer run groups is demonstrating that assumptions about the limited potential of people with severe mental illnesses may indeed reflect negative and inaccurate, though lingering, stereotypes of incompetence and limited recovery potential. Consumers are increasingly rejecting these stereotypes as offensive and harmful.[26 27]

Findings that arc of concern are that positive family history of psychiatric disorder and lower educational attainment among the mentally ill individuals significantly showed higher degrees of stigma. individuals with another member in the family also having a psychiatric disorder experience greater stigma may be because of the associative or courtesy effects of stigma. Lower educational levels are associated with poorer functioning in the community as this sample too showed that individuals with higher educational attainment were mostly employed. Poorer levels of functioning in the community further elicit negative responses.[8] One has to however consider that employment is only one of the areas of functioning.

Cautions and Conclusions

The major caution in considering these results concerns the nature of participants. Respondents are not completely representative of the population of people with psychoses attending outpatient services. Firstly, people with substance induced psychotic disorders; delusional disorders; acute and transient Psychotic disorders, obsessive compulsive disorders (OCD) were left out. Whether or not similar stigmatization occurs for those with the above disorders seeking outpatient treatment is not addressed by these data. A broader sample that includes people with all kinds of psychotic illnesses would be useful in determining the extent to which these diagnoses would lead to similar stigma experiences.

Measures like sources of stigma, coping strategies employed, and effects on individual self-esteem and life satisfaction were not examined. Previous studies have indicated that these variables have strong implications in reducing stigma experienced by people with psychiatric disorders.

These cautions, however, do not negate the conclusion that people with psychotic illnesses experience being stigmatized in their life. These results still may be seen as a call for continued attention to stigma as a central and powerful experience of mental illness. Therefore, individuals with psychosesadditionally who also have another family member with a psychiatric disorder, and those with lower level of educational attainments should be the one’s who are particularly empowered.

TABLES

I. Demographic Characteristics (N=100)

Age in years	
Range	19-66
Mean	34.66
S.D.	11.88
Gender, %	
Male	59
Female	41
Marital Status, %	
Married	64
Unmarried	36
Category, %	
General	33
Others (OBC & SC&ST)	67
Domicile, %	
Urban	46
Rural	54
Education in years	
Range	0-9
Mean	9.80
S.D.	4.53
Employment Status, %	
Employed	20
Unemployed	80
Current living situation %	
Independent living in home	36
Living with parents/other family members	63
Diagnosis	
Mood disorders	75
Schizophrenia	25
Age at first onset	
Range	9-59
Mean	27.82
S.D.	11.66
Duration of Illness in years	
Range	0.5-21
Mean	5.6
S.D.	5.8
Family History %	
Present	43
Absent	57
Past Hospitalization	
Yes	42
No	58

II. Responses to Stigma Items

Item	Never	Seldom	Sometimes	Oftem	Very oftem
I have worried that others will view me unfavorably because I am a patient.	13	4	46	22	15
I have been in situations where I have heard others say unfavorable or offensive things about patient and their illnesses.	29	16	44	11	0
I have seen or read things in the mass media (e.g. Television, movies) about patients and their illnesses that I find hurtful or offensive.	10	15	37	15	23
I have avoided telling others outside my immediate family that I am a patient.	0	7	51	14	28
I have been treated as less competent by others when they learned I am a patient.	4	18	63	9	6
I have been shunned or avoided when it was revealed that I am a patient.	18	12	67	3	0
I have been advised to lower expectations in life because I am a patient.	11	19	50	14	6
I have been treated fairly by others who know I am a patient.	6	16	56	12	10
Friends who learned I am a patient have been supportive and understanding.	4	28	26	12	30

III. Relationship o High and Low Stigma Groups and Demographic Characteristics

Variable	**Low Stigma**	**High Stigma**	**X^2/t-test**
Age in years	34.16+10.17	35.16+10.17	.676
Gender			.103
Male	34	25	
Female	16	25	
Marital Status			.060
Married	23	13	
Unmarried	27	37	
Category			.395
General	19	14	
Others (OBC& SC&ST)	31	36	
Domicile			.316
Urban	20	26	
Rural	30	24	
Education in year	10.68+3.80	6.92+4.45	.000*
Employment Status			.803
Employed	41	39	
Unemployed	9	11	
Current living situation			.408
Independent living in home.	16	21	
Living with parents/other family members.	34	29	
Diagnosis			1.000
Mood disorders	37	37	
Schizophrenia	13	13	
Age at first onset	28.30+12.83	27.34+10.48	.683
Duration of Illness in years	4.55+5.16	6.60+6.19	.076
Family History			.004*
Present	14	29	
Absent	36	21	
Past Hospitalization			1.000
Yes	29	29	
No	21	21	

REFERENCES

1. Fink PJ, Tasman A. Stigma and mental illness. Washington DC: American Psychiatric Press, 1992.
2. Farina A, Felner RD Employment interviewer reactions to former mental patients. J Abonorm Psychol 1973, 82: 268-272.
3. Bordieri J, Drehmer D. Hiring decisions for disabled worker looking at the cause. J Applied Soc Psychol 1986, 16:197-208.
4. Link BG Understanding labeling effects in the area of mental disorders an assessment of the effects of expectations of rejection. Am Sociological Review 1987, 52:96-112.

5. Page S. Psychiatric stigma: two studies of behavior when the chips are down. Can J Community Ment Health 1983;2:13-19.
6. Sosowsky L. Explaining the increased arrest rate among mental patients : a cautionary note. Am J Psychiarty 1980; 137:1602-1604.
7. Stedman HJ. Critically reassessing the accuracy of public perceptions of the dangerousness of the mentally ill. J Health Soc Behav 1981;22:310-316.
8. Farina A. Stigma. In Muesser TK, Tarrier N, editors Handbook of social functioning in schizophrenia. Needam Heights, MA Allyn and Bacon, 1998:247-279.
9. Wahl OF. Mental health consumers experience of stigma. Schizophr Bull 1999;25:467-478.
10. Goffman E. Stigma: notes on the management of spoiled identity. Englewood Cliff, NJ: Prentice Hall;1963.
11. Scambler G. Stigma and discase: changing paradigms. The Lancet 1998; 352: 1054-1055.
12. Prabhu GG, Raghuram A, Verma N, Maridass AC Public attitudes towards mental illness: a review. NIMHANS Journal 1984; 2:1-14.
13. Bhugra D. Attitudes towards mental illness: a review of the literature , Acta Psychiatr Scand 1989; 80:1-12.
14. Hayward P, Bright JA. Stigma and mental illness: a review and critique. J Mental Health 1997; 6:345-354.
15. Mehta SI, Farina A. associative stigma: perceptions of the difficulties of college-aged children of stigmatized fathers. J Soc Clinical Psychol 1988;7:192-202.
16. Campbell J, Scraiber R. The well- being project mental health consumers speak for themselves. Report a survey conducted for the California department of mental health office of prevention 1989.
17. Mansouri L, Dowell DA. Perceptions of stigma among the long-term mentally ill. Psychosoc Rehab J 1989;13:79-91.
18. Herman NJ Return to sender: reintegrative stigma management sttrategies of ex-psychiatric patients. J Contemporary Ethnography 1993;22:295-330.
19. Link BG, Cullen FT, Struening E, Shrout PE Dohrewend BP. A modified labeling theory approach to mental disorders: an empirical.Am Sociological Review 1989, 54:400-223.
20. Link BG, Struening EL, Rahav M, Phelan JC, Nuttbrock L. On stigma and its consequences: evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. J Health Soc Behav 1997;38:177-190.
21. Rosenfield S. Labeling mental illness : the effects of received services and perceived stigma on life satisfaction. Am Sociological Review 1997; 62:660-672.
22. Link BG, Mirotznik J, Cullen FT. The effectiveness of stigma coping orientations: can negative consequences of mental illness labeling be avoided ?, J Health Soc Behav 1991; 32:302-320.
23. Reidy DE. Stigma is social death: mental health consumers/survivors tallk about stigma in their lives; education for community intiatives. Holyoke: M.A;1993.
24. Rapp OA, Shera W, Kisthardt W. Research strategies for consumer empowerment of people with severe mental illness. Social Work 1993; 38: 727-735.
25. World Health Organization. International classification of mental and behavioral disorders. Diagnostic criteria for research. Oxford. Oxford University Press; 1993.
26. Deegan P. Spirit breaking: when the helping professions hurt. J California Alliance Mentally Ill 1990; 5:18-20.
27. Deegan P. A letter to my friend who is giving up, Humanistic Psychologist 1994;18:301-13.