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Stigma in families of individuals in early stages of psychotic illness: family stigma and early psychosis

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Abstract

Aim—Stigma is pervasive among families of individuals with psychotic disorders and includes both general and ‘associative’ stigma – that is, the process by which a person is stigmatized by virtue of association with another stigmatized individual. These forms of stigma may present a barrier to help seeking. However, little is known about stigma in the early stages of evolving psychotic disorder.

Methods—Family members of 11 individuals at clinical high risk and of nine patients with recent-onset psychosis were evaluated for generalized and associative stigma using the Opinions about Mental Illness (modified) and the Family Experiences Interview Schedule.

Results—In this small study, the level of stigma was low, as families endorsed many supportive statements, for example, patients should be encouraged to vote, patients want to work, mental illness should be protected legally as a disability and parity should exist in insurance coverage. Families also endorsed that both talking and a belief in God and prayer can help someone get better. Only ethnic minority families of individuals with recent-onset psychosis endorsed a sense of shame and need to conceal the patient's illness.

Conclusions—This preliminary study suggests that family stigma is low in the early stages of psychotic disorder, a finding that requires further investigation in a larger and more representative sample. This may be an opportune time to engage young people and families, so as to reduce duration of untreated illness. Ethnic differences in stigma, if replicated, highlight the need for cultural sensitivity in engaging individuals and their families in treatment.

Keywords

ethnicity; families; prodrome; psychosis; stigma

Introduction

The World Health Organization World Health Report describes stigma as one of the remaining greatest obstacles to the treatment of mental illness.¹ Stigma is the social process that derives from a situation of power imbalance, in which labelling, stereotyping, separation, status loss and discrimination occur.² In relation to mental illness, stigma refers to the cluster of negative

attitudes and beliefs that motivate the general public to fear, reject, avoid and discriminate against people with mental illnesses. Across the world, the stigma of mental illness causes immense suffering: its consequences include stress and psychiatric morbidity, problems in relationships, restrictions on social participation and limitations in employment and educational opportunities.³ Stigma may also interfere with help seeking, as individuals are motivated to avoid the label of mental illness and to avoid being associated with mental health care.⁴

Schizophrenia, in particular, because of its distinctive symptoms, disruptive behaviour and perceived dangerousness,⁵ is a target for stigma and discrimination. Persons suffering from schizophrenia and their close family members are such frequent targets of stigma that in 1996 the World Psychiatric Association initiated an international campaign to combat the stigma and discrimination associated with schizophrenia in particular.^{6,7} In the ensuing decade, further reports documented the negative impact of stigma on families of schizophrenia patients, leading to sleep and relationship disturbances,⁸ poor psychological well-being⁹ and decrement in quality of life.¹⁰ The stigma experienced by family members is described as 'courtesy',¹¹ or 'associative',¹² stigma, which is the process by which a person is stigmatized by virtue of association with another stigmatized individual. For example, relatives of patients report being stigmatized through assignment of guilt and through experiences of social exclusion and withdrawal by virtue of having a family member with schizophrenia.^{13,14} It has been shown that as many as 70% of caregivers of individuals with mental illness believe that most people devalue patients and that this devaluation extends to their families.¹⁵

In the early stages of psychosis, it is families who primarily seek help for symptomatic family members.¹⁶ The importance of understanding stigma experienced by families of young people with psychotic symptoms is that it may interfere with help seeking,¹⁷ likely through maladaptive coping and increased thresholds for treatment initiation (Michael Compton, pers. comm., 2008). If families do not seek help because of stigma, young people are at risk for longer durations of untreated illness, especially of psychosis (Michael Compton, pers. comm., 2008), which is associated with worse long-term outcome.^{18,19} One study has demonstrated that stigma is associated with family burden for families of recent-onset psychosis patients.²⁰ It is of interest whether families' experience of stigma occurs during the evolution of psychotic symptoms in clinical high-risk individuals.²¹ These are young people who typically have become somewhat odd and socially withdrawn, with symptoms of dysphoria and anxiety and subthreshold psychotic symptoms; that is, suspiciousness instead of paranoia, illusions rather than hallucinations and overvalued ideas that have not yet coalesced into the fixed false beliefs which constitute delusions.²²

In this exploratory study, we evaluated stigma experienced by families of not only patients with recent-onset psychosis but also in young people identified as prodromal or at heightened clinical risk for psychosis.²³ It may be expected that behavioural changes in clinical high-risk individuals might lead to some generalized and associative stigma in their families.²¹ However, we hypothesized that stigma would be endorsed more by families of recent-onset psychosis patients (as compared with those of ultra high risk individuals) as they would have more experience with psychotic symptoms and treatment systems (especially inpatient hospitalization), and would have dealt with stigmatizing diagnoses.

Methods

Sample

The sample obtained for the present study represents a convenience sample of patients identified from both the New York State Psychiatric Institute at Columbia University and Yale University's Department of Psychiatry. The clinical ultra high-risk group of individuals was

identified as prodromal to psychosis using the Structured Interview for Prodromal Syndromes/Scale of Prodromal Symptoms.²³ Herein, they will be referred to as 'prodromal' individuals. For the recent-onset psychosis patients, diagnoses in New York were made using the Diagnostic Interview for Genetic Studies,²⁴ whereas diagnoses in the Yale psychiatric system of care were obtained from chart review. Individuals were asked to nominate a preferred identified family member for interview. Individuals provided consent for their family members to be contacted and to be invited to participate. At both sites, family members provided written informed consent for participation.

No participants were excluded or refused to participate. The only exclusion criterion was an inability to speak English and/or inability to give consent, either on the part of the individual or any family member. (Exclusion of individuals who were unable to speak English restricts the representativeness of the sample, in particular regarding putative ethnic differences in familial stigma.) This study was approved by the Institutional Review Boards at the Yale School of Medicine, New York State Psychiatric Institute and the Columbia Presbyterian Medical Center.

Measures

To assess families' general attitudes about mental illness, we used a modified and expanded version of the Opinions about Mental Illness (OMI) scale.²⁵ The OMI covers salient elements of stigma, such as the linking of mental illness labels to: (i) stereotypes, that is, 'People who are mentally ill let their emotions control them'; (ii) difference, that is, 'There is something about mental patients that makes it easy to tell them from other people'; and (iii) status loss and discrimination, that is, 'Anyone who is in a hospital for a mental illness should not be allowed to vote'. The OMI was modified to reduce social desirability bias, that is, 'All patients in mental hospitals should be prevented from having children by a painless operation' was modified to 'People with mental illness probably shouldn't have children'. Thirteen new items were added to reflect current trends in public attitudes towards mental illness; for example, 'The Americans with Disabilities Act should cover people with mental illness' and 'Celebrities and famous people shouldn't disclose their histories of mental illness'. Each item required a true or false response. To reduce response bias, items were worded either positively or negatively, with a score of 'zero' for the stigmatized response. Therefore, lower scores reflected a more negative attitude towards mental illness, and hence more stigma.

The Family Experiences Interview Schedule (FEIS)²⁶ primarily assesses family burden; it includes a stigma subscale that probes 'associative' stigma, that is, worry about discovery of illness, concern that others would act differently or avoid the family, the impetus to hide the illness or keep it secret and feelings of shame. As with the OMI, stigmatized responses are scored as 'zero', such that a lower score indicates a greater degree of stigma.

Items from both the OMI and FEIS scales were separately summed to calculate total scores for each scale: chi-squared analyses were done to determine differences in family response by stage of illness or ethnicity.

Results

Sample

There were nine prodromal individuals and 11 with recent-onset psychosis. Both groups were primarily male ($n = 8$ per group), although prodromal individuals were younger (15.9 years (standard deviation, SD 2.5) vs. 20.6 years (SD 2.9)) as were their family members (41.1 years (SD 7.9) vs. 47.7 years (SD 7.8)). Additionally, the ethnic distribution of the two groups was different. The family informants for prodromal individuals were primarily white (six of nine),

with only two African American and one Hispanic individuals. By contrast, there were equal proportions (three each) of these three groups among family members of recent-onset psychosis patients, with one Asian American and one 'other' (mixed race) family member. Family members were primarily parents, with only three being non-parental caregivers (adult siblings and aunt).

On the OMI Scale, which measures generalized stigma, family members of both groups endorsed a number of 'supportive' items, including that patients should be encouraged to vote, that patients want to work, that mental illness should be protected legally as a disability, that parity in insurance coverage should exist and that believing in God and prayer could help someone get better (Table 1). There were no supportive items that were endorsed by fewer than 40% of families. Consonant with this, only a small portion of the families endorsed negative or stigmatized items, that is, patients don't pay attention to how they look; patients can only do basic jobs; children shouldn't visit psychiatric hospitals; that it is easy to tell by looking at someone if they have mental illness; mental illness should be listed on driver's licenses and patients should not be police officers (Table 1). No one endorsed the idea that talking doesn't help much with mental illness. There were only a few negative or stigmatized items that had high levels of endorsement ($>75\%$), which included that dealing with a patient could be like dealing with a young child and that mental illness can lead someone to behave in ways that make other people laugh (Table 1).

For generalized stigma, families of prodromal individuals were twice as likely to endorse the idea that people who were once patients in a psychiatric hospital could be trusted as babysitters (Table 1). Consonant with this, some 'stigmatized' items were endorsed more by families of recent-onset psychosis patients: more tax money should be spent on building psychiatric hospitals; it is inadvisable to marry someone with mental illness; patients should probably not have children; celebrities should not disclose their history of mental illness; and a psychiatric patient has many things wrong (as opposed to a heart patient) (Table 1). These discrepancies, however, may be explained by the ethnic differences between the groups, and differential endorsement by ethnicity.

Associative stigma was endorsed more by family members of patients with recent-onset psychosis than by family members of prodromal individuals ($\chi^2 = 2.22$, degrees of freedom (d.f.) = 18, $P < 0.05$) (Table 2). Many of these items were endorsed primarily by the ethnic minority families of recent-onset psychosis patients; for example, worry others would find out about the patient's condition, feeling the need to sometimes hide the illness of their family member and a sense of embarrassment or shame about the illness (Table 2). By contrast, generalized stigma was equal in the two family groups ($\chi^2 = 1.70$, d.f. = 16, $P = 0.11$). Ethnic minority families did not differ overall from white families as to associative ($\chi^2 = 0.879$, d.f. = 18, $P = 0.39$) or generalized stigma ($\chi^2 = 1.205$, d.f. = 16, $P = 0.246$).

The preponderance of associative stigma among these family members of patients with recent-onset psychosis is reflected in qualitative research with this same cohort; for example, concerns that healthy siblings of the patient would be ostracized and teased as a result.²² By contrast, stigma was not a theme that was prominent among families of prodromal individuals.²⁷

Of note, there was no association of associative stigma with subjective or objective family burden (data not shown), which were also measured with the FEIS²⁶ in this cohort of families of individuals in early stages of psychosis.²⁸ This is in contrast to a finding of association of burden and stigma in families of first-episode schizophrenia patients using different scales.²⁰

Discussion

This is an exploratory study of both generalized and associative stigma in families of young people in early stages of psychotic illness. Overall, the level of stigma was low, though families of patients with recent-onset psychosis endorsed more associative stigma than families of young people identified as prodromal to psychosis.

In this small study, families generally agreed that work is good for patients, believing that individuals with mental illness want to work, and can do more than basic jobs, even assuming the roles of police officers or security guards. This may be promising, as supportive employment programmes have proven efficacious for individuals with psychotic disorder, even those with recent-onset psychosis.^{29,30} Additionally, *all* families endorsed the need for parity in coverage of mental illness, which is not surprising, given the difficulties they report having with insurance companies.²² Of note, the Presidential Commission on Mental Health Care has identified unfair treatment limitations and financial requirements placed on mental health benefits in private health insurance as one of the main obstacles preventing Americans from receiving excellent mental health care.³¹ Eighteen of the 20 family members interviewed endorsed that believing in God and prayer can help someone get better. This corresponds to other studies that find a high prevalence of religiosity and religious coping in patients with psychosis.^{32,33} Also, *all* 20 families disagreed with the item 'Talking doesn't help much with mental illness'. Qualitative research and focus groups with family members of patients early in the course of psychotic disorder show that family members greatly desire information.^{14, 22,34,35} Several specialized services for first-episode psychosis patients have implemented multifamily psychoeducational groups, which have been well received, leading to decreases in reported burden.^{34,36}

Associative stigma was endorsed at greater rates by families of recent-onset psychosis patients than by families of prodromal individuals, a finding that merits further investigation in a much larger and more representative sample. If replicated, this finding suggests that the development of a psychotic episode and its treatment may increase families' experiences of they themselves being stigmatized,²² whereas more general attitudes about mental illness may not significantly change. For example, a family member of an individual with recent-onset psychosis articulated: 'The S word – schizophrenia – I'm going to deal with it for the rest of my life.'²²

Of preliminary interest, there was a greater prevalence of ethnic minorities among families of recent-onset psychosis patients. Although this may be simply due to ascertainment differences of these small convenience samples, this finding is nonetheless consistent with literature suggesting that ethnic minorities, in particular African Americans, are more likely than whites to delay seeking help from voluntary professional mental health services.^{37–41} It has been posited that differential stigma among African Americans may account for this racial/ethnic disparity in help-seeking behaviour, a theory lent support by emerging qualitative research data documenting a pervasive fear of the labels of mental illness among African American families of first-episode psychosis patients (Michael Compton, pers. comm., 2008).

A few other preliminary ethnic differences in reported stigma emerged, especially among families of recent-onset psychosis patients, which would be useful to examine in a larger study that was not confined to individuals fluent in English. For example, only a quarter of ethnic minority first-episode families felt that a former inpatient could be trusted as a babysitter, in contrast to two-thirds of ethnic minority family members of prodromal individuals and all white families in the study. This is consonant with documented worries among African Americans about the dangerousness of psychiatric patients,⁴² especially those who have schizophrenia.⁴³ Further, primarily ethnic minority families of patients with recent-onset psychosis endorsed associative stigma items such as a sense of shame and a need to conceal the patient's psychotic

illness. This is consistent with findings in the general population that African Americans are more likely to believe that individuals could be 'contaminated' by mental illness in a family member.⁴⁴ This theme of contamination may also resonate with minority families' opinions that it is inadvisable for patients to marry or have children, and that they should not disclose their history of mental illness. Of note, however, minority families of prodromal individuals did not endorse any of the associative stigma items, suggesting that stage of illness may have an impact on stigma experience by families of young people early in the course of psychotic disorder.

Limitations

This is a small exploratory study of generalized and associative stigma in families of young people with early stages of psychosis. There are several limitations in this study, the primary one being that stigma was evaluated only in those families who had sought treatment and obtained care for family members in early stages of psychotic disorder. This may be less of an issue for the patients with recent-onset psychosis who had been hospitalized, often involuntarily, as a consequence of the crisis of psychosis onset. However, families of prodromal individuals may be far less typical, in that they accessed care to a specialty clinical research programme. Therefore, stigma is likely greatly underestimated for families of prodromal individuals in general, as the study did not capture individuals with prodromal symptoms (and their families) who are in the community and not receiving care.

Another major limitation in this study is the exclusion of individuals and families who do not speak English, which limits the representativeness of the sample, and which also makes very tentative any apparent findings of ethnic differences in stigma for families. Other limitations include the use of scales that do not have established psychometric properties in family members of patients.

Further study of stigma in families of individuals with evolving psychotic disorders will require larger and more representative samples to determine if these preliminary ethnic differences in stigma are replicable, and to evaluate their relationship to other factors of interest, including socioeconomic status^{45–47} and cultural mistrust.^{48–50}

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TABLE 1
Generalized stigma in families of prodromal and recent-onset psychosis patients

Generalized Stigma		(Number of family members who endorsed)					
		Prodromal (<i>n</i> = 9)			Recent-onset (<i>n</i> = 11)		
		Total (<i>n</i> = 9)	White (<i>n</i> = 6)	Ethnic minority (<i>n</i> = 3)	Total (<i>n</i> = 11)	White (<i>n</i> = 3)	Ethnic minority (<i>n</i> = 8)
‘Opinion about Mental Illness Scale’ items (* <i>P</i> < 0.05 for prodromal vs. recent onset)							
Positive statements							
1	Patients in state psychiatric hospitals should be encouraged to vote.	6	4	2	9	3	6
4	Most people with mental illness want to work.	9	6	3	9	3	6
7*	Most people who were once patients in a psychiatric hospital could be trusted as babysitters.	8	6	2	5	3	2
15	Mental illness is caused by a disease of the nervous system.	4	3	1	5	0	5
17	Patients on a psychiatric unit should play a large role in decisions about how the unit is run.	4	3	1	6	2	4
Negative statements							
2	Dealing with a person with mental illness can at times be like dealing with a young child.	9	6	3	8	2	6
3	Most people with mental illness do not pay attention to how they look.	2	1	1	3	0	3
5	Most people with mental illness generally can do only basic jobs, not only complex work.	2	1	1	4	0	4
6*	More tax money should be spent on building psychiatric hospitals.	3	1	2	9	2	7
8	Mental illness is different from other illnesses, such as diabetes.	4	2	2	8	2	6
9	Small children shouldn't visit psychiatric hospitals.	2	1	1	4	1	3
10*	It is not advisable to marry someone with mental illness.	0	0	0	4	1	3
11*	People with mental illness probably shouldn't have children.	0	0	0	4	1	3
12	It is easy to tell by looking at someone if they have mental illness.	0	0	0	2	0	2

Generalized Stigma		(Number of family members who endorsed)					
		Prodromal (n = 9)			Recent-onset (n = 11)		
		Total (n = 9)	White (n = 6)	Ethnic minority (n = 3)	Total (n = 11)	White (n = 3)	Ethnic minority (n = 8)
13*	A heart patient only has one thing wrong, while a psychiatric patient has many problems.	0	0	0	5	0	5
14	Nervous breakdowns can result from working or studying too hard.	4	3	1	9	3	6
16	Although a people with mental illness can look okay, it is important to remember that they are ill.	6	3	3	10	2	8
New items							
Positive statements							
18	The American with Disabilities Act should cover people with mental illness.	8	5	3	11	3	8
19	There should be parity (equal coverage) between mental health and other medical treatment by HMOs and third-party payers.	9	6	3	11	3	8
25	People with mental illness have some control over the course of their illness.	6	4	2	7	2	5
28	Believing in God and prayer can help someone get better.	8	5	3	10	2	8
Negative statements							
20*	Celebrities and famous people shouldn't disclose their histories of mental illness.	0	0	0	4	0	4
21	Mental illness should be listed as a restriction on drivers' licenses, along with corrective lenses, hearing impairment and prosthetic devices.	2	1	1	4	1	3
22	People with mental illness should not be police officers or security guards.	3	2	1	4	0	4
23	Mental illness can lead someone to behave in ways that make other people laugh.	8	5	3	9	3	6
24	When a person develops a serious mental illness, it is as if a part of them has died.	4	2	2	6	1	5
26	Most people with mental illness need to be in the hospital.	1	0	1	1	0	1
27	Talking doesn't help much with mental illness.	0	0	0	0	0	0

Generalized Stigma		(Number of family members who endorsed)					
		Prodromal (n = 9)			Recent-onset (n = 11)		
		Total (n = 9)	White (n = 6)	Ethnic minority (n = 3)	Total (n = 11)	White (n = 3)	Ethnic minority (n = 8)
29	Artistic and creative people are more vulnerable to mental illness.	2	2	0	5	1	4
30	People with mental illness are less rational and more vulnerable to their emotions.	4	3	1	7	3	4

HMO, health maintenance organization.

TABLE 2
Associative stigma in families of prodromal and recent-onset psychosis patients

Family Experiences Interview Schedule Stigma Scale (associative stigma)		(Number of family members who endorsed)					
(*P < 0.05 for prodromal vs. recent onset)		Prodromal			Recent-onset		
		Total	White (n = 6)	Ethnic minority (n = 3)	Total	White (n = 3)	Ethnic minority (n = 8)
a*	You worried whether people would find out about (NAME)'s condition?	0	0	0	6	0	6
b*	You worried that your neighbors would treat you differently?	1	1	0	6	3	3
c*	You sometimes felt the need to hide (NAME)'s illness?	1	1	0	7	1	6
d	You kept (his/her) illness a secret?	1	1	0	5	1	4
e	You worried that friends and neighbors would avoid you after they found out about it?	1	1	0	4	2	2
f	You didn't see some of your friends as often as you did before?	1	1	0	1	1	0
g	You avoided going to large parties or social events with (NAME)?	3	3	0	1	1	0
h	You worried that even your best friends would treat you differently?	0	0	0	1	1	0
i*	You felt ashamed or embarrassed about (NAME)'s illness?	0	0	0	6	1	5