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Spontaneous labelling and stigma associated with clinical characteristics of peers ‘at-risk’ for psychosis

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Abstract

Aim—The public health benefits of utilizing an ‘at-risk for psychosis’ designation are tempered by concerns about stigma. It is therefore of interest to examine whether symptoms associated with this designation might spontaneously induce labels associated with a psychotic disorder, other non-psychotic disorders or non-psychiatric labels. This pilot study explored the labels associated with characteristics of ‘high risk for psychosis’ and the corresponding stigma level.

Methods—A vignette describing an identical character, followed by a series of questions about stigmatizing attitudes towards the vignette character, was administered in the present investigation.

Results—The results indicated that even though most young people (59%) did not spontaneously label the vignette character with psychotic-like diagnostic labels, the single most frequent label provided was ‘paranoid/a’. When such labelling, that is, strongly tied to psychosis, occurred, respondents exhibited stronger stigmatizing attributions of fear compared to those indicating non-psychiatric labels (e.g. ‘weird’).

Conclusions—These results suggest that the majority of respondents did not endorse diagnostic labels spontaneously, thus signaling that stigma in the majority of cases would not naturalistically be elicited. However, a segment of respondents evidenced stigma simply from behavioural changes manifested by individuals exhibiting signs of psychosis, independent of diagnosis. Implications for reducing any stigma associated with an ‘at-risk for psychosis’ designation are discussed.

Keywords

at risk for psychosis; labelling; stigma; ultra-high-risk

INTRODUCTION

The stigma associated with diagnostic labels such as schizophrenia is well documented in the literature and many scholars suggest it is the label, as opposed to the psychotic and other behavioural characteristics of schizophrenia, that drives this stigma.^{1–3} The labels of ‘schizophrenia’ and ‘psychosis’ are known to elicit stereotypical attributes of dangerousness and fear,^{1,3,4} especially in studies using experimental vignette methodology, in which participants respond to a brief case description of symptoms. The desire for social distance from schizophrenia and psychosis has been attributed primarily to a perception of danger, or an underlying fear of potential violence, and may be as much related to the ‘label’ as it is to the psychotic symptoms themselves.^{3–5}

It is an empirical question whether the stigma associated with schizophrenia and psychosis extends to adolescents and young adults who have symptoms consistent with heightened clinical risk for psychosis and schizophrenia,^{6,7} and to what extent that stigma may comprise a desire for social distance, with accompanying fear and sense of danger. This is an important question as the ‘psychosis risk’ designation is increasingly implemented by mental health services worldwide,⁸ and the syndrome will be included in the appendix of the Fifth Version of the Diagnostic and Statistical Manual of Mental Disorders.⁹ The symptoms consistent with clinical risk for psychosis and schizophrenia are psychotic-like symptoms that are subthreshold or attenuated in form, with insight intact, that is, unusual thought content rather than delusions of reference, suspiciousness rather than paranoid delusions, perceptual disturbances rather than overt hallucinations. Of note, it is also not clear to what extent any stigma elicited in peers would be due to these subthreshold symptoms themselves or instead to a label of psychosis risk.

In the majority of research on stigma and mental illness, stigmatizing responses are examined in response to a specific diagnostic label provided for a person described in a vignette.^{10–14} In a prior study using experimental vignettes with potential adolescent and young adult peers, in which each vignette was randomly assigned to a diagnostic label, we found that there was an increase in negative attitudes of stigma and discrimination, specifically desire for social distance, when these psychotic-like symptoms were a priori labelled by researchers as ‘psychosis risk syndrome’ rather than as depression or anxiety.¹⁵ This study is surprisingly consistent with studies in schizophrenia, and demonstrates the power of the ‘psychosis’ label, even when it is qualified as risk only.

However, adolescents and young adults do not, in their daily lives, experience being obviously identifiable as having a psychiatric diagnosis. In the risk-benefit analysis of whether to label psychotic-like symptoms so as to provide treatment, we must also consider what stigma is elicited by symptoms themselves independent of diagnosis. In this second study presented here, using the same vignette but in a different sample, no a priori label was assigned to vignettes by the researchers, and respondents instead determined their own labels spontaneously. This eliciting of spontaneous labels may more accurately capture the process of labelling that occurs in real life as a person’s symptoms unfold in front of their peers without a formal diagnosis.^{16–18} Of note, only a few studies have examined

spontaneous labels and stigma related to schizophrenia and psychosis using unprompted vignette methodology. Whereas some studies found labels such as 'schizophrenia' to be associated with greater stigma than other spontaneous labels,^{19,20} others have found non-diagnostic labels such as 'emotional/psychological problem' to also be associated with stigmatizing responses.¹⁷

The aim of the current pilot study is to describe the spontaneous labels provided by a peer college group in response to a vignette description of an individual with characteristics and symptoms consistent with being at clinical risk for psychosis, specifically whether these labels are related to terms that evoke psychosis and schizophrenia, to other psychiatric diagnoses, or to no diagnoses at all. Based on prior vignette studies in schizophrenia and our own previous study of a priori labelled vignettes, we hypothesized that spontaneous labels evocative of psychosis would be associated with stigmatized attitudes including fear, sense of danger and desire for social distance.

METHODS

Sample and procedures

In the present study, respondents read a vignette that was adapted from a published case study.²¹ The vignette character describes a young adult individual with subthreshold psychotic signs consistent with psychosis risk, developed using the Structured Interview for Prodromal Syndromes/Scale of Prodromal Symptoms.²² In the present study, the individual was not given a label. Instead, young adults from a college population provided their own spontaneous labels to the individual described. Participants were administered self-report paper and pencil attitudinal measures designed to assess various stigmatizing responses to the person described in the vignette. Race (black and white) and gender (male and female) were randomly varied across the vignette descriptions.

A convenience sample of 49 undergraduate college students enrolled in Psychology courses participated in the study. Participants ranged in age from 17 to 33 years (Mean = 19.65, SD = 2.93), with 85% of the participants between the ages of 18 and 22. Forty-seven percent of the participants were male and 53% ($n = 26$) were female. The college sample was ethnically diverse with 22% of the participants identified as Black; 12% identified as White; 31% as Hispanic; 20% as Asian; and 15% as Other.

Measures

Vignette—A vignette describing an identical character (except for race and gender) was administered to all respondents and read as follows:

John is a shy 18-year-old, white, male high school senior who was doing fine until about 6 months ago, with close friends, an A to B average in school, and an interest in movies and basketball. In the past 6 months, John began to stay up most of the night and sleep during the day, showering less and withdrawing from friends and family. John began to feel as if people in the neighbourhood were looking at him more, which made him uncomfortable. When nervous, John sometimes thought he heard his name in the wind, and late at night he sometimes briefly felt a presence

even though no one was there. John is interested in politics and is preoccupied with thoughts about the influence of television and mass marketing on people. In the past month, John has sometimes refused to go to school and spends most of his day alone in his room.

In terms of his family, John's mother was hospitalized 25 years ago for a mental illness, which she promptly recovered from and which has never returned.

What label would you use to describe John?

After the administration of the vignette, respondents were asked about stigmatizing attitudes towards the vignette character. Specifically, respondents in this condition were administered paper and pencil items from the Attribution Questionnaire,²³ which assesses attributions of dangerousness, fear and avoidance. Three items with responses scaled on a 9-point Likert scale (1 = not at all, 9 = very much) were used to assess each domain. The three items were summed to create three scales with the following internal consistency reliabilities (dangerousness: $\alpha = 0.86$; fear: $\alpha = 0.97$; avoidance: $\alpha = 0.81$). Higher scores indicated greater stigma in all scales.

RESULTS

Descriptive labels

In response to the vignette, participants in this study presented a wide range of different spontaneous labels ($N = 33$) and most labels were provided only once (see Table 1). The most commonly reported label was a derivation of 'paranoid' ($n = 11$, 22%), which is a characteristic/symptom associated with psychosis. The next most frequently reported label was 'depressed' ($n = 5$, 13%). Interestingly, only one person labelled the person with a 'schizophrenic' diagnosis. This suggests that peers are more likely to spontaneously formulate non-diagnostic descriptive symptom labels when faced with a person exhibiting clinical characteristics consistent with high psychosis risk, as opposed to a diagnostic label of schizophrenia or psychosis. Furthermore, in general, very few participants indicated any diagnostic label, but four participants (11%) noted that the person had 'mental illness' or mental instability. Some examples of the non-diagnostic labels ($n = 17$; 35%) that participants provided were troubled ($n = 2$, 5%), disturbed ($n = 1$, 3%) and weird ($n = 1$, 3%).

Label groupings and stigma

In order to test our hypotheses regarding the level of stigma associated with these spontaneous labels, we grouped labels according to how well they captured labels associated with psychosis, non-psychotic diagnoses or non-psychiatric lay person terms. The specific labels in their respective groups are shown in Table 1. Labels associated with psychosis included labels such as 'paranoia' and 'serious mental illness'. Labels associated with non-psychotic disorders included labels such as 'depressed' and 'anxiety disorder'. Lastly, labels that were not psychiatric in nature, but rather were characteristics used by lay persons, included labels such as 'troubled', 'weird' and 'shy'.

Among the three spontaneous label groupings, mean level of stigma was highest when labels associated with psychosis were spontaneously offered (Table 2). Three one-way analyses of variance were conducted to determine the effect of the three spontaneous label groupings on each of the three stigma attribution subscales. Results indicated a significant difference in spontaneous label groupings for attributions of fear ($F = 3.29 (2,46), P < 0.05$). Post hoc comparisons using Bonferroni correction for multiple comparisons indicated that participants who labelled the person described in the vignette with a psychosis-associated label exhibited a stronger fear attribution compared to those labelling with non-psychiatric labels. This suggests that people who were spontaneously labelled with terms such as paranoid or mentally ill were more likely to report being afraid or frightened by the person described in the vignette than those applying terms such as weird or troubled. There were no significant overall differences between the three label types on attributions of dangerousness and avoidance.

DISCUSSION

In this study, we evaluated the types of labels spontaneously elicited in peers in response to a vignette describing an individual with clinical characteristics consistent with psychosis risk, and the associations of these labels with stigmatized attributions. Whereas a diverse array of mostly non-diagnostic labels were spontaneously elicited, the psychosis-related term of 'paranoid/a' was the label most frequently elicited. Of the psychiatric illnesses, this term is most closely associated with schizophrenia, especially paranoid schizophrenia. We found that the level of stigmatizing response associated with labels that are closely associated with psychosis, such as paranoid, was strongest specifically for attributions of fear. Participants were significantly more likely to describe fear in response to the vignette character when they also labelled the character as paranoid or mentally ill, as compared to when they employed lay terms such as weird or troubled. By contrast, label type bore no significant association with attributions of dangerousness and avoidance. These findings are consistent with symptoms themselves in some circumstances eliciting spontaneous labels such as 'paranoia' and concurrent attributions of fear among peers, independent of formal diagnostic labels that individuals may have received from clinicians.

Interestingly, depression was the second most frequent label spontaneously offered to describe the vignette character, a label that is considered to evoke less stigma than those related to psychosis or schizophrenia.^{1,24} Consistent with this, the level of stigma associated with the spontaneous label of depression or anxiety (i.e. non-psychotic diagnoses) was intermediate to that of paranoia and psychosis-related spontaneous labels on the one hand, and of lay terms of weird or troubled on the other. This is consistent with our prior larger vignette study, which had a priori (rather than spontaneous) diagnoses, in which similar types of stigma were greater in the context of a psychosis-related rather than mood-related diagnosis.¹⁵ Thus, psychosis-related labels are relatively more stigmatizing than other diagnostic labels, both when ascribed officially and also when made informally and spontaneously by peers in the community.

Finally, the current study has demonstrated that when prompted, participants primarily do not spontaneously come up with diagnostic labels for schizophrenia or psychosis on their

own. This implies that, in the absence of a diagnostic category such as the ‘at-risk for psychosis’ designation, the stigma in the majority of cases would not naturalistically be elicited towards an individual exhibiting signs of psychosis. This suggests that an official designation of ‘at risk for psychosis’ may pose a risk of additional stigma on community members who may not perceive and naturally label individuals in such a way.

Limitations

The goal of this spontaneous vignette study was to explore the types of labels young adults from an ethnically diverse urban college sample would ascribe to a peer with symptoms characteristic of increased risk for psychosis and schizophrenia. Generalizability to adolescents and young adults more broadly is tempered by the educational status of the respondents, although the sample was diverse ethnically and included adequate representation of both men and women. Our sample also comes from an urban, largely ethnic minority and immigrant, working class population which may impact some aspects of our findings. For example, the high percentage of lay person labels attributed to the vignette character may be less in a different majority population (i.e. white, non-immigrant, middle class). Also, a vignette is brief and purely linguistic, such that individuals must imagine the character, which leads to an approximation of applied labels and stigmatizing responses rather than when an individual encounters a peer in real life, which can also elicit visceral responses.

Further limitations of this study include that labels were generated spontaneously and a wide variety of labels were grouped into only three categories. Our findings, however, are congruent with our earlier experimental study that had random assignment of label with the outcome being stigma attitudes. Also, the numbers in each group were small – specifically 20 labels related to psychosis, 12 for non-psychotic diagnostic labels and 17 non-psychiatric labels. Therefore, the study was only powered to detect very large effects, and there is a risk for type II error, such that smaller effects could not be detected. Finally, the study only looked for negative effects of labelling, such that potential positive effects could not be assessed. Also, the extent to which labelling facilitates help seeking was not studied. In summary, this is a pilot study that can inform future research on labels and stigma in larger cohorts, and their relationship to help seeking.

CONCLUSION AND SUGGESTIONS FOR FURTHER RESEARCH

Overall, we found that by and large, young adults do not label peers who have psychotic-like symptoms, and when they do, they tend to use layman’s terms such as weird or troubled. Spontaneous psychiatric labels related to disturbances of mood (i.e. depression) or psychosis (i.e. paranoia) are elicited less often, yet when labels associated with psychosis are elicited, they are related to increasing levels of reported stigma, specifically fear. This suggests that there is a fraction of the young adult population that has discriminatory attitudes and desire for social distance simply from behavioural changes manifested by individuals exhibiting signs of psychosis, independent of diagnosis. It would be of use to determine if public education might mitigate the stigma elicited by these behavioural changes, as such public stigma may promote discrimination or lead to obstruction in help seeking. This is consistent with our prior vignette study,¹⁵ which suggested that simple education as to what psychosis

risk is (even within the context of a vignette) could reduce associated stigma. Another area of future study is to further understand how the spontaneous label of ‘paranoid’, although not a diagnostic term per se, elicits heightened reactions of fear that are similar to formal psychotic labels. Finally, even though we found that the non-psychiatric spontaneous labels elicited less stigma than did labels more closely tied to psychosis, these labels still could lead to peer rejection or even bullying, which may elicit harmful consequences on their own.

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TABLE 1

Description of spontaneous labels entered by participants

Coded labels	Label entered by participant	Number of participants providing label
Labels associated with psychosis	Schizophrenic, inherited mental illness, mentally ill, chronic paranoia, paranoia, paranoid, crazy, nervous breakdown, suffering from mental illness, mentally unstable	20 (41%)
Labels associated with other non-psychotic diagnoses	Anxiety disorder, anxious depressed, bipolar, depressed, depressed teenager, depression	12 (24%)
Non-psychiatric labels	Afraid, a teenager, confused, confused teenager, disturbed, enclosed, isolating from the people around her, loneliness, loner, passive, shy, shy/worry about people's thoughts, thinker, troubled, unlucky, weird, gradually becoming antisocial	17 (35%)

TABLE 2

Mean level of stigmatizing responses by label type

Attribution scale	Psychotic- like diagnostic Mean (SD)	Non- psychotic diagnostic Mean (SD)	Non- diagnostic Mean (SD)	Observed range
Dangerous	11.60 (5.0)	8.83 (4.95)	9.82 (5.65)	3–20
Fear	10.45 (5.42)	8.00 (6.52)	6.18 (3.19)	3–21
Avoidance	16.30 (5.10)	13.83 (6.01)	15.47 (6.89)	3–27