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Schizophrenia literacy: The effect of direct experience with the illness

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ABSTRACT

The present study examined the idea that those who have had direct experience with schizophrenia demonstrate better mental health literacy with regards to the condition compared to those with no experience. A convenience sample of 207 lay respondents (aged 17–73 years) completed a questionnaire that examined knowledge of schizophrenia symptoms, the nature of people with schizophrenia, causes, awareness of related disorders and spectrum/schizotypy theories, stereotypical attitudes about schizophrenic patients, attitudes towards social contact with people with schizophrenia, and whether the respondent or anyone they knew had ever been diagnosed with schizophrenia. There were few differences as a function of contact, but those with direct experience were indeed found to be more comfortable about various interactions with a person with schizophrenia. This study provides modest evidence for the contact hypothesis. Suggestions for increasing mental health literacy with respect to schizophrenia are considered.

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1. Introduction

This study is concerned with *mental health literacy*, or the public understanding of mental health, specifically with regard to schizophrenia. Mental health literacy has been defined as "knowledge and beliefs about mental disorders which aid their recognition, management or prevention" (Jorm et al., 1997, p.182).

There have been a number of different research techniques used in this field. Studies include those which explore recognition of mental illnesses using vignettes, surveys on beliefs about the causes of specific mental illnesses and attitudes towards people suffering from mental illnesses; as well as telephone interviews assessing familiarity, perception of dangerousness, fear, and social distance (Angermeyer and Matschinger, 1996a; Jorm et al., 1997; Link et al., 1999; Angermeyer et al., 2004; Furnham et al., 2009, 2011a,b; Mehta et al., 2009; Furnham and Winceslaus, 2012).

One of the techniques used to explore mental health literacy is to test people's ability to recognise a mental disorder from a description of a patient with prototypic symptoms. Jorm et al. (1997) presented participants with vignette descriptions of different mental illnesses meeting ICD-10 (The International Statistical Classification of Diseases, 10th Revision) and DSM-IV (The Diagnostic and Statistical Manual of Mental Disorders, 4th Edition) criteria and found that only 39% were able to correctly identify depression, and 27% schizophrenia. The ability to correctly identify and label a disorder has been found to be the predictor variable most commonly associated with appropriate mental health first-aid responses (Jorm et al., 2005) as well as suitable help-seeking behaviour and treatment preferences (Wright et al., 2007).

In more recent years vignette studies have demonstrated increases in the recognition rates of mental illnesses. Specifically, schizophrenia recognition has been found to be as high as 73.6% (Lauber et al., 2003) and 88% (Link et al., 1999). Furnham et al. (2009) found 61% of participants could recognize someone as schizophrenic from a vignette. An alternative research tradition employed to study mental health literacy is to examine people's beliefs about the *causes* of specific mental illnesses (Furnham and Bower, 1992). This approach reflects a discrepancy between lay and current professional opinion, as the latter tends to be more concerned with physiological/biological explanations for the aetiology of schizophrenia (Furnham and Wong, 2007).

An important factor which has been found to be associated with improved mental health literacy is having had direct experience with a mental illness. Those who have come into direct contact with a diagnosed individual have been found to be associated with an increase in positive attitudes towards mental illness (Arn et al., 1971) as well as a reduction in anxiety and thus desired social distance (Link and Cullen, 1986). Angermeyer and Matschinger (1996b) found that those familiar with mental illness showed more frequent pro-social reactions, were inclined to react less fearfully, and adopted less distancing attitudes towards people with schizophrenia. Similarly, people familiar with mental illness are less likely to have the belief that schizophrenic patients are dangerous and have less desire for social distance (Angermeyer et al., 2004).

It has also been demonstrated that relatives are more likely to cite biological factors when looking for explanations as to the causes of schizophrenia, whilst the general public are more likely to cite psychosocial factors. However, it is also possible that relatives are more

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likely to cite biological causes in order to absolve themselves from feelings of blame or guilt (Angermeyer and Matschinger, 1996a).

Whereas substantial research has been carried out to explore mental health literacy with regard to people with schizophrenia, little of this has included exploration into knowledge of its subtypes (e.g. residual schizophrenia), its related psychotic disorders (e.g. schizoaffective disorder), and opinions about the schizophrenia spectrum or schizotypy.

It should be noted that clinical researchers and practitioners are still in considerable disagreement about exactly what "schizophrenia" is, what causes it, and how best it is treated.

The present study examines schizophrenia mental health literacy by exploring these broader themes. The following four hypotheses will be tested: Those who have had direct experience of people with schizophrenia will: H_1: hold fewer unsubstantiated stereotypes about the behavior and treatment of schizophrenia. H_2 : have better awareness of its related disorders, and will be more likely to express attitudes in line with spectrum and schizotypy theories; H_3 : be less likely to agree with stereotypical attitudes concerning the nature of the illness; H_4 : will accept greater social contact with a schizophrenic.

2. Method

2.1. Participants

There were 207 respondents of whom 58 were male and 149 female. Their ages ranged from 17 to 73 years old ($M=29.94$; S.D. $=13.23$). In all 76.3% were white and 11.2% Asian. In all 43.9% had a school leaving certificate, 12.1% some post-schooling education and 43.9% a university degree. In all 40.6% were single, 31.9% in a relationship and 21.3% married. Just over 40% had some knowledge of psychology, psychiatry or medicine, and three quarters (74.9%) said they were interested (fairly to extremely) in mental illness. Asked if they had themselves ever been diagnosed with a mental disorder, 19.3% said yes, while 67.5% said they knew someone else who had been diagnosed with a mental disorder. Asked if they had had any connection with a person with schizophrenia, 19.8% said they knew someone while 5.3% said they knew someone well who had had it. They were recruited by the coauthors initially from personal contact and then advertisements online aiming at those who may be particularly interested in schizophrenia: hence they were an unrepresentative, convenience sample.

2.2. Questionnaire

The questionnaire (available in full from either author) contained 9 sections: symptoms, stereotypical attitudes, sufferers, causes, related disorders, schizophrenia spectrum/ schizotypy theories, social contact, informational sources and demographics.

(1) The *symptoms* section contained eight statements which described both the negative and positive symptoms of schizophrenia including one additional symptom (inappropriate affect), for example, delusions: "*Delusional beliefs (e.g. that one's thoughts and actions are being directly controlled by the government)"*. In addition, five statements described the symptoms of different disorders listed in the DSM-IV, for example, obsessive compulsive disorder: "*Repetitive behaviours/mental acts (e.g. counting) that one is compelled to perform in response to an obsession, and which significantly interfere with one's daily life*". Descriptions were taken from Nolen-Hoeksema (2004).
(2) The *stereotypical attitudes/myths* section contained 10 statements representing commonly held assumptions about schizophrenia, for example: "*Most people diagnosed with schizophrenia are likely to commit criminal or violent acts*". These were drawn from Harding and Zahniser (1994) and Furnham and Chan (2004).
(3) The *"sufferers"* section contained 12 statements regarding the epidemiology of schizophrenia, for example: "*Schizophrenia is predominantly suffered by adolescents*".
(4) The *causes* section also contained 12 statements, which explained different potential causes of the illness. Some of these were in line with current professional opinion, for example, "*Schizophrenia is caused by chemical imbalances in the brain*", whereas some were not, for example: "*Schizophrenia is caused by God's will*". These were obtained from Link et al. (1999) and Furnham and Chan (2004).
(5) The *related disorders* section contained seven descriptions of psychotic disorders related to schizophrenia (e.g. shared psychotic disorder) and one description of a schizophrenia subtype (residual schizophrenia). For example, shared psychotic disorder: "*delusional schizophrenic symptoms from being in a close relationship with another who is delusional themselves*". Descriptions were taken from Nolen-Hoeksema (2004). It also contained two fictional descriptions, for example: "*Schizophrenic symptoms after having caught the illness from brief and indirect contact with a schizophrenic stranger in the past 48 hours*".
(6) The schizophrenia *spectrum/schizotypy* section contained 13 statements referring to the schizophrenia symptom spectrum, the schizophrenia continuum with personality disorders and schizotypy, for example: "*There are not varying degrees and types of schizophrenia, a person is either schizophrenic or not, it is a black and white distinction"*.
(7) The *social contact measure* contained nine statements regarding social contact with a schizophrenic person, for example: "*I would be comfortable renting a room in my property to a schizophrenic*". These were inspired by Link and Cullen (1983), Link et al. (1999), and Lauber et al. (2004).
(8) The informational sources section listed 10 different sources referring to where the respondent's knowledge about schizophrenia was gained from, for example: "*Television/radio documentaries*"
(9) The last section of the questionnaire contained demographic features about the respondent, including age, gender and whether the respondent had ever been diagnosed or had known anyone that had been diagnosed with a mental illness.

The full questionnaire is available from the first author.

2.3. Procedure

Ninety-four percent of respondents completed the questionnaire using an online survey software website (http://www.surveymonkey.com) and 6% via paper copy. The link for the online survey was left on a variety of schizophrenia-related websites, for example, forums for relatives, self-help groups for people with schizophrenia, and general discussion groups about the illness. The study used an opportunity sampling technique, which introduced an additional snowballing effect. Inevitably, this was not a random section of the population. The study was submitted to, and was approved by, the research ethics committee of the department.

3. Results

Because of the technical nature of some of the questions, each had a "don't know" option. If participants chose that response, it was treated as missing data and, as a consequence, sample sizes change frequently between analyses. Next, much of the analysis was based on the results of the questions concerning whether the respondent had ever been diagnosed with a mental illness (and, if so, which) and whether the respondent knew anyone with a diagnosed mental illness. This resulted in the classification with around 100 people with no experience, 40 with some experience and 11 individuals who reported having been diagnosed with the condition.

The items in Table 1 are summaries and not necessarily what the participants were shown.

Table 1 shows the results for the three groups for three sections. A multivariate analysis of covariance (MANCOVA) (co-varying gender, age, ethnicity, and religious beliefs) was performed on each section of seven parts of the questionnaire. Three were significant. When significant, we computed ANCOVAs per item to show where the differences arose. The section on *Symptoms* ($F(26,272)=2.24$, $p<001$) was significant. Four items showed significant differences. Those with no experience of schizophrenia believed a person with a diagnosis of schizophrenia would be more likely to have reduced speech, a split personality, lack of remorse and be repeatedly deceitful.

The Myths section was not significant. The *Suffering* section was marginally significant ($F(24,\ 262)=1.86$, $p<0.05$) showing those with schizophrenia believing it rarer than others. The Causes, Related Disorders and Spectrum sections MANOVAs performed for the Causes, Related Disorders and Spectrum sections did not show significant differences between the three groups. The Related Disorders section was also not significant. The final section on *Social Contact* was highly significant ($F(18,282)=2.52$, $p<0.001$) with seven of the nine items showing significant differences. The results were clear and consistent: Those with no experience of schizophrenia were far more hesitant to have any sort of contact, particularly to have a patient as a baby sitter or rent a room to one. Thus (only) hypotheses H_4 was clearly supported.

4. Discussion

The *first hypothesis* explored whether those who have had direct experience with schizophrenia demonstrate a better overall understanding of the illness, as it is currently explained by mental health professionals. Direct experience was not found to cause significant improvements in overall understanding. However, having suffered

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