Personal consequences of the diagnosis of schizophrenia: a preliminary report from the inquiry into the schizophrenia label

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Abstract

Purpose – The purpose of this survey was to describe the impact of the diagnosis of schizophrenia on the lives of people who receive the diagnosis.

Design/methodology/approach – The authors designed a questionnaire to investigate attitudes to and experiences of the diagnosis of schizophrenia. After a pilot study, they made the questionnaire available online and, through a network of service user and other organisations, solicited responses.

Findings – Of the 470 responses, 27.4 per cent were from service users. Content analysis of their responses revealed three main categories: concern with the consequences of the diagnosis and its negative impact on their lives, the life contexts of individuals before receiving the diagnosis, and concerns with medication and treatment. This paper deals with the first two.

Research limitations/implications – It is impossible to generalise the results of this survey because respondents self-selected, and thus might be expected to have strong feelings against (or for) the diagnosis of schizophrenia.

Practical implications – The diagnosis of schizophrenia in this sample had devastating negative implications. It was experienced as harmful and stigmatising. Very few people understood their experiences as a biomedical disorder.

Social implications – A gulf exists between the experiences of people diagnosed with schizophrenia and the concerns of academics and others currently involved in debates about the merits of different systems of diagnosis.

Originality/value – This survey is valuable because it draws attention to experiences of diagnosis that are easily lost in the storm of academic controversies about diagnosis in psychiatry.

Keywords Schizophrenia, Service user experience, Stigma, Social exclusion, Psychiatric diagnosis, Psychiatry, Mental illness

Paper type Research paper

The publication of DSM-5 has reinvigorated the controversy surrounding the role of psychiatric diagnosis, especially schizophrenia. Whilst academic debates about the scientific validity of the diagnosis continue (Kendell and Jablensky, 2003; Anckarsäter, 2010), and estimates of its economic cost approach £7 billion annually (Mangalore and Knapp, 2007), the real impact of the diagnosis falls on the lives of service users and carers who must live with it, an impact felt even more keenly by members of England's black communities, who are more likely to be diagnosed with schizophrenia and experience coercion in treatment (Bhui and Bhugra, 2002). Amidst the growing concern over the role and function of diagnosis in psychiatry, we decided to investigate the impact the diagnosis of schizophrenia has on people's lives and, more generally, what different groups of people thought about the diagnosis. We were particularly interested in the experiences of people who had received the diagnosis, their families and carers.

Method

We designed a questionnaire to elicit people's views about and experiences of the diagnosis of schizophrenia. Some of the questions used Likert-type scales to establish the extent of agreement or disagreement with statements about the diagnosis. Other questions were open-ended, inviting respondents to report their experiences at length. We piloted the first draft on ourselves, students at a college of further education in South London and a small number of colleagues known to have different views about the diagnosis. Following this we made a number of minor changes to the wording of some questions. The completed questionnaire was then put online on a web site we set up specifically for the project (www.schizophreniainquiry.org). We advertised the survey as widely as we could given that we were unfunded, by soliciting support from over 40 service user and professional organisations, who agreed to cascade information about the survey through their e-mail lists. We also used social media (FaceBook and Twitter) and blogs to promulgate the survey.

The web site also invited individuals to submit extended testimonies enabling us to access personal narratives about the experience of receiving a diagnosis of schizophrenia. In addition we gave people the opportunity to submit testimonies by telephone or face-to-face interviews. Finally, because we were particularly concerned to find out about the experiences of black people with the diagnosis, the Manchester African-Caribbean Mental Health Services carried out a focus group with 12 people (a mixture of service users and carers) using key questions from the online questionnaire as a topic guide.

In this paper we report preliminary findings of the analysis to responses to the web survey question three. "If you have been diagnosed with 'schizophrenia' or 'psychosis' yourself, please tell us what happened to you that resulted in you getting the diagnosis". We carried out a thematic analysis (Braun and Clarke, 2006) to identify patterns (themes) that captured "something important about the data in relation to the research question" (Braun and Clarke, 2006, p. 82). The usefulness of a theme is not dependent on how often it appears within the data, but rather on what it captures in relation to the research question. Data were managed on computer software (Nvivo).

Results

We received 470 responses to the online survey. Just over a quarter (27.4 per cent) were from people who had received a diagnosis of schizophrenia, and 17.9 per cent from people given other psychiatric diagnoses. Nearly a third of responses (29.7 per cent) described themselves as friends or relatives of someone with a diagnosis of schizophrenia. The responses of the 97 people who responded to question three fell into three main categories: the consequences of the diagnosis; the context they found themselves in before receiving the diagnosis; and the consequences of medication and treatment. Here, we focus on the first two categories.

Consequences of the diagnosis

The most frequent comments made here (25 per cent) concerned the harmfulness of the diagnosis of schizophrenia, particularly the stigmatisation they experienced as a consequence. People found the diagnosis harmful, and the harm associated with the use of the diagnosis was a greater problem in personal terms than the experiences of distress that led it:

> The humiliation of being labelled schizophrenic threatened to become a self-fulfilling prophecy. In the hospital, shelters, group homes and programs I was put in, I was socialised into being a mental patient. I was encouraged to see myself as a broken invalid, to forget my strengths, and instead focus on my weaknesses and vulnerability (Respondent 73).

People described a wide range of negative impacts on their lives as a result of receiving the diagnosis. These included not being able to find work, loss of successful careers and being unable to support their families. Some said they were unable to obtain life insurance or emigrate beyond the EU. One person was told not to have children because schizophrenia is inherited; another felt coerced into having an abortion. Others described how the diagnosis adversely

affected their relationships with family, friends and with doctors. They experienced stigma because of the way the label changed the way other people saw them.

Some respondents described the diagnosis as a life sentence from which there was no recovery. One said that any attempt to disagree with or challenge the diagnosis was interpreted by psychiatrists as a symptom of the illness. Another described how doctors interpreted all areas of his life, his political beliefs, his reading interests, even his concern about sexual matters, as symptoms of illness. One respondent was told that past trauma was "a figment of the imagination". These people's lives and personal beliefs were devalued by stigmatising medical assumptions.

Concerns about the process of making the diagnosis were expressed by 14 per cent of people. They felt that doctors' assumptions about them as individuals led to hasty decisions about the diagnosis without undertaking a full assessment. For example, one person said she received a diagnosis of bipolar disorder because she was a middle-class, white woman, whereas she believed that a black male with similar experiences would be diagnosed schizophrenic. Another person described how a psychiatrist's belief that schizophrenia had a genetic basis led to the doctor failing to acknowledge the importance of difficult life experiences in distress. Some people expressed concern and scepticism about the frequency their diagnoses changed whenever they saw a different doctor (10 per cent), and some (8 per cent) were unhappy with the way they found out about their diagnosis. In this group, 63 per cent said they had discovered the diagnosis by chance. One person described being told bluntly that "I was schizophrenic". There were few positive comments about receiving a diagnosis of schizophrenia. Only 6 per cent of respondents found the outcome of the diagnosis, and the treatment that followed helpful.

The context before diagnosis

Over two-fifths (42 per cent) of respondents described experiencing a different reality before receiving the diagnosis, including hearing voices, seeing things and believing things that others didn't. These experiences were very distressing, and sometimes associated with suicide attempts and strange behaviour. A small proportion were not distressed by their experiences, however, and saw them as an integral part of their identity. Others understood these experiences in spiritual or religious terms, seeing a close relationship between spirituality and mental health. About a quarter of respondents related these experiences to difficulties that they had had earlier in life, including traumas such as bereavement, rape or bullying. Some had experienced abuse within the family, some outside it, and others referred to tensions in family relationships before diagnosis. Some people also referred to drug use (cannabis and LSD) prior to being diagnosed, and some (14 per cent) said their diagnosis was preceded by a bout of depression or a stress-related "breakdown" related to work (including the army), or being a single parent. In broad terms, respondents tended to experience pressures in different areas of their lives before receiving the diagnosis.

Discussion

Although all the respondents to this question had received a diagnosis of schizophrenia, that's not how they saw it. Most of them did not use the word "schizophrenia" to describe what was happening to them before they received the diagnosis. They preferred to see it as a different reality, or a spiritual or religious experience. A significant proportion related the experience to stress or difficulties earlier in life. These findings are broadly consistent with the experiences of service users from earlier service-user led research (e.g. Mental Health Foundation, 1997, Kalathil, 2011). In addition, this is also consistent with recent research drawing attention to the important but widely overlooked association between trauma and schizophrenia (Read *et al.*, 2001, 2005).

The most frequent comments about the diagnosis concerned its harmfulness (25 per cent), particularly in terms of the stigma associated with it. Again, this is consistent with earlier user-led research (Faulkner and Layzell, 2000). The harmful nature of the diagnosis is born out by the impact the diagnosis has on people's lives, which include unemployment, loss of careers and being unable to support families. All this has to be seen against the wider socio-economic context of the recession, and the widespread vilification of people forced to rely on benefits

through chronic ill-health (*The Guardian*, 2012). These times are even more difficult than usual to have to live with a diagnosis like schizophrenia, and this has additional negative implications in terms of social exclusion and for self-esteem. It is also clear that receiving the diagnosis has a negative impact on citizenship. Some respondents had been unable to obtain life insurance, or had experienced difficulty with plans to emigrate. Two people experienced direct challenges to their reproductive and parenting rights. Again these findings are consistent with earlier studies that confirm the widespread social exclusion experienced by psychiatric patients, and especially those with a diagnosis of schizophrenia (Sayce, 2000).

There is little evidence here to indicate that psychiatrists are moving away from the Kraepelinian view of schizophrenia as a brain disorder with poor prognosis. It is clear from the evidence submitted by our respondents that some psychiatrists continue to see schizophrenia as a condition from which recovery is unlikely, a "life-sentence". Furthermore, some respondents' psychiatrists tended to interpret all aspects of the person's life in terms of the diagnosis. Any attempt to challenge this was interpreted as symptoms of the condition. Such responses invalidate and silence the person, compounding the sense of hopelessness and futility, and adding to the sense of having a "spoiled identity". A view popular in psychiatry has been that the best way to tackle stigma is through the use of campaigns to educate the public that schizophrenia is a brain disorder. Our findings do not support this but are more in line with findings that the rise of the biomedical view of schizophrenia has been overwhelmingly associated with a negative impact on public attitudes to people with the diagnosis of schizophrenia (Read *et al.*, 2006).

This study has limitations that make it difficult to generalise the findings. The people who responded to the survey self-selected, and thus might be expected to have strong feelings against (or for) the diagnosis of schizophrenia. However, one reason for undertaking the study was to access the views and experiences of service users and others who were not prepared to accept the concept of schizophrenia uncritically. This in our view is in contrast to the Schizophrenia Commission, which appeared to accept the concept as given, and which also appears to have had limited input from service users and carers.

Conclusions

Clearly, firm conclusions cannot be drawn from analysis of one question of the survey conducted during the inquiry into the "schizophrenia" label. However, this analysis points towards the need to take seriously the harm that this label may be doing to people given the diagnosis and to society in general, not to speak of the way its use seems to be limiting our attempts to understand the nature of the real mental suffering that people face in our society today.

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Further reading

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