

Qualitative

## **People with schizophrenia believe that they are stigmatised at work and in the community**

*For correspondence: B Schulze, University of Leipzig, Department of Psychiatry, Germany. BeateMSchulze@web.de*

*Schulze B, Angermeyer MC. Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals. Soc Sc Med 2003 Feb; 56: 299-312.*

**QUESTION** How does stigma affect the everyday lives of people with schizophrenia?

221, 84, 348, 138, 356, 395

### **Design**

Cross sectional focus group study.

### **Setting**

4 German outpatient centres involved in the “WPA Global Programme against Stigma and Discrimination because of Schizophrenia” (no further details are provided); timeframe April 2000 - March 2001.

### **Participants**

25 people with an ICD diagnosis of schizophrenia receiving outpatient treatment, 31 relatives of people with schizophrenia and 27 mental health professionals (psychiatrists, psychologists, social workers, occupational therapists and nurses) participated in 12 focus groups. 64% of participants were women. Invitation letters were distributed through outpatient departments, psychiatrists’ offices, relatives’ organisations, and local co-ordinators of an anti-stigma programme.

### **Data collection**

This qualitative study defined stigma broadly as “reactions of the social environment” to people with schizophrenia. Separate focus groups were conducted with people with schizophrenia, relatives of people with schizophrenia (not necessarily relatives of the patients participating), and mental health professionals. The authors aimed to elicit concrete situations in which people with schizophrenia felt they were “disqualified from full social acceptance” and information about how stigma affected their everyday lives.

### **Analysis**

Focus group sessions were audio and video recorded. Transcripts were coded using inductive methods, aiming to establish a typology of stigmatisation experiences. Transcripts were analysed separately for the 3 main themes covered: stigma experiences, stigma causes and suggestions for projects aimed at reducing stigma.

### **Main results**

4 dimensions of stigma were identified: interpersonal interaction, structural discrimination, public images of mental illness, and social roles.

*Interpersonal interaction* refers to stigma experienced in social relationships. Most participants said that a diagnosis of schizophrenia resulted in reduced social contacts. Patients said they were often ignored by neighbours and family members.

*Public images of mental illness*: Patients and relatives felt that the negative stereotypes of mental illness in the media were discriminating and hurtful. Images of people with mental illness as violent and dangerous were seen as intrinsically stigmatising.

*Structural discrimination*: Participants felt that stigma and discrimination were evident in imbalances and injustices in social structures, political decisions, and legal regulations. Improvements to mental health services were suggested as a way of overcoming some structural discrimination. Improvements included increased community-based and outpatient services, a focus on prevention rather than acute treatment, patient involvement in planning treatment, and greater access to information about treatment and support.

*Social roles*: Patients felt that schizophrenia was a major obstacle to employment and professional roles. Relatives and health professionals agreed that patients often encountered criticism, mistrust and denial of their skills when returning to work following psychiatric treatment.

## **Conclusions**

Patients and the relatives of people with schizophrenia believe that discrimination and negative attitudes have a great impact on their quality of life. They felt that they were structurally discriminated against in the provision of health services and access to appropriate information. There were few differences in the views of patients, relatives and health professionals.

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## **COMMENTARY**

This is an interesting and well designed study on the subjective experiences of stigma in schizophrenia. The tripartite nature of the respondents (patients, families and mental health professionals) makes it comprehensive. Although using focus groups allows only small numbers of participants, the depth and richness of data compensates for this. Indeed, the depth of information available from qualitative studies is often unequalled by that elicited using quantitative methods. As such, qualitative and quantitative methodologies should be combined whenever possible in order to enhance the evidence-base in mental health.

In this study, Schulze and Angermeyer suggest that reduced social contacts, problems with social identity, the need for secrecy, problems with work, and adverse effects from medication all contribute to the experience of stigma. These factors have been recorded in earlier studies. What is striking, and may impact on the planning of health services for the mentally ill, is the perceived low priority accorded to mental health services and the allocation of resources for people with schizophrenia and their carers. Increased awareness of rights and resources and the proliferation of support groups in recent years may have contributed to this perception among those directly affected by the illness, but there is also supporting quantitative evidence. For instance, WHO's 2001 World Health Report collated figures of health budgetary allocation to mental health in various countries. In many countries, spending on mental health was miniscule.[1]

When interpreting the findings of studies, it is important to place them in their social and cultural context. This study was conducted in Germany, but the descriptions of stigma could well have been from families and patients in developing countries. One difference may be the importance of marriage as a stigmatising experience.[2] In many developing countries, marriages are still arranged by families. The stigma attached to mental disorders may limit the marriage choices available to people and have a negative impact on others in the family. On the other hand, in the developing world there is some recourse to traditional and religious methods of healing disorders of the mind. These healing methods may serve to mitigate the stigma attached to formal mental healthcare systems.

Stigma is a ubiquitous and universal experience of pain, discrimination and marginalisation cutting across all cultures and societies. While an attitude change is critical, this may be difficult to fashion. Planning better mental health services, improving access and encouraging more positive attitudes in the professionals manning them may be steps towards this goal. Similarly, improving the orientation of general practitioners and other healthcare providers and enhancing the mental health curriculum in undergraduate medical education may augur for a gradual diminution of stigma throughout the world.

Dr R Thara  
Director, Schizophrenia Research Foundation  
West Anna Nagar Extension  
Chennai  
India

1. WHO. *World Health Report 2001*. Geneva: World Health Organisation, 2001.
2. Thara R, Srinivasan TN. How stigmatising is schizophrenia in India? *Int J Soc Psychiatry* 2000; **46**: 135-41.