

# What people with schizophrenia think about the causes of their disorder

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**SUMMARY.** **Aims** – To describe what users with schizophrenia think about the causes of their disorder. **Methods** – In each of the 10 participating Italian mental health centres, 25 users with schizophrenia were consecutively recruited and asked to complete the Users' Opinions Questionnaire (UOQ). **Results** – 150 out of 198 respondents mentioned at least one social cause for their mental disorder, and 114 reported exclusively social causes. Family conflicts were the most frequently reported social cause (21%), followed by traumas (20%), work and study difficulties (17%), and psychological disturbances (17%). Ten percent of the respondents mentioned biological causes. Biological causes were more frequently reported by users who were aware of their diagnosis of schizophrenia, whereas social causes by those who just knew they suffered from a psychosis. Difficulties in social relationships were more frequently pointed out by respondents with an earlier onset of the illness and a higher number of compulsory admissions in the previous 12 months. These users expressed more scepticism about the usefulness of the treatments they received, and perceived a greater social distance. **Conclusions** – Users' beliefs about the causes of their disorder should be taken into account by psychiatrists in order to improve their working alliance with them.

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## INTRODUCTION

In recent years, there has been an increasing interest in explanatory models of illness in patients with long-term diseases. Patients' beliefs about causes, severity, and out-

come of their illness significantly influence their reactions to the illness, their adherence and response to treatments, and their confidence in professionals (Fisher & Farina, 1979; Pennebaker, 1982; Becker & Maimon, 1983; Borkan *et al.*, 1995; Salmon & May, 1995; Peters *et al.*, 1998; Haley *et al.*, 2003). When sufferers' beliefs about their illness differ greatly from those of physicians, this may generate patients' feelings of being misunderstood, a low subjective relief following treatments, and frequent shifts in therapies (Foulks *et al.*, 1986; Lobban *et al.*, 2003; Schomerus & Angermeyer, 2008).

Studies on patients' models of illness reveal that these models are significantly influenced by cultural factors

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(Moodley & Perkins, 1993; Saravanan *et al.*, 2007a, b), such as the interpretation of the illness in patients' social context (McCabe & Priebe, 2004; Read *et al.*, 2006); by socio-demographic variables, particularly gender and level of education (Maher & Kroska, 2002); and by patients' psychological characteristics, such as appraisal and coping styles (Perlin & Schooler, 1978; Lobban *et al.*, 2004).

The etiological models of illness, which have been extensively explored in patients with physical diseases, have recently been studied also in persons with mental disorders, such as schizophrenia (Haley *et al.*, 2003; Lobban *et al.*, 2003; McCabe & Priebe, 2004; Kinderman *et al.*, 2006). Available data highlight the fact that the large majority of users with this mental disorder consider schizophrenia as being due to social causes, while only a few include hereditary and other biological factors among the possible causes.

Studies carried out in Germany (Angermeyer & Klusman, 1988; Holzinger *et al.*, 2001) found that 48% of patients with schizophrenia attributed their mental disorder to stress due to acute life events or long-term problems in work, social and family context. Moreover, 32% of users stated that their disease was due to their weak personality or poor parental care; 10% stated they suffered from a brain disease and 15% that their mental disorder was a consequence of hereditary factors.

A further study carried out by Holzinger *et al.* (2003) in Leipzig found that stress due to overwork, overly demanding study activities, relationship problems and life events, was the most frequent cause of schizophrenia, reported by 66% of sufferers. Hereditary causes were mentioned by 27% of users, and other biological causes, such as metabolic dysfunctions and infectious diseases, by 29% of them.

Similarly, in a study carried out in UK on samples of second generation immigrants and white English users with schizophrenia (McCabe & Priebe, 2004), the most frequently cited were social causes (43%), followed by non-specific causes, including psychotic symptoms (27%), supernatural explanations (16%) and biological factors (13%).

Other studies have found that a biological interpretation of schizophrenia was associated with higher levels of perceived stigma, possibly due to a more pronounced perception of unpredictability, i.e., that the illness was not under the patient's control (Maher & Kroska, 2002; Mak & Wu, 2006; Charles *et al.*, 2007).

In 2005, the Department of Psychiatry of the University of Napoli SUN coordinated a participatory survey on the opinions of 241 users with schizophrenia about the causes and the social consequences of their disorder (Magliano *et al.*, 2008; in press). In this paper, we describe what users think about the causes

of their mental disorder and explore the relationships of reported causes with users' socio-demographic and clinical features, and with users' opinions about the usefulness of treatments, the right to be informed on their mental disorder, and the social consequences of schizophrenia.

## METHOD

### Study design

The study was carried out at the Department of Psychiatry of the University of Naples SUN, the mental health centres of Arezzo, Campobasso, Battipaglia, Ferrara, Ravello, Rho, Torino, Trieste, and the Fatebenefratelli Institute of Brescia.

In each centre, 25 users with schizophrenia were consecutively recruited if they met the following criteria:

- a) age between 18 and 60 years;
- b) no hospital admission in the previous three months;
- c) at least one psychotic episode in the previous 5 years;
- d) ongoing treatment with antipsychotic drugs. Each individual was asked to complete the Users' Opinions Questionnaire (UOQ).

The study protocol was approved by the reference review board. After a complete description of the study to the participants, written informed consent was obtained. Data were collected from May 2005 to February 2006. In the period November 2006 – February 2007, the results were presented in each centre to users and staff, and suggestions were collected on their use.

### Assessment instruments

The UOQ is a self-reported questionnaire developed by users with schizophrenia and mental health professionals, using a focus-group procedure (Magliano *et al.*, in press). The instrument includes 24 items grouped into 6 subscales, exploring the respondent's opinions about:

- a) *usefulness of drug and psychosocial treatment*;
- b) *affective problems* (i.e., difficulties that persons with schizophrenia may experience in family and affective relationships and in caring for children);
- c) *social distance* (i.e., exclusion and dangerousness attributed to mentally ill people);
- d) *right to be informed*;

- e) *recognizability* (i.e., the respondent's feeling of being identifiable by other people as mentally ill);
- f) *social equality* (i.e., likelihood of recovering and of being treated like other people). Each item is rated on a three-point scale, from "completely true" to "not true", plus an "I don't know" code. Moreover, the questionnaire includes 12 open questions on topics covered by the above items and on the respondent's beliefs about the causes of his/her own mental disorder, knowledge of his/her own diagnosis, possibility of recovering, and perception of personal limitations due to schizophrenia. The psychometric properties of the UOQ have been formally tested and found to be satisfactory (intra-rater reliability: Cohen's kappa coefficient from .55 and .92; Cronbach alpha coefficient performed on the six subscales: from .55 to .74; factor analysis accounting for 53 percent of total variance).

In this study, the respondents' beliefs about the causes of their mental disorder and their knowledge of the diagnosis of schizophrenia were explored in relation to a-f subscales' mean score.

### Statistical analysis

Statistical analyses were planned in order to test whether:

- users who believed their mental problems were due to biological causes had been more often informed of their diagnosis of schizophrenia, had been more often hospitalized, and perceived a higher level of social distance;
- users who viewed their mental disorder as due to social causes were more firmly convinced that they would be well again and attributed lower levels of recognisability and social distance to persons with schizophrenia;
- users who regarded psychotic symptoms themselves as the cause of their mental disorder had a longer duration of illness, and less interest in receiving information on their disease.

Chi square and ANOVA tests were performed, as appropriate, to explore the associations between causes and users' socio-demographic characteristics (sex, age, marital status, years of education, current occupation, problems with the law) and clinical variables (duration of illness, age at onset, number of previous voluntary and compulsory hospital admissions, suicide attempts, psychotic episodes in the previous 12 months). Mann-Whitney test was used to verify the associations between causes and respondents'

beliefs about the social consequences of schizophrenia (QO-U subscales). Statistical significance was set at  $p < .05$ . Data was processed by SPSS 11.5 (2002).

### RESULTS

Twenty-five out of 250 selected users refused to be involved in the study and they were replaced by others in 16 cases. Refusals did not differ from participating users as regards to sex and age. Therefore, the sample included 241 users with schizophrenia (62% males; mean age  $39.4 \pm 9.6$  years; 75% single; 27% employed; 46% with a secondary school education, 41% with a high school/professional education and 5% with university education; mean duration of illness  $15.6 \pm 10.3$  years; attending the mental health centre for  $7.7 \pm 6.6$  years; mean number of voluntary and compulsory admissions  $3.9 \pm 4.9$  and  $0.8 \pm 1.4$ , respectively; 26% with suicide attempts). All users were being treated with antipsychotic drugs; 38% were receiving individual psychological support, 58% were participating in social group activities, and 4% in a vocational skills programme. Thirty percent of the respondents reported they had been informed by psychiatrists that they suffered from schizophrenia, and 23% that they had a psychosis.

One-hundred and ninety-eight out of 241 users (82%) reported their views about the causes of their mental disorder. Users who missed this question more frequently believed they suffered from a mental disorder other than schizophrenia ( $\chi^2=9.8$ ,  $df=1$ ,  $p < .002$ ). Fifty-eight percent of the respondents mentioned a single cause, 28% two causes, and 14% from three to five different causes (mean  $1.6 \pm .8$ ).

Twenty-six percent of respondents reported that the cause of their mental disorder was the occurrence itself of psychiatric symptoms (Figure 1), such as "voices" (15 respondents), delusions and persecutory ideas (16), depression (12). Thirty-four respondents considered their mental disorder as *due* only to the occurrence of symptoms.

One-hundred and fifty out of 198 respondents (76%) mentioned at least one social cause for their mental problems, and 114 reported exclusively social causes. Family conflicts were the first most frequently reported social cause, followed by traumas, such as love breakdown (17 cases), losses (11 cases), physical assaults (5 cases), severe and unspecific traumas (5 cases). Seventeen percent of respondents mentioned work and study difficulties as causal factors, mainly dismissal and unemployment (12 cases), and overly-demanding study load (7). Seventeen percent of respondents mentioned psychological disturbances, such as irritability (7 cases), extreme shyness (5 cases), and emotional hypersensitivity (3 cases).

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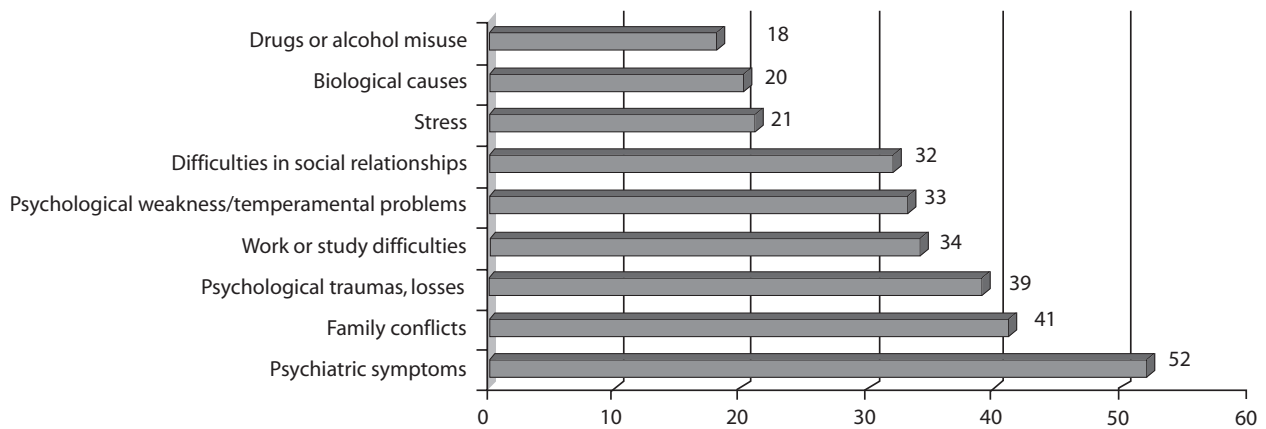


Figure 1. – Causes of their mental disorder reported by users with schizophrenia (N=198).

Ten percent of the respondents mentioned biological causes. These were more often wrong therapies (5), physical illness, and unspecified biological factors (4), and hereditary factors (5).

Respondents mentioned family conflicts and psychological difficulties as the most important determinants of the onset of their disorder (16% and 15%, respectively), while difficulties in social relationships and loneliness were mentioned as the most important determinants of their *current* disorder (13%).

The number of reported causes increased in relation to the respondent's years of education (Spearman's  $r = .17$ ,  $p < .02$ ), number of prior compulsory admissions ( $r = .19$ ,  $p < .02$ ), earliness of onset ( $r = -.21$ ,  $p < .002$ ) and level of perceived social distance ( $r = .17$ ,  $p < .02$ ). Biological causes were more frequently reported by users who were aware of their diagnosis of schizophrenia ( $\chi^2=9.6$ ;  $df=1$ ,  $p < .002$ ), whereas social causes by those who just knew they suffered from a psychosis ( $\chi^2=7.7$ ;  $df=1$ ,  $p < .005$ ). Alcohol or drug abuse was more frequently reported as a cause by respondents who were male ( $\chi^2=9.2$ ;  $df=1$ ,  $p < .002$ ), younger ( $F=9.4$ ,  $df=1$ ,  $195$ ,  $p < .003$ ), with a shorter duration of illness ( $F=6.3$ ,  $df=1$ ,  $195$ ,  $p < .01$ ), and with previous problems with the law ( $\chi^2=4.7$ ;  $df=1$ ,  $p < .03$ ).

The occurrence itself of psychiatric symptoms was more frequently considered as a cause of the illness by respondents who had a longer duration of illness ( $F=4.5$ ,  $df=1,195$ ,  $p < .04$ ), previous suicide attempts ( $\chi^2=4.0$ ;  $df=1$ ,  $p < .04$ ) and a higher number of hospitalizations ( $F=4.4$ ,  $df=1,185$ ,  $p < .04$ ). Furthermore, these respondents were more firmly convinced that persons with schizophrenia are easily recognizable (Mann-Whitney  $test=2440.5$ ,  $p < .0001$ ).

Difficulties in social relationships were more frequently pointed out by respondents with an earlier onset of the illness ( $F=4.9$ ,  $df=1,196$ ,  $p < .03$ ) and a higher number of compulsory admissions in the previous 12 months ( $F=7.1$ ,  $df=1,139$ ,  $p < .009$ ). These users expressed more scepticism about the usefulness of the treatments they received ( $M-W=1921.0$ ,  $p < .01$ ), and perceived a greater social distance ( $M-W=1864.5$ ,  $p < .007$ ).

Stress was more frequently mentioned among the causes by respondents with higher educational level ( $F=7.7$ ,  $df=1,195$ ,  $p < .006$ ), while family conflicts were found to be associated with a higher number of prior hospital admissions ( $F=4.7$ ,  $df=1,155$ ,  $p < .03$ ).

Finally, respondents who considered their mental disorder as exclusively due to social causes acknowledged lower levels of recognizability of persons with schizophrenia ( $KW=9.5$ ,  $df=3$ ,  $p < .02$ ).

## DISCUSSION

This is the first study carried out in Italy which specifically explored the beliefs of users with schizophrenia about the causes of their disorder, and the relationships of the perceived causes with socio-demographic and clinical variables.

The involvement of a large number of users who were receiving community care and took part in all study phases (Magliano *et al.*, 2008) can be considered as a methodological strength of this study. However, caution should be used in interpreting the results, given the consecutive recruitment of cases, which may limit the generalisability of the findings. Another limitation of the study is that

exploring users' opinions without taking into account their family members' and health professionals' beliefs could be insufficient to have a complete perspective of the whole field (Noiseux & Ricard, 2008).

Consistent with previous research (McCabe & Priebe, 2004; Read *et al.*, 2006; Angermeyer & Klusmann, 1988; Holzinger *et al.*, 2001; 2003), the results of this study indicate that users view schizophrenia as mainly due to psychosocial causes, and give a limited weight to co-occurring biological factors. As outlined by Holzinger *et al.* (2003), this finding may reflect beliefs that, at the moment, prevail in the society. These common beliefs should be taken into account by psychiatrists in order to improve their working alliance with the users (Foulks *et al.*, 1986; Colombo *et al.*, 2003).

In line with literature data, the respondents' beliefs that their mental disorder is the consequence of social causes alone was associated with a low perception of recognizability of persons with schizophrenia (Read *et al.*, 2006). This finding supports the idea that perceived stigma is lower when mental illness is viewed as a reaction to problematic or unfavourable social conditions rather than as a biologically determined entity (Fisher & Farina, 1979; Corrigan & Watson, 2002; Sevy *et al.*, 2004; Read *et al.*, 2004; 2006).

Nearly one respondent out of four believed that his/her mental disorder was due to the occurrence of the symptoms themselves, mainly delusions and hallucinations. It is likely that this causal explanation reflects respondents' difficulties to relate current state to previous conditions or the denial of psychosis (McGlashan *et al.*, 1975; Falloon & Talbot, 1981; Chadwick *et al.*, 1996; Mak & Wu, 2006). The fact that this perceived cause was associated with suicide attempts, a higher number of hospitalisations, and a longer duration of illness suggests that these users particularly need professional support to identify factors that may influence the course of their illness and to reinforce their coping strategies (Falloon & Talbot, 1981; Wearden *et al.*, 2000; Magliano *et al.*, 2006).

Family difficulties were the most frequently mentioned social cause and were associated with a higher number of previous compulsory treatments. According to literature data on expressed emotions and relapse (Wearden *et al.*, 2000), this association could be interpreted as also due to poor family skills to manage psychotic episodes. From a practical point of view, this finding outlines the need to involve relatives in long-term management of schizophrenia, to provide them with information on this mental disorder, and to support them in dealing with the burden of care (Magliano *et al.*, 2006).

In line with literature data (McCabe & Priebe, 2004; Read *et al.*, 2006), biological causes were reported by

few respondents, mainly those who were aware of their diagnosis of schizophrenia. It is likely that professionals who communicate to users about their diagnosis also provide them with information on the nature of their mental condition.

In our sample, less than one third of respondents reported that they had been able to discuss freely with their psychiatrists about their illness. This is a powerful cultural factor influencing models of illness that should be specifically investigated and taken into account in clinical practice (Magliano *et al.*, 2008).

Forty-two percent of respondents listed two or more causes of their mental disorder, which is a significantly higher percentage than that reported by Holzinger *et al.* (2003). Furthermore, the number of reported causes increased in relation to level of education. This may be due to the fact that seeking information is an easier process in more educated people (Perlin & Schooler, 1978). On the other hand, the fact that the number of reported causes increased in relation to earliness of onset and number of prior compulsory admissions may be seen as supporting the notion that when several causes interact over time with a person's vulnerability, the clinical course of the illness could be more severe (Zubin & Spring, 1977; Read *et al.*, 2004).

Causal interpretation of schizophrenia in sufferers is an important issue from both a research and a practical point of view. Further studies are needed to specifically explore:

- a) differences in causal interpretation of schizophrenia between users, relatives and professionals, and whether these differences influence adherence and response to treatments and levels of stigma perceived by users;
- b) the relationships between the causes reported by users and the strategies they adopt to cope with them and whether users' coping strategies have an impact on the course of the illness as well as on their perception of personal limitations due to schizophrenia;
- c) the impact of rehabilitative and educational interventions on users' beliefs about the causes of their disorder;
- d) the relationships between the causes reported by users and the clinical course of schizophrenia.

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