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Qualitative

A 4 stage model described how clients and their relatives experienced the process of developing schizophrenia

Barker S, Lavender T, Morant N. *Client and family narratives on schizophrenia*. *Journal of Mental Health* 2001;10:199–212.

QUESTION: How is the process of developing schizophrenia presented in the narratives of clients and their family members?

Design

Narrative analysis.

Setting

South London.

Participants

8 clients with schizophrenia (6 men, age range 25–50 y), who were living in a hospital, hostel, or supported accommodation, and 8 close relatives (6 mothers and 2 fathers of clients).

Methods

Semistructured interviews of 40–80 minutes were tape recorded, transcribed verbatim, and analysed using constant comparison.

Main findings

A 4 stage model was developed, which focused on events occurring before and during the first psychotic episode, at the first hospital admission, and current experiences. In narratives relating to *events preceding the first psychotic episode*, clients and relatives described how the onset of schizophrenia was precipitated by changes associated with adolescence, particularly difficulties in personal relationships, which disrupted a previously “normal” life.

Clients’ narratives about the *first psychotic episode* portrayed a “catastrophic disruption to their sense of self and their life world.” Relatives’ narratives focused on their struggle to make sense of the changes and feelings of fear and confusion. Clients and relatives had similar descriptions of the psychotic episode, particularly around hearing voices. Clients felt that their experiences were not understood. Many relatives attributed behavioural changes such as increased aggression and avoidance to typical “teenage” behaviour.

The *first hospital admission* was a major event for both clients and relatives, marking their first exposure to experts in the field. Clients and relatives felt that their opinions and belief systems were not considered by professionals. Clients felt confused and distant from the admission process. Although relatives were grateful for the containment offered through admission, they felt that the episode was made worse by professionals who did not listen or offer support or choices.

Narratives about *current experiences* focused on 4 themes: disability, relationships, self development, and coping and services. Clients and relatives described the *disabling* aspects of schizophrenia and its negative effects on thinking and daily functioning. Clients were concerned with the continual effort needed to manage their problems, whereas relatives were concerned with issues of control (ie, the extent to which clients had control over symptoms). Clients described how *relationships* had been adversely affected, but also highlighted the importance of continued friendships and staff support in helping them to define themselves and achieve tasks of daily living. Relatives noted the stigma of mental illness and how clients were separated from society. Clients and relatives related the experiences of schizophrenia to *self development*. Surprisingly, all clients talked about how their illness experience enabled them to be more “themselves” and to develop their own separate identities. Relatives stressed how fluctuations in the psychosis affected their perception of the client as a person. In narratives about current *coping and services*, clients and relatives were complimentary about the support they received from residential and community mental health staff, although some still felt that they were not understood. Narratives of coping focused on medication, with both groups expressing ambivalent feelings arising from the beneficial effects of antipsychotic drugs and the accompanying difficult side effects.

Conclusion

The narratives of clients and relatives about the process of developing schizophrenia were represented in a 4 stage temporal model of events preceding and during the first psychotic episode, the first hospital admission, and current experiences.

Source of funding: not stated.

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COMMENTARY

The qualitative study by Barker *et al* adds to the current understanding of the lived experiences of individuals with schizophrenia and their families. The authors described their analysis in sufficient detail, enabling readers to easily grasp their process. It adds to existing knowledge by using a narrative approach.

The findings of this study are consistent with previous qualitative studies of living with schizophrenia.^{1,2} An enduring sense of self, which has been challenged by early illness experiences, continues to be important. This study also reinforces that the prodromal period is fraught with difficulties for clients and families.

This study had a small sample size, even for qualitative research. If client-family dyads are considered, only 8 stories were examined. Although the paired participant approach assists in establishing the “truth” of the experiences, the study should be replicated with other pairs in other settings.

Clinicians interested in working closely with individuals with schizophrenia and/or their families will find this paper useful. It suggests that (1) prodromal issues may be related to changes in behaviour or strained relationships, (2) clinicians should listen carefully to the concerns of clients and their families during the first hospital admission, and (3) clients and families may feel that despite years of treatment, they still lack adequate explanations. Clinicians should be encouraged by the recent publication of qualitative studies, particularly narratives. These stories contain some potential approaches that may be useful when a clinician is at a loss about what to try next with a specific individual.

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- 1 Moller P, Husby R. The initial prodrome in schizophrenia: searching for naturalistic core dimensions of experience and behavior. *Schizophr Bull* 2000;26:217–32.
- 2 Davidson L, Strauss JS. Sense of self in recovery from severe mental illness. *Br J Med Psychol* 1992;65:131–45.