

Loss and Grief in Patients With Schizophrenia: On Living in Another World

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Aim: Schizophrenia enormously impacts the lives of the patients who have this psychiatric disorder. This study addresses the lived experience of grief in schizophrenia.

Method: A qualitative study based on the grounded theory was designed. Ten patients were interviewed in depth on their feelings of loss and ways of coping.

Results: All respondents experienced significant feelings of loss. Internal and external losses were distinguished. Respondents dealt with their losses by accepting their diagnosis and treatment, identifying with other patients, learning about schizophrenia, and searching for meaning.

Discussion: Respondents were able to identify their significant losses and verbalize the accompanied feelings. They went through an intensive grieving process that to a certain extent led to coming to terms. During the interviews, the presence of grief was evident, whereas clinical depression was excluded.

Clinical implications: Interventions may be improved by the following factors: (a) optimal assessment and treatment of symptoms; (b) adequate information about symptoms, treatment and its effects, and prognosis; (c) opportunities to identify with other patients; (d) strengthening of social support; and (e) a relationship of trust with care providers based on an accepting attitude.

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SCHIZOPHRENIA IS A serious psychiatric disorder that deeply affects the lives of patients who have it. The illness and its consequences can substantially impair personal life and social functioning (American Psychiatric Association, 2000; Horowitz, 2002; Lewis, 2004; Lewis & Langer, 1994; Lorencz, 1991; Siris & Docherty, 1990). Living with schizophrenia means losses in several areas of life such as emotional and cognitive functioning, social contacts, study and employment, and daily activities. To come to terms with these losses, a patient must go through a mourning process that may well entail feelings of grief and depression (Appelo, Slooff, Woonings, Carson, & Louwerens, 1993; Witmann & Keshavan, 2007). The increased risk of suicide among patients with schizophrenia in the first years after the illness manifested itself is indicative of their suffering (Addington, Williams, Young, & Addington, 2004; de Hert & Peuskens, 2000;

Lewis, 2004; Mamo, 2007; Pinikahana & Happell, 2003). According to the *Practice Guideline for the Assessment and Treatment of Patients with Suicidal Behaviors*, 23%–55% of patients with schizophrenia engage in a suicide attempt at some point in their lives (American Psychiatric Association,

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Precis: This article describes a qualitative study on the experiences of loss and grief in patients with schizophrenia.

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2003). The lifetime risk of suicide in schizophrenia is estimated to be approximately 5% (Palmer, Pankratz, & Bostwick, 2005). In comparison, suicide accounted for 1.4% of total deaths in the United States in 2004 (National Center for Injury Prevention and Control, 2005). In providing care to patients with schizophrenia, nurses need to be open to these experiences of loss and grief to offer effective care aimed at helping patients come to terms with the fact that they are ill and accept the losses that they feel (Appelo et al., 1993; Glass, 1993; Horowitz, 2002). *Grief* can be defined as a complex but stereotyped reaction pattern to losses, with both psychological and physiological aspects playing a role, such as social withdrawal, restlessness, difficulty in carrying out routine daily activities, fatigue, sleep disorders, and loss of appetite. Feelings are dominated by hopelessness, heavy heartedness, and fear. Aggression and guilt feelings also occur regularly (Clayton, 1990; Worden 2001). The losses experienced by patients can be classified into internal and external losses (Appelo et al., 1993). Internal loss includes cognitive impairments (lack of concentration and memory defects, confusion, and lessened problem-solving ability), low self-esteem, and loss of future prospects. External loss refers to a decline in social contacts and a change in a patient's role and position in society.

It is unclear how grief is expressed in relation to schizophrenia. It is often difficult to distinguish reactions of depression from those of grief (Clayton, 1990) or negative symptoms (Appelo et al., 1993; Lewis, 2004). Apart from some case studies (Horowitz, 2002; Witmann & Keshavan, 2007), no reports have been published of scientific research specifically focused on grief in schizophrenia (Lewis, 2004). This article describes the results of an exploratory study conducted with the objective of gaining better insight into the losses experienced by patients with schizophrenia and the reactions of grief that may follow. Insight into these aspects will enable nurses to better understand the specific losses felt by these patients. This will contribute to nursing interventions supporting patients to cope more effectively with these losses.

The following research question was asked:

How do patients with schizophrenia experience and come to terms with the loss that their illness entails?

METHOD

Grounded theory was selected for the research design (Strauss & Corbin, 1998). This approach is used within the context of symbolic interactionism. Grounded theory aims at understanding how people define their reality via social interactions (Hutchinson, 1993). Loss in schizophrenia has a large impact on the individual's definition of reality and on his or her social interactions. The choice for this design was motivated by the emphasis on the significance that the respondents attributed to their experiences of loss and on how they continue to live their lives based on this newfound meaning. The qualitative method was considered appropriate because of the complexity of the concepts of grief and loss and because of the relatively new scientific articulation of these concepts in schizophrenia (American Psychiatric Association, 2000; Lewis, 2004). After the approval of the institutional review board, the respondents were selected based on the following inclusion criteria: (a) *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* diagnosis of schizophrenia confirmed by the Comprehensive Assessment of Symptoms and History interview (Andreasen, Flaum, & Arndt, 1992; American Psychiatric Association, 2000); (b) between 6 months and 7 years since the first psychosis so that the experienced losses by the patients were relatively recent; (c) engaged in active treatment as day patients or outpatients at the university hospital where the researchers worked; (d) ability to verbalize ideas and experiences; (e) absence of clinical depression according to the clinical judgment of the psychiatrist; (f) absence of overt psychosis; and (g) legally competent adults.

Ten patients took part in this exploratory study, 9 men and 1 woman. The mean age was 26.6 years (range = 21–38 years), and the mean duration of illness was 3.45 years (range = 0.5–7 years). Six lived with their parents at the time of the interview, and 4 lived independently. Six patients received day treatment, and 4 were treated as outpatients. All respondents had previously received clinical treatment in the university hospital and were now in the rehabilitation phase.

Data were collected in 10 semistructured interviews lasting up to 1 hour. On the basis of the literature, the following "sensitizing concepts" were used: internal loss, external loss, and grief (Appelo

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