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Illness Perception in Turkish Schizophrenia Patients: A Qualitative Explorative Study

Perihan Güner *

Mental Health Nursing, Koç University, School of Nursing, Istanbul, Turkey

A B S T R A C T

Background: Schizophrenia is a serious mental illness that is highly complex and not fully understood. Individuals with serious mental illnesses like schizophrenia experience difficulty trying to access mental health services. Few have the opportunity to receive the most optimal evidence-based treatment and only half of those who do actually adhere to the recommended treatment. Understanding what it is like to have this illness would help in our approaches to treatment.
Methods: In-depth interviews were conducted on nine Turkish patients with schizophrenia in order to explore the illness from the perspective of patients in remission.
Results: Five themes emerged from the patients' descriptions of schizophrenia: schizophrenia is a complicated illness, a mystery, a lost life, a dynamic journey towards recovery, and a developmental process of recovery.
Conclusion: This study has identified areas of concern about reflecting the patients' perspectives on their experiences thoroughly, which should help improve healthcare provision and guide future research.

Schizophrenia is a complex, multi-dimensional condition that is not yet fully understood and is among the most difficult mental illnesses to treat (Davidson, Schmutte, Dinzeo, & Andres-Hyman, 2008). Approximately one in every 100 people is diagnosed with schizophrenia worldwide (Lobban, Barrowclough, & Jones, 2005); however, when one also includes patients' friends and family members, the number of people who are affected by this illness is much higher. Schizophrenia not only affects an individual's psychological, occupational and social functions (Mwansisya et al., 2013) but also is accompanied by complex disruptions in emotions, thoughts and perceptions (Graor & Knapik, 2013; Phanthunane, Vos, Whiteford, & Bertram, 2010). The literature shows that individuals with serious mental illnesses such as schizophrenia experience difficulty accessing mental health services. Few patients have the opportunity to receive the most optimal levels of evidence-based treatment and only half of those do actually follow the recommended treatment (Davidson et al., 2008). According to a World Health Organization (WHO) report, untreated mental disorders account for 13% of the total burden of disease worldwide and a wide gap remains between the need for mental illness treatment and its provision. For example, between 76 and 85% of people with severe mental illnesses receive no treatment for their mental health problem in low- and middle-income countries, while a high percentage (between 35 and 50%) receive no treatment in high-income countries (World Health Organization, 2011).

Schizophrenia is also one of the most financially debilitating illnesses (Phanthunane et al., 2010; Soygür, 2003). When considering only the disability component in the calculation of the burden of disease, mental illnesses account for around 30% of all years lived with a disability (YLD) in low- and middle-income countries (World Health Organization, 2011). In Turkey, among the top 20 causes of YLD, schizophrenia was the ninth leading cause among men and the eleventh among women (Erkoç, Çom, Torunoğlu, Alataş, & Kahiloğullari, 2011). Financing for the treatment and prevention of mental illnesses remain insufficient. Globally, annual spending on mental health is less than 2 USD per person and less than 0.25 USD in low-income countries (World Health Organization, 2011).

Studies worldwide have shown a wide variation of annual costs for schizophrenia treatment, but it is difficult to compare data because some studies calculate total annual healthcare spending instead of costs per patient. Furthermore, there are considerable differences in population, which help determine these figures. In Taiwan, the average annual total cost per patient was approximately 16,576 USD (Lee et al., 2008). In Australia, the annual in-patient mental health care costs averaged 13.800 AUD (Carr, Neil, Halpin, Holmes, & Lewin, 2003). In the USA, the average annual total cost per patient was 5984 USD (Desai, Lawson, Barner, & Rascati, 2013). In China, the average annual total cost per patient was 2586.21 USD (Zhai, Guo, Chen, Zhao, & Su, 2013).

* Corresponding Author: Perihan Güner, PhD, RN, Mental Health Nursing, Koç University, School of Nursing, Guzelbahce sok., No: 20, 34365 Nisantasi-Istanbul.
E-mail address: pguner@ku.edu.tr.

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In a study conducted at a Turkish teaching hospital, the annual cost of schizophrenia treatment in 2006 was only 1,760 USD per patient and totaled 616 million USD for all patients diagnosed with schizophrenia (Yıldız & Cerit, 2006).

While schizophrenia is one of the leading causes of disease burden and disability, many patients do not receive treatment (Davidson et al., 2008; World Health Organization, 2011). Therefore, minimizing the negative impact of schizophrenia on patients and society is among the priorities of many countries like Turkey (Phanthunane et al., 2010). To this end, a comprehensive report about a new service delivery model was outlined by Turkish mental health authorities. The model focuses on treatment through establishing community-based models of services (Erkoç et al., 2011). This model criticizes that the patients receive no additional care or follow-up from healthcare services once they are discharged and left the hospital-based system. As a consequence, this model claims that it is necessary to give up the hospital-based model and apply a community-based model instead (Erkoç et al., 2011).While pilot projects for these models have recently been initiated, they have yet to be implemented throughout Turkey. Currently, the Turkish Ministry of Health is preparing a new in-service training program for this new model of service to mental health professionals across Turkey. Learning how patients perceive their illness would be a valuable component to add to this training program, which would help caregivers better understand their patients and provide the opportunity to develop appropriate new treatment approaches and practices.

BACKGROUND

The concept of illness perception can be broadly defined as the sum of all beliefs related to how a patient conceives and construes his or her illness (Lobban, Barrowclough, & Jones, 2003). It is widely accepted that understanding how patients with physical illnesses perceive their condition will be useful in predicting their coping strategies and health outcomes for those illnesses (Fortune, Smith, & Garvey, 2005; Higbed & Fox, 2010). Today, the researchers are examining how illness is perceived in the field of mental health by taking into account the views and experiences of the patients first-hand (Petrie, Jago, & Devcich, 2007).

The most widely studied theoretical illness perception model is the Self-Regulation Model (SRM) developed by Leventhal, Nerenz, and Steele (1984). It is also referred to as the Parallel Processing Model, Information Processing Model or Common Sense Model (CSM) (Leventhal et al., 1984). According to this model (see Fig. 1), individuals are regarded as actively trying to understand their own symptoms. People's beliefs about their symptoms affect their emotional responses to the illness and how they cope. This is a dynamic process where changes in the knowledge or symptoms of individuals can cause individuals to reevaluate their illness perceptions and as a result, change their coping and support-seeking patterns and emotional reactions (Leventhal et al., 1984; Lobban et al., 2005). The main attributes of the SRM concern the following dimensions of experience: beliefs about symptoms (illness identity), recurrence of the condition (time-line and cyclical time-line), consequences, personal control, treatment control, illness coherence, causes of the condition, and the patient's emotional response to his or her condition (Fortune et al., 2005).

The measurement tools [e.g. The Illness Perception Questionnaire (IPQ); Lobban et al., 2005] most widely applied to assess illness perception are based on the SRM of Leventhal et al. (1984). SRM measures have shown how illness perception can have significant value in predicting the variations in coping abilities and health outcomes across a wide range of physical illnesses, which in turn has led to the development of particular interventions that have improved health outcomes (Petrie, Cameron, Ellis, Buick, & Weinman, 2002). These measurement tools are often used to evaluate physical illnesses. However, when used to evaluate mental illness, information relevant to key areas of mental health disorders can be missed (Kinderman, Setzu, Lobban, & Salmon, 2006; Petrie, Broadbent, & Kydd, 2008). For example, beliefs relating to mental illnesses may not be easy to establish because individuals with schizophrenia may change their beliefs depending on being in an acute phase or having distorted thoughts even when stable (Kinderman et al., 2006). Barrowclough, Lobban, Hatton, and Quinn (2001) also found, in regards to schizophrenia, that some beliefs were important in understanding how caregivers adapt to the illness. However, their findings also show the potential difficulties in applying models based on physical illness to mental illness. As a result, while measurements may be conceptually straightforward for physical health, their use is not as appropriate for mental health illnesses.

Qualitative research is reported to be a rich source of data related to patient beliefs (Higbed & Fox, 2010); however, there have been few qualitative studies regarding illness perception and schizophrenia. Studies have varied from evaluating disorders other than schizophrenia

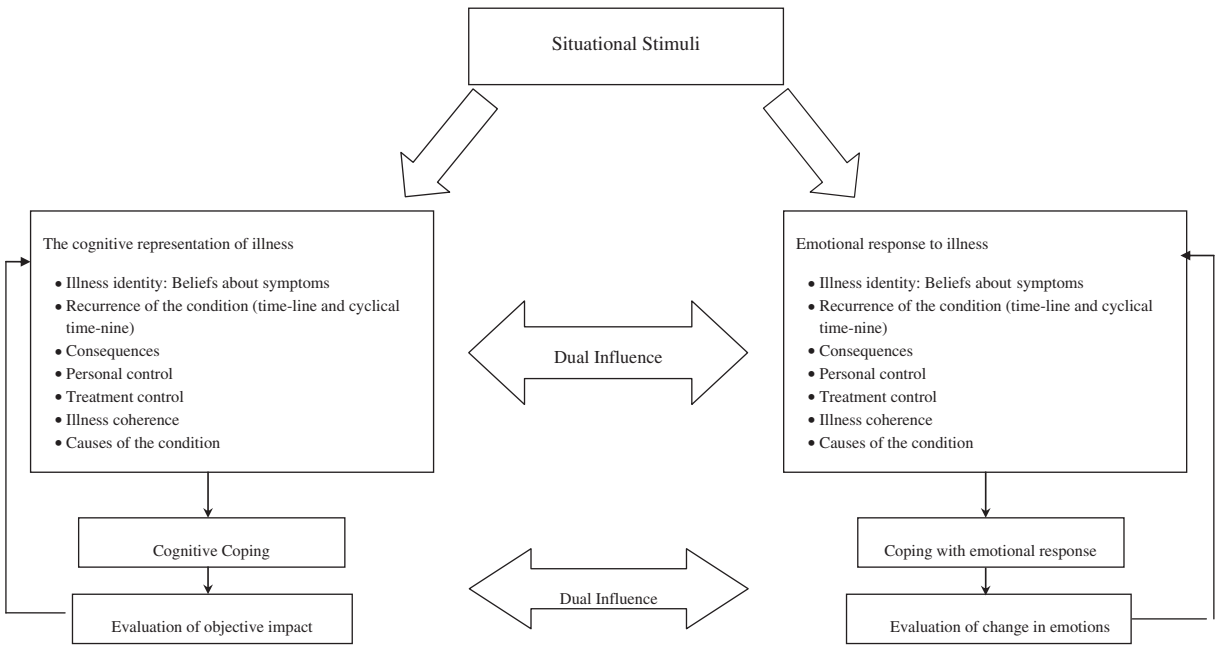

Fig. 1. Leventhal Self-Regulation Model. Modified from: Jayne & Rankin, 2001; Fortune et al., 2005.