



Sense of Belonging and Hope in the Lives of Persons with Schizophrenia



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ABSTRACT

This qualitative study used semi-structured interviews to explore the meaning of sense of belonging and hope in the lived experiences of 20 persons with chronic schizophrenia-spectrum disorders receiving acute inpatient treatment. Experience of treatment was also explored. Sense of belonging and hope were both identified as valuable or even vital, yet the experiences of not belonging and/or feeling hopeless was more prevalent. Participants frequently felt like an outsider and experienced loneliness and isolation, suggesting a need for further exploration of the impact of sense of belonging and hope on recovery and even treatment adherence in persons with schizophrenia.

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Schizophrenia is a severe mental disorder that causes alterations in a person's cognition, emotional responses, perceptions of reality and social interactions with others. The social cognitive deficits of schizophrenia frequently result in difficulty engaging in normal interpersonal interactions at work, school or with friends and family (Aghevli, Blanchard, & Horan, 2003). In addition, symptoms of schizophrenia result in behaviors and experiences that are outside of social norms and further impede social functioning due to stigma and marginalization (Wahl, 1999, 2012). The combination of the above factors contributes to social isolation, loneliness, and feelings of hopelessness commonly experienced by persons with this disorder. Loneliness and isolation are connected to decreased quality of life and are identified as roadblocks to illness remission and recovery (Boyer et al., 2013; Chiu & Tsang, 2004; Hayhurst et al., 2013; Kukla, Salyers, & Lysaker, 2013; Wahl, 2012). Considering the prevalence of loneliness and hopelessness, the obverse states of sense of belonging and hope may be keys to supporting recovery in persons with schizophrenia.

THE IMPORTANCE OF BELONGING

Having a sense of belonging has been identified as important to health, from Maslow's inclusion of belonging in his hierarchy of basic human needs (Maslow, 1954) to more recent exploration of the role of sense of belonging and mental health (Anant, 1967; Choenarom, Williams, & Hagerty, 2005; Hagerty, Lynch-Sauer, Patusky, Bouwsema, & Collier, 1992). Humans seem to be hard-wired to be with other people; isolation or alienation is not only detrimental to overall health, but is also viewed as socially unacceptable or as an unfavorable state of being. Feeling as if one belongs, on the other hand, is identified as important to health, particularly mental health (Anant, 1967; Hagerty et al., 1992). Sense of belonging is a vital mental health concept that is

closely correlated with social and psychological functioning (Hagerty & Williams, 1999; Hagerty et al., 1992).

Little is known about the experience of belonging in persons with schizophrenia. Social support is identified as vital to well-being and improved outcomes in this population and is also identified as an area of common deficit (Agarwal, Sharma, Kumar K, & Lowe, 1998; Beels, 1981; Pyne et al., 2006). Social support is a related concept to belonging, and it has been found to mediate sense of belonging in persons with depression (Choenarom et al., 2005). It has been suggested that sense of belonging plays a more important role in improving psychological functioning than increasing social support (Hagerty & Williams, 1999). It may be that the focus on social support alone in interventions for persons with schizophrenia is insufficient in that it does not encompass sense of belonging. A person may have social supports available, but may not be as meaningful if these supports do not make the person feel as if he/she belongs. A shift from interventions that increase social support to enhancing the person's sense of belonging could result in enhanced quality of life and improved outcomes. First, because the literature on sense of belonging in schizophrenia is extremely limited, the concept needs to be explored further to explicate meaning and determine significance in persons with schizophrenia.

THE NECESSITY OF HOPE

Hope involves looking toward the future with a sense of positive expectation and intentionality. It provides a sense that one has a future and enables coping with events in the present while supporting the individual to use crises as opportunities for growth. Hope has been identified as a positive coping strategy for dealing with chronic illness (Herth, 1995; Miller, 1989), and as an important value in recovery from schizophrenia and mental illness in general (Corrigan, McCracken, & Holmes, 2001; Substance Abuse and Mental Health Administration, 2006). Hope has been found to improve depression, anxiety, well-being, coping and even immunity (Schrack, Stanghellini, & Slade, 2008).

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The sequelae of schizophrenia, including apathy and anhedonia, are conducive to hopelessness; in fact, hopelessness is a common symptom of schizophrenia (White, McCleery, Gumley, & Mulholland, 2007). Hopelessness has been found to be higher in persons with schizophrenia who committed suicide, the leading cause of premature death in people with schizophrenia (Lyu & Zhang, 2014). Even when the person follows treatment recommendations, symptoms of schizophrenia often persist and this may enhance hopelessness about future ability to lead a normal life. Hopelessness is further compounded by stigma and social rejection commonly experienced by persons with this disease (Dickerson, Somerville, Origoni, Ringel, & Parente, 2002; White et al., 2007).

The literature on hope in schizophrenia, while more robust than that on sense of belonging, is still limited. The importance of hope as a basic resource of life (Kylma, Juvakka, Nikkonen, Korhonen, & Isohanni, 2006) necessitates further examination of the experience of hope in the lives of persons with schizophrenia.

Factors that influence recovery, such as feeling a sense of belonging and hope, may differ for persons with schizophrenia than for those with other illnesses. Engaging people in discussions about their lives provides an avenue for making meaning and coherence out of individual experiences with a resulting broader understanding of commonalities among people with schizophrenia. Because these individuals often have perceptions and experiences that are not routinely faced by others, understanding their lived experiences is vital to not only improving understanding of the illness, but also to developing successful interventions.

Qualitative inquiry using a phenomenological approach will help to build an understanding of the relevance and meaning of sense of belonging and hope in persons with schizophrenia that will guide future research and intervention development. The purpose of this study was to explore sense of belonging and hope in the lived experience of people with chronic schizophrenia spectrum disorders. A secondary aim of this study was to provide insight into patients' perceptions of treatment for their mental illness.

METHODS

Subjects and Procedure

After receiving institutional review board approval, participants were recruited from a freestanding psychiatric hospital that is part of a tertiary academic medical center. Participants included 20 English-speaking persons aged 18 to 65 years, with primary diagnoses of a chronic schizophrenia spectrum disorders and who were current hospital inpatients. For the purposes of this study, chronic was defined as having been hospitalized more than twice, and/or having received treatment for greater than 1 year. This criterion was enacted to ensure that the participant had a diagnosis long enough to be able to describe the impact of the disorder on his or her life.

Persons were excluded from the study if they had a substance-induced psychotic disorder, and/or if their inpatient treatment focus was on drug or alcohol detox during the hospitalization. Individuals with known significant impairments in cognition or prohibitive psychopathology (including unresolving agitation) were excluded in order to reduce risk of psychological distress and to ensure all participants were able to engage in informed consent. The attending physician was consulted prior to approaching each patient and the physician gave feedback on the person's ability to provide informed consent. Those determined to have capacity to consent were approached, and if interested were provided with the details of the study, including review of the purpose and procedure of the study, risks, and benefits.

A screening tool was used to ensure informed consent occurred. The screening tool used in this study was modified for persons with schizophrenia from the University of California San Diego Brief Assessment of Capacity to Consent (BACC) (Jeste et al., 2007). The BACC scores each item from 0 to 2, which results in a score with a range of 0–20 where intermediate response may be acceptable. The modified version of this

tool for schizophrenia includes yes/no response for each question; any response of no is a positive screening. If a positive screening occurred, indicating questionability of ability to consent, the individual was excluded from the study. The participants signed a consent form with the understanding that participation in the study was voluntary and would not affect their treatment at the hospital, that they could withdraw from the study at any time, that they did not need to answer questions if they felt uncomfortable, and that their information would be kept strictly confidential. Interviews were conducted in a private room at Vanderbilt Psychiatric Hospital. All interviews were recorded using an electronic voice recorder with the participants' consent. The interviews were conducted between November 2014 and March 2015. Upon completion, each study participant was given a \$25 gift card. Nineteen of the twenty participants answered all interview questions. One participant became notably anxious a few questions into the interview and the primary investigator (PI) ended the interview early to avoid additional participant distress.

DATA COLLECTION AND ANALYSIS

This qualitative study involved semi-structured interviews. Additionally, two measures of sense of belonging, the General Belongingness Scale (Malone, 2011) and the Sense of Belonging Instrument, Psychological Subscale (Hagerty & Patusky, 1995) were administered for pilot testing. This article will only report the results of the qualitative interviews.

The purpose of the interviews was to extrapolate the lived experience of the person with a focus on sense of belonging and hope. The interview guide included questions such as 1) Describe a normal day in your life. 2) Describe a difficult day in your life. 3) Describe a special day in your life. 4) Describe your experience of treatment for mental illness. Probing questions included 1) Did you feel any hope on that day? 2) Did you feel as if you belonged on that day?

The PI completed all participant interviews. Audio recordings of interviews were transcribed verbatim and compared to the audio recording by the PI who corrected any discrepancies. Each transcript was independently analyzed line by line by the PI and an independent reviewer to identify themes and key phrases within the text. After this initial review, the PI and secondary reviewer met to categorize the codes identified into broader themes and subthemes. Line by line analysis using ATLAS.ti software was conducted independently by the PI and then together with the secondary reviewer to confirm agreement of themes and textual examples.

Data were analyzed using SPSS Version 21. Descriptive statistics were used to summarize the sociodemographic characteristics of the sample and are summarized in Table 1. Mean and standard deviation were used for the normally distributed continuous variable age.

RESULTS

Sample

The PI, who had legal access to the records, screened medical records of adult inpatients at VPH during the study timeframe. Twenty-seven individuals were approached for consent, 21 were consented and 20 participants were interviewed. Characteristics of the 20 participants are reported in Table 1. The majority of the participants were white (70%) males (65%). While predominantly single (85%), most did not live alone, either living with friends/family members (65%) or in a group home (15%). Seventy percent of participants had a high school education or greater.

Qualitative Results

Five a priori primary themes were confirmed during data analysis: Sense of Belonging, Not belonging, Hope, Absence of hope and

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