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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.

Introduction

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

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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, Patusk, 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 et al., 1992; Hagerty & Williams, 1999). 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. V, & 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 (Schrank, Stanghellini, & Slade, 2008).

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, Sommerville, 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 18-65 years, with primary diagnoses of a chronic schizophrenia spectrum disorder 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 0-2, 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 & 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 Treatment. The following sections discuss these themes along with related subthemes.

Theme 1: Sense of Belonging

Having a sense of belonging was defined as the experience of feeling as if one belongs or fits in with other people, communities, or society. Participant descriptions of belonging were in alignment with this definition and centered on fitting in. Sense of belonging was described as being with and/or communicating with others. Some participants defined sense of belonging as:

“It means to be part of a group where they don’t pick you out and say, “Look, this person’s something that we don’t want to be.” It’s to be part of a group and to be included in kind of a category within a group of people that people want to be like, that this person that fits into the idea of what we should be.”

“It feels pretty good to belong to something, it... makes you want to wake up and keep doing the things you have been doing every morning”

“It makes me normal. It makes me feel like I’m really doing something right and really special in somebody’s life.”

Having a sense of belonging included contact and connection with others, and when the person felt a sense of belonging, it generated positive feelings. Sense of belonging was identified as a vital element in their lives, without which life was more difficult.

Subtheme: Being with others

This subtheme was the most predominant in the Belonging category, and can also be described as ‘having someone be there’. Seventeen out of the 20 participants identified the importance of having others be there for them and being with other people.

“I like working around other people. I have to have other people in my life.”

“I can’t take it without having somebody in my life.”

“It’s like (when) everybody around me, nobody’s judging you. I love it.”

More than just being with others, three participants described the importance of having someone who is a supporter and an advocate.

“She was always the one that cheered me on. She wouldn’t just get on the sidelines of the race, she’d get right in there with you.”

“ She always fought for me and tried to make sure I was happy”

Four participants described that being with others helped them to cope with the symptoms of schizophrenia, and in some cases being with others even lessened those symptoms.

“It’s like a sponge. Sometimes I’m filled with water and sometimes I’m not, just depending on how tightly the voices are squeezing at me. When I’m alone, it’s usually at it’s worse. I try to, as much as possible, try to integrate myself back into society because that’s the only thing that can fix it.”

“When I’m present with someone else, it’s much easier to manage. It’s much easier to control. It’s much easier to manipulate what’s really going on mentally.”

Being with others was more than just superficial interactions or being around people in a way that did not involve genuine and meaningful connection. Having someone be there included an element of caring and being cared for, whether by a friend, a family member, or in some instances, a beloved pet. The implication of reciprocity suggests that sense of belonging entails more than just having social support or social contacts, it may also include having opportunities to be supportive in return.

Subtheme: Connecting/Being a Part of Something

In addition to being with others, ten of the participants described belonging as being a part of something and connecting with others.

(When I feel like I belong)... *“I feel like I’m part of something. Instead of being like one piece of pie that’s already been eaten, I’m part of the whole pie that’s left.”*

“To belong means to be tightly knit into a network of people emotionally and physically, family, friends. Communication on a regular basis. Maintaining a status quo with others. Never just becoming disconnected or falling away from the herd.”.

Communication was identified as playing a role in belonging (8 participants). For some it was just being able to communicate with people regularly as indicated above. For others it

was about staying connected, whether in person, by phone or through social media, such as Facebook.

“(Belonging means) constantly making contact with friends, no matter how few you have, family, girlfriend, whatever. You have to maintain those things in order to have a belonging, at least I feel so. Those are the things that make up a human.”

Four participants identified that the primary place that they felt a sense of belonging was with other people with mental illnesses:

“because there is this tight-knit community of people with mental illness. And they will stick together and be supportive and try to help you through anything. So if I belong anywhere, I belong with people with other disorders or mood disorders or anything.”

“...it kind of makes me feel like I belong because I know that they’ve also been through something similar to me. Because I can help talk to them and they can talk to me and we can be there for each other.”

Being a part of something added meaning and value to life. Communication was identified as important for supporting the connection with others and that continued connection was needed. While many of these connections were with family and friends who were not identified as having a mental illness, connecting with people who had similar experiences enhanced sense of belonging.

Theme 2: Not Belonging

Not feeling as if one belonged or fit in was a predominant experience, with 146 data segments coded for not belonging compared to 126 for belonging. Nineteen participants described what it felt like to not belong.

“Belonging wise, I just felt like I didn’t belong anywhere. Very little value or asset to life. There are times where I felt suicidal... You start to run out of options. When you run out of options as a human, you start to question what’s left.”

“I have no friends and no family. I’ve been here nine months. I have not one friend and no family and I’m on my own”.

One participant, when describing what it felt like to her when she did not feel as if she belonged stated:

“It’s miserable because I feel like I’m at the bottom of the garbage pile, almost, if that makes any sense. Everything’s just dumped on you and nobody remembers what’s at the bottom of the garbage pile, so they empty it and throw it away.”

Feeling isolated and alone compounded this lack of connection, and participants described a thwarted longing to be able to simply talk to other people in a way that made them feel accepted and understood. When this didn’t happen, it had negative impact on their emotional state.

Subtheme: Being an Outsider

Fifteen participants experienced a feeling of being outside of society or feeling like an outsider. Being marginalized for having a mental illness was a normal experience.

“You know I am around seven people all day they don’t talk to me for almost two and a half years. They don’t talk to me. And then I just sit there, drink, I smoke my cigarette, they just look at me.”

“I feel like the odd man out, like everybody is playing a game that I’m not.”

There were stark descriptions of feeling different from others and not being accepted for being one’s self. Participants described powerlessness over not belonging because of having a mental illness, and wanting to connect with others but not knowing how. Some participants commented on wanting to integrate back into society by getting jobs, going to college or finding ways to connect with other people.

Subtheme: Loneliness

Participants described that the experience of not belonging resulted in feelings of isolation and loneliness that was hard to cope with. Participants described being alone because of their illness, and some articulated that being alone with the illness was detrimental to their emotional and mental health.

“Sometimes I feel outcast, and I don’t talk a lot. I don’t know how to talk a lot unless I really have to.... It feels bad, like I ain’t got nobody to share my feelings with.”

“Alone is even worse, especially with such a diagnosis. You don’t want to be alone with this diagnosis or you’ll just become Galileo. You’ll go crazy in a cave. That’s not something anyone wants to be alone with.”

“You’re very alone. When you’re alone like that, it damages the mind. It weakens it especially. If you don’t get ahold of it or a grip of it, it destroys you ultimately.”

Eight participants described the feeling of not belonging as being connected to the experience of losing a person, such as a mother, grandmother, or spouse, that made them feel like they belonged. Sometimes this loss had occurred in the distant past, but was the best, or even the only, experience they had of feeling a sense of belonging.

“I didn’t feel like I belonged anywhere but with her. I still feel that way a lot of times...Don’t belong anywhere but in the ground with her, I guess.”

“I was like, “Oh my God! I have nobody else in this world who understands me.” She was always the one I talked to when I felt bad, so I didn’t have anybody, now.”

Others seemed to have hardened themselves to the experience of not belonging and described the experience with a self-protective distance or an attitude of indifference.

“I don’t think I’ve ever fit in (laugh). I’ve never felt like I fit in. Even when I was little, I never felt like I fit in. I just...I’m different in a lot of ways. But I’m okay with that usually.”

“I just get to the point where I figure well this is the way it’s going to be. I’m just going to be a lonely person. Or, you know, I don’t want to deal it and commit suicide. I kind of struggle between the two”

“I really can’t say that I want to be a part of anybody else’s life, or something like that, you know what I mean? So I’m not trying to belong with other people. I’m just trying to be in society, mind my own business, live my life, and do what I want to do with my life, and not be involved with others.” Participants who described this attitude of indifference also made contradictory statements about loneliness or wanting to feel a sense of belonging. This last participant quoted above later said that: *“At times, I feel like, uh, just hearing voices, stuff like that, maybe I feel like I’m ... uh, I guess maybe I get lonely at times.”*

When speaking of these intense feelings of loneliness, there was often a despairing quality to the discussion, and many did not have hope for increased connection with others and seemed resigned to being isolated and alone. Others struggled with recurring thoughts of suicide.

Theme 3

Hope was defined as having future orientation or positive expectation of something in the future. This aligned with participants’ definitions of hope.

“Hope means to have something waiting. Not necessarily waiting, but to have ... When I think of ‘hope’ the word, I think of future. You have a grasp for the future. You feel like it’s going to occur no matter what. If you don’t have any hope, you will burn out really quickly, especially with something like schizophrenia. It’s not something that you can run low on.”

“Hope means a lot because everybody needs to hope in something or believe in something. I want to be hopeful that I have a bright future myself, even if it’s not going to be a big event or anything. I just want to be able to have a decent life.”

“Hope gives people a reason to do something. What hope means for me is a reason to live.”

Having a future orientation was valued, even though it was not experienced by all participants. Hope provided meaning and motivation to keep trying despite obstacles encountered.

Goals/Purpose

Eighteen participants connected hope to having goals. Hope was described as having a sense of purpose in one’s life and as having a reason to go on, to get up and live another day.

“I’d have hope for my future if I can get to see my daughter for the first time... but that’s something that I really look forward to in life, to really get to see my daughter for the first time.”

“I think it’s an important thing to try to maintain is being busy. Not just being busy, but being busy doing stuff that is productive for what the inside of the person is

wanting to make. Like, whatever I want to make on my inside, whatever I'm trying to thus show on the outside"

When asked to describe a special day, one participant described the importance of simple goals"

"When I can set another goal for myself to push myself to strive better for things that I enjoy doing with my family...When I wake up, having a good feeling that I can- that I can achieve what I set out for praying last night, like getting my son to school, go get a shower, basically, uh, taking care of myself so I can take care of my family, um, the things I enjoy doing."

The content of the goals or the person's identified purpose varied per participant, ranging from being able to accomplish routine activities like showering to finding a career or engaging in an activity that was meaningful to the person.

Subtheme: Faith

Eight of the participants connected hope to their faith or religious beliefs.

"I want to go to heaven. That's what hope gives me. God's given me a hope and that chance of not going to hell. I want to take that as much as possible."

"I feel like I got other things in life to do and like my mom said, "God got a great anointing on you in life." ... I keep an open mind and I continue to pray and read and seek him. He'll show me."

"Hope means to me... getting connected with my Father, who's in heaven, because without him I can't do anything."

Patients described the strength of faith that gave them hope even when they were the most despairing and most alone. The participants that connected hope with God did so in a way that was almost synonymous; that with God in their lives they had hope, but when they did not feel that connection with God, hope was lost.

Theme 4: Absence of Hope

Twelve participants described experiences of feeling no hope or hopelessness. Some participants, while able to describe what having hope would feel like, were currently experiencing an absence of hope. This was difficult for these participants to discuss and two participants in particular were unable to describe the feeling further than the following:

"No, I don't (feel hope). (small laugh) I don't feel anything. I don't feel happiness. I don't feel sadness. I don't feel anything."

"No, I don't feel hope. I don't feel hope at all because there is no hope."

Not feeling hope also occurred in the face of challenges encountered in their lives.

"(You feel no hope) when you don't get your goals accomplished, and you have major problems, that's when I get panicky, and you want to be angry at those that

have major influences on your life, like the government, and those that are in power.”

Subtheme: Symptoms

An absence of hope was discussed in the context of symptoms. Severe and persistent symptoms contributed to a lack of hope and for some directed feelings of suicidality.

“I want to live but I just don’t really understand how I can go on, you know, being depressed like that and hearing voices. You know, something’s gotta be done, it seems like.”

“When I try to commit suicide, it’s not a sad feeling. It’s not like, “Ah, I’m about to die.” When I try to commit suicide, I’m thinking I’m benefiting myself. I’m thinking, “Man, if I don’t commit suicide now, I’m going to get tortured. I’m taking the easy way out.”

For these few participants, they described this hopelessness as the reason for being in the hospital. They did not see a way out of the distressing or overwhelming experience of psychosis and could not envision the possibility of a future without unmanageable symptoms, therefore they had no hope for the future and suicide seemed a viable option for relief.

Theme 5: Treatment

Treatment was defined as medications, seeing a therapist and/or provider, hospitalization or any other type of care they received for their mental illness.

“My nurses, they let me know what to do, and if I don’t do it, I see it. I see it. If I don’t take my medicine, I see what’s going to happen...it’s when you get off the medicine. It don’t make you feel good. And I- that’s my number one priority to try to do every day. And I like going to the doctor because it’s my responsibility.”

Participants had varying experiences of treatment. Some were very positive about treatment and identified that they needed treatment and that they had a personal responsibility to follow through.

Subtheme: Non-adherence

Five participants revealed that they did not believe they had a schizophrenia spectrum disorder. Two stated that as soon as they were out of the hospital they would stop taking their meds. Since they did not believe they had an illness, they saw no reason to take medications.

“I’m not getting any treatment. Not taking any medicine at all because what I know is for real. Medicine ain’t going to fix this...I’m not going to take any medicine because it’s going to hurt me, or it’s not benefiting me, so it’s going to hurt me”

“I just try to deal with taking my medication, which sometimes I have to force myself to take it because I don’t want to. Because I don’t think I need it.”

Others described previous non-adherence:

“At first, it was medicine all the time for two years, then the last two years it’s been like medicine for two months then for six months I won’t have medicine or something like that.”

“I don’t know why I go so long without taking my medicine. I have a really hard time remembering to go get my shot. Then when I don’t I feel so bad. I’m like, “Okay. Let me call my caseworker. I need my shot.” Then she’s busy. I have to wait another week. Then, when she’s free, I’m busy.”

Eight participants reported unwanted and bothersome side effects of medications, and for some this contributed to non-adherence. Others described non-adherence in the context of medications not producing the desired results.

“It (medications) turns all the voices into like a mushy ball of loud. ... It sounds like a drunk or kind of like Snoopy’s, or Charlie Brown’s teacher. That’s how it sounds a lot. Which is great. I’d rather hear blah, blah, blah instead of actually hearing voices telling me my impending doom is in 10 minutes. The medicine does help, but it doesn’t do what I truly want it to do.”

Ten participants related that the medications diminished but did not eliminate symptoms. For some this made them not want to take the medications, but for others it was better than nothing.

Subtheme: Sense of Belonging, Hope & Treatment

Some participants made connections between hope and belonging and treatment. One participant, when asked if she generally felt that she belonged, stated:

“When I’m on my medicine, yes. When I’m not on my medicine, I don’t feel like I belong anywhere. That’s why it’s so important for me to stay on it. That’s the only way I feel any hope, any sense of belonging.”

Another participant expressed that:

“(Medications) help me feel level like a normal person. I feel like an outsider when I don’t take my meds. I don’t feel like I understand things and I don’t feel like I fit in. I see and hear things that tell me I don’t fit in. I just push myself back and don’t come any closer to the crowd, if that makes any sense.”

“I can maintain very well on my medicine and I’m so grateful for the medicine. It gives me so much hope.”

The participants who clearly made associations between taking medications and sense of belonging or hope also described more positive experiences of sense of belonging and hope, whether in the present, or in the past.

Theme Overlap: Hope and Sense of Belonging

There was overlap between hope and sense of belonging in the transcripts of eight of the participants. One participant's hopes (goals) were specifically related to being with other people:

"I frequently hope that I'll be able to find some way to maintain my way of life, while also living around some of the people that I really enjoy."

Belonging was related to setting goals or having a purpose in life. There was hope in being with other people they could relate to and in communicating and connecting with others.

Discussion

Themes discussed in this article portray sense of belonging in the lives of persons with schizophrenia as having substantive meaning. Most participants could describe having had a sense of belonging at some point in their lives, if not current, and identified it as being a valuable, even an essential human experience. Participants described the need to be a part of the "outside world" and maintain communication and connection with others. Feeling a sense of belonging was best achieved by being with other people. There was a need to feel needed, and reciprocal relationships where the participants were able to be there for someone else contributed to having a sense of belonging. Being a part of something also evoked a sense of belonging, whether it was a family group, peer group, or a group of other people with mental illnesses with whom they could relate shared experiences and who would understand them.

There was a strong component to the narratives of the experience of not feeling a sense of belonging, of not fitting in. Being lonely and feeling like an outsider in most situations was a common experience for participants. Some of the lack of sense of belonging experienced by individuals with schizophrenia may be imposed by the illness. However, it may also be that the emotional distancing cultivated by some to protect themselves from the pain of this lack paradoxically keeps them distant from others and perpetuates feelings of not belonging.

Hope for the future is important to recovery and important to life for persons with schizophrenia. As one participant stated, "...everybody needs to hope in something or believe in something." Despite the importance of hope, the absence of hope was a common occurrence and participants described struggling with feelings of hopelessness. Severe symptoms of schizophrenia were a cause for many to experience a lack of hope, even to the point of feeling suicidal. One participant described the experience of hopelessness due to unrelenting auditory hallucinations "... the voices have harassed me to the point of where I was at a breaking point. Even though I didn't really feel that way emotionally. I felt that way because I felt like there was nothing left I could do. Hopelessness."

Participants in this study had varying experiences of treatment. For some, treatment was identified as necessary and something that they could not do without. Some of these participants identified that treatment made them more hopeful and that it enhanced their sense of belonging through increasing ability to interact with others. Others did not believe they needed treatment, or even that they had schizophrenia. For some, treatment did not

make them feel more hopeful or make any difference in their sense of belonging. A major challenge of treatment for many was that it decreased, but did not fully eliminate symptoms. This may be a cause for treatment self-discontinuation if the person doesn't believe the benefits of the medication outweigh risks such as side effects.

Limitations

This study has several limitations. Participants were recruited from an inpatient psychosis unit with the intent to capture experiences at a time when they were recovering from a crisis period and would be able to recall contrasting experiences of illness and improving mental health. Narratives from this cross-section of time may not reflect their typical daily experience. Some of the participants had recent or current thoughts of suicide, which may have resulted in an overemphasis on hopelessness. Feelings of sense of belonging may have been different in the hospital environment than would have been the case in their home and other usual settings. Additionally, the depictions of experience of treatment may have been overly influenced by their hospital experience and inadequately reflected the outpatient treatment experience. Generalizability is limited to the geographical location, setting and sample composition. Inclusion of more stable and functioning outpatients from multiple sites in the U.S. could provide a more complete portrait of the lived experiences of persons with schizophrenia.

Conclusion

The study has confirmed that sense of belonging and hope are both important constructs in schizophrenia. Having a positive sense of belonging has been found to enhance interpersonal, professional and academic success, improve self-concept, to be a protective factor for suicide and overall to be vital to psychological functioning (Brown, Silvia, Myin-Germeys, & Kwapil, 2007; Drolet, Arcand, Ducharme, & Leblanc, 2013; Hagerty, Williams, Coyne, & Early, 1996; Kissane & McLaren, 2006). The data underscore that meaningful connections and presence of others in the lives of persons with schizophrenia can impact well-being and mental health. The participants of this study commonly experienced a lack of hope and sense of belonging, and this lack negatively affected mental and emotional health, in some instances most severely. The findings indicate that sense of belonging is more than just having social contact with others, which has implications for research on sense of belonging in the context of social support interventions for schizophrenia. There is some indication that sense of belonging and hope may have a role in treatment adherence, and this needs to be more thoroughly investigated. These findings indicate that more quantifiable research on sense of belonging and hope is needed to examine the role these concepts play in mental health and recovery. Particularly, further study is needed to explore the possible link between sense of belonging and/or hope with treatment adherence to enable development of more effective strategies to promote recovery and even treatment adherence.

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Table 1

Sample Characteristics

Characteristic (N=20, no missing data)	<i>n</i>	%
Gender		
Male	13	65
Female	7	35
Race		
Black	6	30
White	14	70
Level of Education		
Grade School	2	10
Some High School	4	20
High School	6	30
Some College	7	35
Graduate Degree	1	5
Marital Status		
Single	17	85
Married	3	15
Employment Status		
Employed Part-time	1	5
Retired	2	10
Disabled	10	50
Unemployed	7	35
Living Arrangements		
Lives Alone	4	20
Lives with Family/Friend	13	65
Lives in a Group Home	3	15
	<i>n</i>	M(SD) Min-Max
Age	20	40.2(13.8) 21-62