How People With Schizophrenia

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The view of schizophrenia as a progressive, deteriorating disease is being challenged by current research and self-reports. A new paradigm of recovery is emerging. Long-term follow-up studies have demonstrated that the majority of people with schizophrenia significantly improve or recover over time, with substantial heterogeneity within the illness itself, among people with schizophrenia, and within a given individual (Davidson & McGlashan, 1997). In addition, consumers with the illness are writing and speaking out in greater numbers, describing their subjective experiences with the illness and the health care system (Deegan, 1988, 1996; Leete, 1988; Lovejoy, 1984).

Hope is considered an essential element in recovery and rehabilitation. Many first-person accounts of schizophrenia describe regaining hope as a turning point in a person’s recovery. Hatfield and Lefley (1993) summarized the consumer literature on schizophrenia and found that hope was linked to some of the most poignant statements made by consumers. However, they noted that little was known about the way professionals and families could instill hope effectively.

**BACKGROUND**

Serious mental illness threatens personhood and the self because it can affect every facet of life, including thought processes, survival in the marketplace, and susceptibility to exploitation, and it can restrict choice and movement (Sullivan, 1998). Deegan (1996) described the existential challenges faced by many people because their lives and dreams have been shattered by mental illness. Many consumers become hard of heart because not caring is a "strategy that depletes people who are at the brink of losing hope, adopt in order to remain alive" (Deegan, 1996, p. 93). Deegan (1996) noted that this strategy is critical because hope and biological life are inextricably intertwined.

Hope has been linked with several other concepts. Haase, Brit, Coward, Leidy, and Penn (1992) applied simultaneous concept analysis to four concepts that nursing practice suggested were interrelated—spiritual perspective, hope, acceptance, and self-transcendence. The authors concluded that the four concepts were all dynamic responses to life experiences, and connectedness was the central theme across the four concepts. Self-transcendence was identified as an outcome attainable through spiritual perspective, acceptance, or hope. The critical attributes of hope were:

- An energized action orientation.
- A general or particular goal.
- A feeling of uncertainty.

Miller (1992), a nurse-researcher in the area of hope, viewed hope as a private and powerful resource, an intrinsic component of life. Miller (1992) defined hope as a state of being, characterized by an anticipation of a continued good state, an improved state or a release from a perceived entrapment. The anticipation may or may not be based on concrete, real world evidence. Hope is an anticipation of a future that is good and is based upon: mutuality (relationships with others), a sense of personal competence, coping ability, psychological well-being, purpose and meaning in life, as well as a sense of “the possible” (p. 413).

Miller (1992) differentiated between “to hope that” and “to hope.” “To hope that” refers to a specific object of hope, with the insecurity of whether or not that object will be realized. “To hope” is an existential orientation of striving for a generalized sense of being. Based on research of hope in critically ill people, Miller (1992) identified several ways to inspire hope. These included using:

- Cognitive strategies.
- Determinism.
- A philosophy of life and world view.
SOMEONE TO HOLD THE HOPE

"I'd say the most important thing is to listen to the person and try and understand why they don't feel hopeful, which is probably because they have an illness over which they have very little control. To try and understand, it's something that until you've experienced it, you can't understand. But it's important for others to try and see themselves in that person's shoes and have empathy for them. It is important to realize that hope is something that is difficult for them to achieve, but it's not impossible. If you can hold the hope for someone who has no hope, at that moment when they start to feel better, you can pass the hope back over to them. It's nice to have someone who holds the hope for you, especially when you feel like you have no hope."

- Spiritual strategies.
- Relationships with caregivers.
- Family bonds.
- A sense of being in control.
- Goal accomplishment.

Hope comes from within a person. However, others can have an impact on a person's hope, and the way this can be done for people with major mental illnesses is an increasing focus for clinicians (Adams & Partee, 1998; Deegan, 1996; Russinova, 1999; Spencer, Davidson, & White, 1997). Russinova (1999) described three types of hope-inspiring strategies. The first explores the healing potential of supportive relationships; the second focuses on increasing the consumer's inner resources; and the third facilitates the use of external resources.

Two additional studies demonstrated positive hope-specific outcomes of broader treatment interventions (Holdcraft & Williamson, 1991; Littrell, Herth, & Hinte, 1996). In previous research (Kirkpatrick et al., 1995), clinicians working with people with schizophrenia identified several hope-instilling strategies:

- Building relationships.
- Facilitating success.
- Connecting to role models.
- Managing the illness.
- Educating both clients and the community.

The most frequently noted strategy involved the client-clinician relationship. Essential to that relationship was being present for the person; listening to, valuing, and accepting the person; and understanding the person's perspective. As one clinician noted, "understanding is the intervention" (Kirkpatrick et al., p. 17).

Although researchers have studied ways to inspire hope from the perspective of clinicians and people with physical illnesses, the ways in which people with mental illnesses inspire their own hope has not been studied. Therefore, this article describes a qualitative study designed to examine hope from the perspective of people with schizophrenia. How the participants built their own hope was explored.

METHOD

The study reported in this article represents one portion of a larger study, which included an analysis of the associations among hope, symptom severity, and quality of life in people with schizophrenia. The larger quantitative study was completed with 55 participants with schizophrenia attending a community-based, psychosocial rehabilitation program. Results have been reported elsewhere (Landeen, Pawlick, Woodside, Kirkpatrick, & Byrne, 2000).

Hope was measured using the Miller Hope Scale (Miller & Powers, 1988). It is notable that levels of hope were related to subjective positive quality of life but not to symptom severity. The participants' hope scores were significantly lower than the hope scores of clinicians previously studied.

Participants in the quantitative component were asked to participate in the qualitative portion of the study. From 22 volunteers, purposive sampling was used to select 10 participants based on gender, years ill, severity of symptoms, and level of hope, as measured by the Miller Hope Scale. Selection of the 10 participants was designed to capture as broad a range of experi-
ences as possible and to obtain a group that was representative of the larger group (i.e., 55 in the quantitative study).

Participants, two women and eight men, ranged in age from 28 to 46 (mean age = 34.7). They had been living with schizophrenia from 4 to 17 years (mean = 9.9 years). Their age at time of diagnosis ranged from 18 to 42 (mean age = 24.8). All had some high school education, with two participants having university education. All had stable housing and incomes. Their demographics were similar to the larger group, except that they had been ill for fewer years (9.9 versus 13.9).

Semi-structured interviews were conducted by one of two authors (H.K. or C.B.) who did not know the participants. The interviews lasted 45 to 60 minutes and were audiorecorded. Transcripts from the audiotapes were read by all researchers, coded related to content, and then analyzed by content themes.

Because understanding the experience of people with schizophrenia was identified by clinicians as important in earlier research (Kirkpatrick et al., 1995), this article will focus on strategies consumers used to build and maintain their own hope. The relevant interview questions included:

- What things in your life help you to feel hopeful?
- Do you have beliefs that assist you in coping with difficult times?
- From your experience, how can health professionals enhance hope?

RESULTS

All 10 participants identified strategies that were helpful in igniting or nurturing their hope. Several key themes emerged:

- Maintaining relationships.
- Experiencing success.
- Taking control.
- Finding meaning.

Maintaining Relationships

All participants discussed aspects of relationships that were hope inspiring, describing close family members, significant others, and peers who were particularly helpful. Helpful aspects of relationships were identified as:

- Being there.
- Providing encouragement.
- Showing understanding.
- Giving support.

One participant described his parents as very understanding and supportive (e.g., “They give me a sort of anchor in life that I wouldn’t have if I didn’t speak to them every week”). Some participants talked about a sibling’s belief in them (e.g., “He listens to me and understands I’m not well and that there are things I can and cannot do, but he always has the utmost faith in me”).

Friends also were important. One man said when he felt depressed, he found talking to friends helpful (e.g., “There is not much I can do really, but I guess I am lucky. So that’s the main thing...just friends, friends help me”). However, several participants described aspects of relationships that were not hope inspiring—relationship breakdowns, overprotective families, or family members who do not understand the illness.

Seven participants spoke of the importance of their relationships with staff in supporting their hope. The key was the staff providing emotional support and genuinely listening. During a crisis, staff exhibiting a sense of caring and taking time communicated the message that there was hope and that something better was possible (see the Sidebar on page 48).

One woman discussed several staff members who were instrumental in keeping her hopeful, especially in dark times when she became very ill and her family and close friends pulled back from supporting her (e.g., “One of the nurses actually told me she calls herself my number one cheerleader. She always said, ‘No matter what happened, you’re going to get better.’”). Another participant talked of a case manager who had linked him with another client to attend a movie. He was excited about the possibility of making a new friend (e.g., “So that’s a little ray of hope that’s entered my life.”).

Experiencing Success

Eight participants talked about accomplishing goals or experiencing success as crucial in facilitating hope. Experiencing success had many different steps and dimensions:

- Finding a specific object of hope.
- Setting realistic goals.
- Accomplishing small daily tasks or changes in self-destructive behaviors.
- Achieving life goals in work.

One participant described it as follows: “The seed of hope is something that comes to you when you want something whether it’s a job or a family or if you want some type of help in some area...you need something to hope for.”

Some participants focused on short-term goals such as going for a walk or recognizing a daily
accomplishment. The time orientation was short term, but the accomplishments gave them hope.

Other participants identified long-term goals such as volunteering or having success at work. Having activities that were meaningful to them was important in maintaining hope for several participants. For one participant, accomplishment meant self-improvement (e.g., "I think what really brought [hope] around was when I went into a treatment program 6 months ago for marijuana use and now I have 6 months of being clean."). Some participants identified the significant role clinicians played in helping them set and achieve goals by offering encouragement and support (see the Sidebar on this page).

Participants also described having direct knowledge of successful peers as helpful, as well as reading first-person accounts and hearing inspirational lectures. One participant remarked, "So my suggestion is to get as many success stories from those who have schizophrenia to give a sense of hope to those just beginning their journey in schizophrenia." Prominent people, who were public about coping with their own or their relative's schizophrenia, inspired hope. For example, Bill McPhee started a magazine (Schizophrenia Digest) in Canada and is very public about his ongoing struggle with schizophrenia. A participant who had one of the lowest hope scores of the 55 subjects and who described himself as "pessimistic" rather than hopeful experienced some feelings of hope when he heard Bill McPhee speak (i.e., "...he had come from so far and was incapacitated for a number of years and to be functioning at that level gave me some feelings of hope.").

Taking Control

Participants discussed the importance of gaining control over their lives and their symptoms. Four participants mentioned specific medications that helped them gain control over their symptoms and have a greater sense of hope for the future. One participant had been working to recognize early signs of decompensation and prevent relapse. At one point, she said it was just luck whether or not she became ill, but later she said, "...I have more control over my illness than I ever realized.... Knowing that gives me more hope because I know the next time when I start to get ill I can turn it around. You don't have to let your illness run your life."

Another aspect of regaining control considered being hopeful an active process that required the person to change his or her own thoughts. This could involve seeing oneself as capable of making a change, thinking and talking about hope, or actively changing one's thoughts. As one participant said, "...you have to work it out in your mind. It takes work to become hopeful. Nothing comes free, including being hopeful. You have to work at it."

Several participants talked about this active sense of taking control:
- "I became motivated to persevere, no matter how things looked."
- "...making a conscious effort in my own self."
- "...I made the effort [I did it]."
- "...what made me hopeful is I understood... [italics added]"

HAVING A DREAM

"[It] was a dream of mine to become a scientist, a computer scientist or something.... [The occupational therapist] started getting me involved with computers, and I really did not want to do them, and then I started doing them, and for 8 months it was very stressful, well, yes for about a year at least it was stressful, and then I started enjoying them, and now I really enjoy them. I didn't want to do it at all when I started, but [the occupational therapist] got me involved in them."

One participant said he sometimes lapsed into thinking negatively, that his life was set and that it was terrible and would never change. However, he worked on positive thoughts (e.g., "...I tell myself that I have been thinking those thoughts.... I counsel myself that things will get better. It is only a thought, so if I change my thinking, hopefully my mood will change.").

Finding Meaning

In some sense, finding meaning in one's life was identified by all participants. One participant described being hopeful as "...feeling like there is some purpose in my life. I'm not just a person here on earth meant to take, take, take, but I have something to give."

Six participants discussed spiritual beliefs that were important sources of hope, such as a belief in God or specific religious rituals like praying or reading the Bible. It is striking that, for four of the six participants, spiritual beliefs included an interactive, comme-de-like relationship with God. One participant reflected this sense of God being there for him by saying, "...I do pray. I talk, sometimes just walking down the street. If I'm feeling crummy, I'll just say, hey this is a bummer God.... I don't talk to Him, I just say it in my head." Another participant used imagery to receive comfort (see the Sidebar on page 51).

For some participants, a belief in God helped them accept their illness. One participant considered schizophrenia to be a gift from God. He felt that without it he probably would be living at home, unemployed. He said, "I wouldn't have nearly as good a life—the
Drop In Centre, my friends, programs, my apartment, and my music and cigarettes—all those things. I wouldn’t have much of a life at all I don’t think.”

Another participant thought God had a purpose for him although he was not sure what it was (i.e., “I think there’s a purpose for me having schizophrenia so that’s kind of a hope.... It is to tell the world something, but I’m not exactly sure what it is.”).

The four other participants identified themselves as not being religious or spiritual (e.g., “I tend to look to success in life as being the more important thing rather than to make it into the afterlife,” “I have faith in real things, material things. Like the sun is going to come up tomorrow, rivers are going to flow, the rains going to fall.... These are the only things you can trust.”). However, these participants did identify a belief in science and the natural order of things, which they found helpful (see the Sidebar on page 52). One participant said he took hope from watching the television show Star Trek (i.e., “…I get some hope from watching that show—that there is a future for beings in the 24th century.”).

**DISCUSSION**

The 10 participants interviewed in this study have struggled with schizophrenia for many years. Whether or not they considered themselves hopeful, they identified strategies that have helped them build and maintain hope. These strategies reflected Miller’s (1992) concepts of “to hope that” and “to hope.” “To hope that” can be seen in their goal setting and experiencing success. “To hope” is exemplified in finding meaning for the person, or as one participant stated, “to put my life in perspective.” The strategy of taking control can be considered a link between the two concepts.

Several themes were similar to staff’s responses in previous research, with the importance of relationships and experiencing success identified by both staff and consumers (Kirkpatrick et al., 1995). As clinicians, it is confirming to be constantly reminded of the importance of a truly respectful and solid relationship in facilitating hopefulness in clients struggling with debilitating chronic illnesses, such as schizophrenia.

However, it is notable that the strategy of finding meaning in one’s life was not identified by clinicians in the first phase of this research. A personal relationship with God has been described in other qualitative research with mental health consumers (Sullivan, 1993). Fallot (1998) reviewed spiritual and religious dimensions of recovery narratives and found that spirituality was a core element in the narrative context of recovery for many consumers. An element of such importance to consumers has implications for practice and suggests the need to assess spiritual beliefs and activities and how they are, or can be, helpful to the person. Clinicians need to discuss spirituality and meaning by asking, “How does this person put their life into perspective?,” and include this information in a holistic plan.

While the impact of schizophrenia may have unique characteristics due to the effects of the symptoms on the mind, the hope-enhancing strategies identified by these participants are
consistent with those identified by people with physical illnesses, as noted by Miller (1992). Searching for meaning is consistent with using spiritual strategies, having a philosophy of life, and developing a world view. The concept of taking control is consistent with three of Miller's strategies: cognitive strategies, determinism, and a sense of being in control. Participants perceived that their own knowledge and actions could affect an outcome, that thought processes could be used consciously to change unfavorable perceptions, and that they themselves could make the difference.

CONCLUSION
These findings have important implications for clinicians working in this field. For example, many consumers currently are writing about their successful experiences in coping with their mental illnesses, accompanying issues, and recovery. However, they often are published in professional journals. Clinicians must make these articles available to clients and discuss the information with them individually or in groups to help them achieve a sense of connectedness and hope.

Psychosocial rehabilitation recognizes and emphasizes the importance of goal setting and goal attainment. Clinicians need to help clients identify and meet goals, which can be broad, life goals or simple, daily goals. It also is important to remember the medical model and what it can contribute for people living with a major and chronic mental illnesses. Clinicians can help clients regain the best control over symptoms that current medical science allows. Both these participants and outcome-oriented research (Holdcraft & Williamson, 1991; Littrell et al., 1996) identified the importance of symptom relief.

Participants reinforced the need to feel connected to significant others and health professionals. Qualities they identified as helpful were being there, encouragement, understanding, and support. Health professionals were particularly important during times of illness when significant others may retreat. As part of the client-therapist relationship, clinicians need to talk about hope openly, realistically, and strategically, recognizing that being hopeful is an active process. They can help people gain control over their lives by having greater control over the environment, their symptoms, and their thoughts.

Hope is important in enhancing the lives of people with schizophrenia, and they have much to tell clinicians about what is helpful in nurturing that hope. Health care professionals again are reminded of the need to listen.

REFERENCES


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KEY POINTS

1. Both clinicians and consumers identified the importance of maintaining relationships and experiencing success as helpful in building and nurturing hope for consumers.

2. To provide holistic care, clinicians need to discuss spirituality and meaning with clients.

3. Because being hopeful is an active process, clinicians need to talk to clients about hope, openly, realistically, and strategically.

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