How Occupationally High-Achieving Individuals With a Diagnosis of Schizophrenia Manage Their Symptoms

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Objective: The study objective was to elucidate coping strategies utilized by individuals recovered from schizophrenia.

Methods: This qualitative study enrolled individuals with schizophrenia who had reached a level of recovery defined by their occupational status. Diagnosis of schizophrenia was confirmed with the Structured Clinical Interview for DSM-IV. Current symptoms were objectively rated by a clinician. Surveys gathered information on demographic characteristics, occupation, salary, psychiatric history, treatment, and functioning. Audio-recorded person-centered qualitative interviews gathered accounts of coping strategies. Transcripts were summarized and coded with a hybrid deductive-inductive approach.

Results: Twenty individuals were interviewed, including ten men. The average age was 40 years. Sixty percent of participants were either currently in a master's-level program or had completed a master's or doctoral degree. Eight categories of

coping strategies were identified: avoidance behavior, utilizing supportive others, taking medications, enacting cognitive strategies, controlling the environment, engaging spirituality, focus on well-being, and being employed or continuing their education. Some strategies were used preventively to keep symptoms from occurring; others were used to lessen the impact of symptoms. Strategies were flexibly utilized and combined depending on the context.

Conclusions: Use of strategies in a preventive fashion, the effectiveness of the identified strategies, and the comfort individuals expressed with using several different strategies supported these individuals in achieving their occupational goals. The findings contribute to an overall shift in attitudes about recovery from schizophrenia and highlight the importance of learning from people with lived experience about how to support recovery.

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Treatment of schizophrenia is undergoing transformation. Outpatient clinical services are transitioning from a medical model with an illness focus to a patient-centered model with a holistic emphasis on well-being and functioning (1,2). Recovery from serious mental illness has various operational definitions, but there is consensus around definitions that emphasize the ability to live a fulfilling and productive life in spite of symptoms (3,4). Recovery has been defined in both objective and subjective ways, incorporating concepts beyond symptom stabilization to include well-being, quality of life, functioning, and a sense of hope and optimism (5–11).

This study adds to a small but growing number of qualitative studies that have examined how individuals manage their schizophrenia. For example, Cohen and Berk (12) reported on 86 low-income patients with schizophrenia "who could tolerate a 30-minute interview." Participants were asked how they coped with each of 29 symptoms across the categories of anxiety, depression, psychotic symptoms, and interpersonal stress. Explanation of coping was limited to brief responses. The most frequent coping used across all categories was "fighting back," an active response, followed

by a passive response of "doing nothing," either in a helpless or an accepting way. In a study with 47 low-income males with schizophrenia, Corin and colleagues (13,14) categorized participants by the number of psychiatric hospitalizations after the initial hospitalization. The authors found that those who were never rehospitalized frequented public spaces (for example, restaurants) often and on a schedule that kept a routine and some social interaction, had an active spiritual life, and had a particular way to restructure demeaning language (for example, "lazy") into something more constructive (for example, "relaxed approach").

To the best of our knowledge, no studies have addressed how individuals with schizophrenia who also meet some definition of recovery manage their symptomatology. Occupational functioning is one objective measure of recovery. The unemployment rate among individuals with serious mental illness is around 80% (15), and thus gainful employment connotes a considerable degree of stability and recovery. The objective of this analysis was to provide first-person accounts of coping strategies utilized by recovered individuals with schizophrenia.

METHODS

Study Participants

The study used purposive and snowball sampling methods to identify eligible individuals in Los Angeles. Study clinicians distributed letters and flyers to local National Alliance on Mental Illness (NAMI) groups and community clinicians. In addition, a study investigator who is also a consumer (ERS) made several presentations to various groups about her own recovery and scholarly work, which generated referrals. Interested individuals contacted the study clinical psychologist (ANC), who explained the study goals and methods. If the individual indicated a willingness to participate, eligibility criteria were assessed.

Eligibility criteria were 21 years or older; diagnosis of schizophrenia; experience of at least one persisting psychotic symptom in the past month at the level of 3 (mild) or higher on the Positive and Negative Syndrome Scale (PANSS) (16); employed in an occupation categorized as professional, technical, or managerial (per the *Dictionary of Occupational Titles*) or responsible as a stay-at-home caretaker of children or elderly family or engaged as a full-time student; maintained occupation for six continuous months within the past two years; and available to be interviewed in person and willing to have the interviews recorded.

Forty-eight individuals responded, and 21 enrolled. Of the 27 not enrolled, some did not meet the study criteria for diagnosis (N=4) or employment (N=15). Others chose not to enroll because they lived too far away (N=2) or were not interested after hearing the methods (N=2). Four individuals called about the study but were then unreachable for screening. Of the 21 individuals who were enrolled, one completed the study procedures but later requested that the data be excluded. Therefore, the analytic sample comprised 20 participants.

The study was approved by the institutional review boards (IRBs) of the University of California, Los Angeles, and the University of Southern California. Interviews were conducted from 2007 to 2010. Participants were compensated $100 per hour.

Procedures

Up to three in-person meetings were held with each participant.

First meeting. At the first meeting, the study psychologist explained the study procedures and consent form and completed the Structured Clinical Interview for DSM-IV (SCID) (17,18) to confirm the diagnosis of schizophrenia and assess current and lifetime psychiatric symptoms. The PANSS was also completed. Eight items from the Brief Psychiatric Rating Scale (BPRS) (19) were completed, including delusions, conceptual disorganization, hallucinations, blunted affect, social withdrawal, lack of spontaneity, manners and posturing, and unusual thought content. The diagnostic interview session lasted approximately 1.5 hours. The psychologist was trained to a standard of reliability on the SCID, PANSS, and BPRS and met annual reliability and quality assurance standards. Individuals who consented and met criteria for schizophrenia were scheduled for the second meeting.

Second and third meetings. At the second meeting, participants completed a brief background survey and the Behavior and Symptom Identification Scale–24 (BASIS-24) (20). The BASIS-24 assesses current symptoms and functioning. After these brief measures were completed, the study psychological anthropologist (ABH) conducted the person-centered interview.

Person-centered interview. Derived from a psychotherapeutic, Rogerian model (21), person-centered interviewing is a phenomenological approach that avoids imposing a preset structure on the way in which the participant describes his or her experiences (22,23). As such, the method elicits what the participant, rather than the researcher, perceives to be important or salient (24). In this study, as required by the IRB, a list of key domains of interest was used to guide the content of the interview so that consistent types of information would be gathered across interviews. However, participants were encouraged to describe their experiences and perspectives extemporaneously, with minimal structure imposed by the interviewer, and for some participants thorough coverage across key domains was not possible.

The first interview generally addressed family of origin, illness history, education, and social functioning. The second interview generally addressed current life, views of illness and treatment, career, living situation, and daily life. Throughout both interviews, past and present coping strategies were noted and highlighted. It is important to note that although these general domains were proposed for the two interviews, participants were not prohibited from talking about present-day experiences during the first interview or historical experiences during the second interview. Instead, participants were encouraged to discuss their lives and coping strategies in ways that made sense and felt comfortable to them as each aspect of their development and illness course was discussed.

Data Analysis

The interviews were recorded and professionally transcribed. Transcripts were reviewed and edited against the recordings by the study anthropologist as they were generated. ATLAS.ti was used for management and analysis. All transcripts were read by the psychologist, anthropologist, and three research assistants (RAs), who summarized each interview. A preliminary codebook was developed collaboratively, focused on key domains and subdomains. Transcripts were then independently coded by the RAs who were trained in ATLAS.ti. During the coding process, the RAs, psychologist, anthropologist, and a study investigator (ERS) met regularly in order to elaborate and adjust the codebook by using the constant-comparison analytic approach (25).

After coding of the interviews, multiple queries were conducted to examine the relationships between the codes, and axial coding was used to link categories. For purposes of this analysis, all text segments coded as "compensatory strategies," "important quotations," "medication compliance," or "mental health treatment routine" were reviewed by the psychologist to ensure that coding was representative of the category and the sample and to facilitate a visual depiction (via Excel) of the connections between coded segments, topics, and participants. Although the codes of interest appeared in all 20 transcripts, we found upon careful review that four individuals did not mention any specific coping strategies. The four individuals were not different in demographic or psychiatric characteristics from the other participants; there was no difference in the severity of their hallucinations or delusions, degree of unusual thought content, or level of education achieved.

RESULTS

Of the 20 participants, 13 completed all three sessions, and seven completed two sessions. Of the seven individuals who did not complete a third session, two were lost to follow-up, three moved, one died, and one completed all components in two sessions because scheduling a third was anticipated to be difficult. The mean±SD time between the initial and the second meeting was 23±14 days (range four to 69 days). The mean time between the second and the third meeting was 48±54 days (range ten to 188 days).

Sample Characteristics

All participants had a confirmed diagnosis of schizophrenia. Demographic information is presented in Table 1. Half the participants were men, the average age was about 40 years, and participants were from various racial-ethnic groups. Sixty percent of the sample was either currently in a master's-level program or had completed a master's or doctoral degree. Across the sample, most participants were employed full-time, and most made less than $50,000 a year. Information about psychiatric and psychosocial functioning is presented in Table 2. Most participants had a history of at least one psychiatric hospitalization and were currently prescribed psychotropic medications. In the past week, on average, participants experienced a moderate level of hallucinations and delusions.

Person-Centered Interviews: Coping Strategies

Eight categories of coping strategies were identified: avoidance behavior, utilizing supportive others, taking medications, enacting cognitive strategies, controlling the environment, engaging spirituality, focusing on well-being, and being employed or continuing their education. The 16 individuals who identified strategies typically identified multiple strategies. Use of strategies varied, with some used consistently and others used only when the person was faced with a particular symptom. Illustrative quotes are

TABLE 1. Demographic characteristics of 20 individuals with schizophrenia

Characteristic	N	%
Age (M±SD)	39.8±10.1	
Male	10	50
Race-ethnicity		
Caucasian	7	35
African American	6	30
Hispanic or Latino	4	20
Asian	2	10
Persian	1	5
Marital status		
Never married	11	55
Divorced	4	20
Married	3	15
Living with a partner but unmarried	1	5
Separated	1	5
Has children	6	30
Living situation		
Rent	15	75
Own home	4	20
Board and care	1	5
Lives with		
Roommate, nonfamily	7	35
Married or romantic partner	5	25
Alone	5	25
Children only	1	5
Parents only	1	5
Children and parents	1	5
Education		
High school diploma only	2	10
Some college, no degree	1	5
Currently in college	1	5
College degree	4	20
Currently in master's program	3	15
Master's degree	5	25
Doctoral degree	4	20
Length in current job (M±SD months)[a]	43.1±41.1	
Salary less than $50,000[b]	16	89
Full-time employment	15	75

[a] Five participants were excluded: four were current students, and one was a caretaker of parents.
[b] Two participants did not respond.

provided below. [Additional quotes are available in an online supplement.]

Avoidance behavior. Participants discussed avoiding specific behaviors or situations to maintain stability. Individuals discussed avoidance of alcohol and illegal drugs to circumvent symptom exacerbation. Participants also mentioned avoiding situations that could be personally stressful or interpreted as chaotic. If such situations arose without their effects being anticipated, the situation was abandoned. For example, one individual said, "If I'm seeing something that is frightening . . . I can't watch the sci-fi channels 'cause if it's gory and bloody I know it'll start my symptoms, so I get away from that." Avoidance of specific behaviors or situations most often was the result of a trial-and-error process over the individual's lifetime rather than a result of education or

TABLE 2. Symptoms and functioning of 20 individuals with schizophrenia

Variable	N	%
Psychiatric history		
Age at first symptom (M±SD)	18.9±7.2	
Males	19.3±3.7	
Females	18.4±9.8	
Age at first hospitalization (M±SD)	23.8±7.0	
N of hospitalizations		
0	3	15
2–5[a]	13	65
6–9	3	15
Too many to count	1	5
Psychotropic medications		
Currently	19	95
Ever	20	100
Psychotherapy		
Currently	12	60
Ever	19	95
Symptom severity (past week) (M±SD score)[b]		
Hallucinations	3.3±1.8	
Delusions	3.2±1.6	
Conceptual disorganization	1.9±1.0	
Blunted affect	2.1±1.3	
Social withdrawal	2.8±1.6	
Lack of spontaneous conversation	1.6±.9	
Mannerisms	1±0	
Unusual thought content	2.1±1.2	
Functioning (past week)[c]		
At least half the time		
Get along with family[d]	16	89
Get along with nonfamily[e]	19	100
Get along in social situations	17	85
Feel close to another person[d]	9	50
Have someone to turn to if need help	16	80
Little or no difficulty		
Managing day-to-day life	5	25
Coping with problems	13	65

[a] No participant reported one hospitalization.
[b] Measured with the Brief Psychiatric Rating Scale. Possible scores on each item range from 1 to 7, with higher scores indicating more of that symptom in the past week.
[c] Measured with the Behavior and Symptom Identification Scale.
[d] Two participants did not respond to this question.
[e] One participant did not respond to this question.

instruction that these should be avoided. Typically, the individual experienced the situation multiple times, always or often followed by an exacerbation of symptoms, and then decided that it was best avoided.

Utilizing supportive others. Most participants described connecting with family, friends, or professional supports as an important strategy to provide objective insights into symptom exacerbation (for example, psychotic thoughts and odd behavior) and nonjudgmental support during those times. One participant said, "I think, 'Who can I talk this [symptom] out with?' and generally it's [a friend]. It is not to fix what's going on [symptoms] but to restore me to where I am comfortable." Several discussed participating in therapeutic groups (for example, NAMI) that provided considerable peer support. Some participants highly valued

working or being involved in a recovery-oriented group or organization, where they were with like-minded individuals and felt implicitly understood.

Taking medications. Most participants discussed medications as a key part of their regimen to maintain or regain stability. For some there was a distinct point (for example, a specific hospitalization or achieving a desired life goal) at which they recognized the necessity of medication, and for others it was knowledge gained after many medication trials. One individual stated, "I realized that I felt better on the medication. . . . A light bulb went off on my head. And then after that I pretty much understood the importance of taking the medication, which became more fully engrained into me." Individuals discussed the challenge and frustration of finding the medication that best addressed symptom reduction and dealing with troublesome side effects (for example, lethargy and weight gain). Participants explained that medication adherence did not mean disappearance of symptoms, but rather enhanced stability. Medication adherence was varied, with a few participants saying they had always been adherent, whereas others said they had been nonadherent intentionally at times during their lives.

Enacting cognitive strategies. Participants discussed specific cognitive strategies that they used in the face of symptoms—some self-taught and others learned from a professional. These strategies involved ways to systemically reason through their problematic thinking, its basis in reality, and possible alternative interpretations. For example, one person said about hearing derogatory comments from voices when driving alone down the road, "I think to myself is this—is this logical. I mean, we both have our windows closed, we're on opposite sides of the freeway . . . that couldn't be possible." The cognitive strategies mentioned are similar to those taught and practiced as part of evidence-based cognitive-behavioral therapy (CBT) for psychosis (26), and although individuals did not specifically speak of engagement in CBT, they discussed how professionals had taught them cognitive techniques.

Controlling the environment. Participants described adjusting their surroundings to help prevent, minimize, or address symptom exacerbation. One participant said, "I have to kinda prep my environment around me to be able to be the way I am because I don't like to be alone in my bedroom when I'm symptomatic. It just freaks me out, ya' know." Some participants preferred quiet, calming environments that are clear of clutter or distraction, and others liked to drown out the thoughts and voices with environments filled with sounds and activity.

Engaging spirituality. A few participants described ways in which they found support through religion and spirituality, including one who said, "I [use] my Buddhist meditations." Use of spirituality was for some a form of social support and for others a place to avoid stress and find solitude.

Focus on well-being. A few participants talked about the importance of exercise, diet, or wellness as a component of staying psychiatrically stable or combatting symptoms. One participant said, "I started working out like five days a week and that helped immensely . . . with symptoms, and like everything . . . like my head is so clear."

Being employed or continuing their education. A few participants discussed the benefits of education or employment, especially because of its absorbing and distracting nature but also for providing a sense of belonging. One participant said, "I work on the weekends too because it's just distraction, it's good, it's what I call the distraction factor."

DISCUSSION

During the course of in-depth interviews, 16 participants with a diagnosis of schizophrenia identified coping strategies that helped them with their symptoms. Most participants described knowledge and use of multiple strategies—a menu of coping strategies. Typically, strategies were discussed in relation to positive symptoms of the disorder (for example, hallucinations) rather than negative symptoms (for example, avolition). Four participants did not identify any specific strategies, perhaps because they were not aware that they were using strategies.

Participants articulated active strategies to combat symptom exacerbation; they did not describe passive acceptance of symptoms, as found in the Cohen and Berk (12) study. Furthermore, many strategies were preventive to keep symptoms from occurring. As in the sample in the Corin (13) study, participants described the value of routine, the role of spirituality, and the importance of recovery-oriented language. We surmise that the use of strategies in a preventive fashion, the effectiveness of the identified strategies, and the fact that individuals were comfortable with several different strategies supported these individuals in achieving their occupational goals.

It is important to note that although participants identified strategies for coping with symptoms, they experienced life challenges that related, at least in part, to their illness. Half the sample did not feel close to another person in the past week. Many reported difficulty managing day-to-day life and experienced recent hallucinations or delusions or both. These findings highlight the fact that having ongoing symptoms and struggles does not mean that individuals cannot pursue occupational and educational goals that are important to them. If fact, the results indicate that at least some participants felt that being employed or continuing their education was an important coping strategy, contributing to quality of life (27).

The study had some limitations. Data were collected in only one city, and recovery was defined solely through occupational functioning. Despite these limitations, the study revealed unique perspectives on how individuals cope with symptoms of schizophrenia while maintaining occupations that require a high degree of responsibility, productivity, and accountability. The legitimacy of the findings is strengthened by the gold-standard diagnostic approach, the careful and systematic operationalization of functioning, and the phenomenological method used to elicit participants' experiences.

Although there are a considerable number of evidence-based practices for treating people with schizophrenia, these practices are limited in terms of long-term symptom reduction, psychosocial rehabilitation, and overall recovery. Most patients continue to face symptoms throughout their lifetime and, in order to achieve their goals, will need a menu of coping strategies to draw upon. Some of the coping strategies identified in this sample align with the skills taught in evidence-based practices, but some are unique. This is the benefit of gathering information directly from recovered individuals. We propose that the next wave of revisions to evidence-based practices would benefit from the incorporation of consumer input, particularly from consumers who have developed successful strategies to manage symptoms and lessen their impact on functional roles.

CONCLUSIONS

The shift of mental health services to a recovery orientation has been slow, and the social stigma associated with psychiatric illnesses, such as schizophrenia, continues, perpetuated by popular culture and media. This research demonstrates that individuals with serious mental illness can articulate numerous ways in which they manage their symptoms while also achieving their goals. Service providers, consumers, caregivers, and researchers can reflect and expand on the strategies shared by our participants in order to reconceptualize and advance what is possible in mental health recovery, especially when consumer voices and lived experiences are prioritized.

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