

Recognizing and Responding to Early Psychosis: A Qualitative Analysis of Individual Narratives

Abigail M. Judge, M.A.

Sue E. Estroff, Ph.D.

Diana O. Perkins, M.D., M.P.H.

David L. Penn, Ph.D.

Objective: The ways in which individuals recognize and respond to emerging psychotic illness remain poorly understood. This retrospective study explored when and how individuals recognized changes in themselves and responded to these changes.

Methods: This study used qualitative methods to explore when and how 15 individuals recognized changes and identified how they responded. Standardized information on the onset of psychosis was also collected.

Results: Themes relating to recognizing and responding to emerging psychosis were identified through qualitative analysis of interview transcripts. Themes included normalization, explanatory models, withdrawal, avoiding help, and coming to terms with psychosis.

Conclusions: Participants recognized changes in themselves but tended not to understand the observed changes as part of a men-

tal illness. Individuals avoided professional help because of stigma concerns and identified domains of recovery beyond the management of symptoms and medication. Qualitative methods offer a promising strategy for understanding subjective illness experience and suggesting psychosocial treatment approaches. (*Psychiatric Services* 59:96–99, 2008)

The recognition that one has an illness requiring treatment is considered the earliest stage of help seeking (1), and this phase seems particularly complex for individuals experiencing early psychosis. Retrospective reports suggest that although individuals and family members recognize changes in mood, thinking, and behavior early on, they tend not to identify these as symptoms of a psychotic illness (2). Individuals and families are more likely to attribute observable changes to a developmental stage, passing phase, or less stigmatized syndromes (3). Prior qualitative research suggests that how individuals subjectively experience changes in themselves strongly influences whether they identify as having an illness (4). Thus individuals' conceptualizations of changes may have important implications for why individuals do not seek help when problems become apparent. However, very few published studies of help seeking in psychosis have employed rigorous qualitative techniques, despite repeated calls for this research (5).

The purpose of this study was to examine the narrative processes by which individuals make sense of psychosis, and this study is the first to explore these processes in relation to help seeking in a United States sample. The investigation presented here used qualitative methods to describe two dimensions of help-seeking behavior: recognizing the presence of illness and responding to observed changes. We employed a qualitative approach in order to elicit and then analyze the subjective meanings, concerns, and lay knowledge individuals describe with respect to illness recognition (6).

Methods

A retrospective study investigating how individuals recognized and responded to early psychosis was carried out in 2004–2005. Participants were 15 adults referred through clinicians in a public outpatient psychiatry clinic. Eligibility was established by using the Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I) (7), which was administered by raters trained to a gold standard criterion. SCID-I diagnoses were as follows: seven individuals (47%) had schizophrenia, five (33%) had schizoaffective disorder, two (13%) had schizophreniform disorder, and one (1%) had psychotic disorder not otherwise specified. The mean age of participants was 24.4 ± 5.28 years. Eight individuals (53%) were male. Twelve respondents (80%) were Caucasian, two (13%) were African American, and

Ms. Judge is affiliated with the Department of Psychology, Dr. Estroff is with the Department of Social Medicine and the Department of Psychiatry, Dr. Perkins is with the Department of Psychiatry, and Dr. Penn is with the Department of Psychiatry and the Department of Psychology, all at the University of North Carolina at Chapel Hill. Send correspondence to Ms. Judge at the Department of Psychology, University of North Carolina at Chapel Hill, CB 3270 UNC-CH, Chapel Hill, NC 27599-3270 (e-mail: judgea@unc.edu).

one (1%) was Asian. Thirteen (87%) were single or never married. Duration of untreated psychosis (that is, the time between the onset of psychotic symptoms and administration of antipsychotic medication) averaged 21.7 ± 31.1 months (median 11; mode 12).

Eligible individuals were recovering from early psychosis (that is, first-time schizophrenia spectrum diagnosis in the past year) with no medication changes or hospitalizations in the previous six weeks. Institutional review board approval was obtained before data collection. After complete description of the study to participants, written informed consent was obtained.

Data collection included the following. First, onset of psychotic symptoms was established by raters using a standardized interview designed for this population (8). There were two additional qualitative interviews. First was a semistructured interview designed to elicit an in-depth narrative of participants' subjective experience of early psychosis. Questions included when and how participants first observed changes in themselves, what they observed, and how they understood and responded to changes. The second interview was based on an unpublished, semistructured interview (Pathways to Care Interview, 1999) designed to collect data on help seeking in this population. The interview probes were often captured in the first qualitative interview, but using this protocol for a repeat interview enhanced the validity of the data. The participant's self-report was the primary source of information and was supplemented by chart review.

Fifteen interviews were conducted, with the qualitative portion ranging in length from one to three hours. For most participants ($N=11$, or 73%), qualitative interviews were conducted on a different date than those that established diagnosis and symptom onset. Participants received an honorarium of \$50. Approximately 40 hours of narrative data were collected from the qualitative interviews. Interviews were audiotaped and transcribed.

Analyses of interview transcripts

were conducted by using inductive principles, including grounded theory and content analysis (9). Grounded theory is based on a method of constant comparison of transcripts, which requires that data be coded (for example, defined, organized, and analyzed) multiple times. Constant comparison across transcripts identified themes (9,10) by using an iterative process in which codes developed based on the analysis of one transcript are applied to another to either validate the code or expand the coding scheme. Comparison occurred throughout data analysis, across respondents and incidents; in this way, interpretations were constantly scrutinized and refined. Themes were then grouped together to form conceptual categories, derived inductively from the narrative data, enabling systematic description of the study's primary questions (6).

Intercoder agreement was based on recommended practice (11) in which two independent raters coded randomly selected transcripts according to a coding scheme developed by the first author in consultation with the second author. Raters were psychology graduate students with experience conducting qualitative analysis. The first author met with one coder to reconcile discrepancies in the coding scheme, which served to clarify the original coding scheme and inform recoding. The second coder then reviewed a different, randomly selected transcript using the revised coding scheme and again met with the first author to reconcile differences.

Results

Results take the form of two conceptual categories that both contain several themes. The first category is recognizing changes and refers to alterations that individuals observed in themselves during early psychosis and how they identified and made sense of these changes. The second category is responding to changes and encompasses themes relating to how individuals responded to psychosis-related changes in the self. Themes corresponding to these two categories are described below. Because of space constraints, narrative data are

illustrative rather than exhaustive.

Many participants ($N=9$, or 60%) described being the first to observe differences in their thinking, emotions, and behaviors. Two related themes within the category of recognizing changes are described next.

The theme "it was normal" indicates that noticing changes in the self did not necessarily correspond with a perceived need for intervention. Rather, most participants ($N=11$, or 73%) initially perceived even unusual experiences such as hallucinations as "normal" and simply part of who they were. For example, participants explained how they made sense of positive symptoms. One said, "I thought that was just the way I was." Another said, "The doctors asked [about voices], but I related it to my actual self. It was that close." For participants, changes were readily assimilated into the self rather than immediately recognized as an illness, a process known as normalizing (4). The participants' normalizing work may reflect a complicated fusion and indeed, confusion, between psychotic symptoms and the self.

For the second theme, all participants generated "explanatory models" or meaningful accounts of the changes they experienced. No participant attributed changes in the self to mental illness before receiving a psychiatric diagnosis, which is consistent with past reports (2,5,11). Twelve participants (80%) attributed changes to psychosocial events (for example, "stress"), cultural factors (for example, "[My father] said, 'Maybe they are real demons, maybe you need to change your life.' He blamed it on everything from my lifestyle to Harry Potter"), and other personal experiences (for example, medical illness).

The category of responding to changes refers to the ways that participants responded to changes in themselves, which included, but are not limited to, help-seeking behaviors. Narrative data from this category are provided in the box on the next page.

Withdrawal or social isolation is associated with lengthier periods of untreated psychosis (5). Nine participants (60%) described withdrawal as a means to cope (see box). Interview responses suggest that withdrawal

Three themes and illustrative quotations from personal narratives of responses to psychosis

Withdrawal

"I tried to help myself. I stayed in solitary for six months . . . in a motel room."

"I wasn't feeling [like] myself, and things were strange, and I guess I was reluctant to tell people. It was kind of outrageous what was going on, and it was hard to put into words because it was so complicated . . . so I did pull back."

Avoiding help

"Because everyone would think you was crazy. . . . I don't want people to be paranoid around me."

"I wouldn't tell anyone about the voices. It never felt safe to do that. I pictured myself being locked up in a cell if I told the truth."

Coming to terms with psychosis

"I don't like to think of myself as someone with a mental illness. I don't think anybody does. Because that makes you feel vulnerable, a person who has to be cared for, and I like to be an independent kind of guy."

"I want to have a nice job, I want to get married, I want to have a family, I want to be a normal person, like everyone, but schizophrenia doesn't help with that."

functioned as a way to manage aberrant experiences privately, in part because of the difficulty of explaining their experiences to others. For example, one participant said, "When I think I have the flu coming on, I can tell somebody. But I have no prior experience of psychosis . . . I couldn't say, 'I think this is what is going on with me.'"

Avoiding help was one way that participants expressed awareness of schizophrenia as a stigmatized illness, and approximately one-third (N=5, or 33%) described stigma concerns as a barrier to earlier help-seeking attempts (see box). These reports underscore that even when experiencing psychosis, participants accurately perceived prevailing stigmatizing attitudes about schizophrenia.

All participants described coming to terms with psychosis, a theme that described the challenge of coming to terms with events that occurred within the psychotic episode. For example, receiving a diagnosis of schizophrenia altered what participants hoped to achieve in life (see box). Another dimension of coming to terms involved realizing that past experiences that participants believed to be authentic (for example, delusions) actually reflected symptoms. Once stabilized on medication, most participants actively questioned their prior sense of reality. One participant said,

"Everything I thought was real and had worked on in my head for helping myself . . . didn't do anything at all. None of this was even real. I didn't know if my feelings or passions were even real." Another explained, "I came to know it was delusions. Every time I came to believe God was closer, I worry that I might have a delusion again. It's hard to believe in God the right way, without the delusion. Little by little my faith became destroyed . . . I don't have my self. My brain is a little bit strange. It was delusion. I thought it was my way."

The transcripts reflect differences and tensions in how recovery is defined within research and how it may be experienced by individuals. Recovery is typically operationalized in clinical research as a cross-sectional outcome—that is, level of symptoms (12). A complementary perspective, based on the psychiatric rehabilitation literature and views of mental health consumers (12), conceptualizes recovery as a process in which the individual's understanding of and response to symptoms have significant prognostic value (4,11,13). Finding meaning in the illness experience and developing an identity apart from that of someone who has been ill are priorities in psychiatric rehabilitation, values reflected in the results presented here. Indeed, the extent to which a psychotic episode is effec-

tively integrated into broader life experience as something to be learned from rather than avoided longitudinally predicts outcome among first-episode patients (13).

All participants expressed interest in having someone help them understand how psychosis had changed their life. One participant said, "And as far as what people could have done differently, maybe talking to me a little bit more, not treating me like this black box, say to me, 'I think this is going on.' I think this would have helped me understand." Another explained, "They put me on Seroquel, started me in the study. I talk to her [the clinician] and she explains what the medication is doing, but she doesn't really analyze my issues or get inside my head. I'm not getting any psychological help. They're just curious about how much weight I've gained."

The finding that few participants received psychotherapy and psychosocial services is striking in light of a recent review reporting the promise of these treatments for this population (14). Adjunctive psychotherapy may directly address the challenges of "coming to terms" that participants described.

Thus the need to "figure out what's going on" begins early in psychosis and continues long after the administration of medication. Participants described a precarious situation in which they avoided professional help because of stigma concerns, but they also struggled to articulate their experience to lay individuals and to seek appropriate care. All participants received medication management but received limited adjunctive psychotherapy or psychosocial treatment, potentially signaling a missed opportunity for promising interventions. Participants described dimensions of recovery that are highly consistent with the emerging recovery orientation in services research (12).

Discussion

This study is the first to explore narrative processes in relation to help seeking among individuals experiencing early psychosis in the United States. Consistent with prior research, individuals did not initially recognize emerging changes as part

of a mental illness, but unlike prior investigations, the study presented here explored how else individuals understood emerging psychosis. Our findings highlight attempts to incorporate psychotic symptoms within a familiar self and to avoid services as a result of stigma concerns. Indeed, it does not seem to be that individuals “fail” to recognize symptoms as problematic, but instead they do not recognize what these symptoms might signify and thus how best to respond. The individuals we interviewed were indeed aware of changes, rationally anticipated the consequences of treatment (for example, stigma), and often responded with an avoidance of services.

Relatively high thresholds for help seeking among participants (that is, until active psychosis) suggest that a perceived need for services is influenced not merely by the presence of altered experiences and illness but also by the social contexts and decisions people make in response to symptoms. Indeed, a qualitative study exploring why women with advanced breast cancer delay treatment seeking suggests similar processes to those described here (15), with women responding to this unprecedented experience by relating their symptoms to folk and cultural theories of disease, not seeking treatment even in the presence of painful lumps. Importantly, it was not merely a failure to recognize changes that contributed to deferring treatment, but rather it was different conceptualizations of the nature of such changes. Individuals’ conceptualizations require integration within any true therapeutic partnership, as well as theoretical models of help seeking. Empirical efforts to synthesize the views of patients and professionals within services research are thus highly recommended (12).

Conclusions

Our results have potential clinical implications, although these should be generalized cautiously given our study’s design. The need to understand the confusing experience of early psychosis was great among all participants. Thus eliciting an individ-

ual’s narrative of his or her illness experience over time may help engage patients, an enduring challenge in clinical work with this population. Additional implications include the multiple domains of recovery individuals described. The importance of recovering a sense of self apart from psychotic illness has been described (11), and recent attention to functional outcomes in addition to symptom amelioration (14) is an important step toward integrating clinical and rehabilitative goals.

A major limitation of qualitative research is the general inability to prove a hypothesis; qualitative data may instead help to generate a hypothesis or conceptual framework and provide evidence for its plausibility or implausibility. Thus the results presented here suggest the plausible role of individual sense making and emergent explanatory models of illness in treatment seeking behaviors, an area requiring quantitative research. Another limitation may be the sample’s lack of representativeness. Although qualitative research generally does not make claims about the generalizability of findings in a probabilistic sense, it is concerned with contributing theoretically to a general class of phenomena (6). Thus the few participants from ethnic minority groups in this study may limit conclusions, because help seeking for psychosis varies among ethnic minority groups (5).

In sum, methods that consider schizophrenia “from the inside” represent important tools in advancing our understanding of help seeking and illness experience in subjectively nuanced ways.

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