

Self, Identity, and Subjective Experiences of Schizophrenia: In Search of the Subject

by Sue E. Estroff

Abstract

Schizophrenia is an *I am* illness—one that may overtake and redefine the identity of the person. This essay explores concepts of personhood and subjectivity from social science that are useful in understanding the experiencing subject in schizophrenia. Relationships between the self and sickness have not been investigated adequately with reference to their influence on prognosis. Chronicity is conceived of as a loss of self and of positive social roles and identity. Methods for the study of self and identity in relation to schizophrenia include analysis of illness-identity representations made by persons with schizophrenia.

Something has happened to me—I do not know what. All that was my former self has crumbled and fallen together and a creature has emerged of whom I know nothing. She is a stranger to me. . . . She is not real—she is not I . . . she is I—and because I still have myself on my hands, even if I am a maniac, I must deal with me somehow. [Jefferson 1974, pp. 11–25]

As Lara Jefferson's narrative illustrates, schizophrenia (and other severe, persistent psychiatric disorders) is more than an illness that one *has*; it is something a person *is* or may *become*. Unlike having other debilitating, enduring disorders such as cancer or heart disease, having schizophrenia also may entail "becoming a schizophrenic." Having schizophrenia includes not only the experience of profound cognitive and emotional upheaval; it also results in a transformation of self as known inwardly, and of person or identity as known outwardly by others. Schizophrenia, like epilepsy and hemophilia, is an *I am*

illness, one that is joined with social identity and perhaps with inner self, in language and terms of reference. A comprehensive account of schizophrenia would include the person, the subject, the self that both *has* and *is* this (or these) disorder(s). To study the subjective experience of schizophrenia, we must identify and know the subject. These tasks require substantial adjustments in the ways we think about and respond to persons who have schizophrenia.

This essay outlines a rationale and some means for taking the subject, the person, back to the center of inquiries into the nature and consequences of schizophrenia. This is not a new project. It is more of an "intellectual renewal project," meant to renovate and rejuvenate preexisting but neglected areas of inquiry. Concepts of the self and identity have been central concerns in the study of schizophrenia before. A disturbed sense of self and "extreme perplexity about one's own identity" remain as symptoms of schizophrenia in *DSM-III-R* (American Psychiatric Association 1987, p. 189). What is different about our efforts is emphasis, careful attention to experience and phenomenology of self, interdisciplinary collaboration and trespass, and a particular enthusiasm for developing rigorous methods with which to investigate these difficult topics. The articles in this issue of the *Schizophrenia Bulletin* present evidence in abundance that the pursuit of subjectivity, identity, and person is not only possible, but illuminating and amenable to scholarly inquiry.

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While the study of selves and subjectivity may have become peripheral to psychiatry as Strauss (1989) argues, sociomedical and social psychological scientists continue to devote considerable attention to these areas. It is my intention to synthesize, translate, and apply those formulations that I find of most relevance to the study of persons with schizophrenia. Both Fabrega (1989) and Lally (1989) discuss cultural and psychological perspectives on the self, identity, and mental illness, and this essay anticipates and complements those contributions. Then building on this foundation, a person-centered, self-conscious formulation of chronicity is proposed. Reference to relevant research and conceptualizations is selective rather than comprehensive; the formulations and puzzlements here are intended to be more evocative than conclusive, more interrogative than declarative.

A Conceptual Inventory of the Subject

To begin, there are several basic tenets of social psychology and symbolic interactionism that have long informed and framed understandings of identity formation and transformation. I cannot hope to convey here the complex debates and conceptualizations that characterize the study of self, person, and identity (Lee 1982; Lapsley and Power 1988). Despite the verbal density and near unintelligibility of many of these conceptual propositions, there are general domains of agreement about selves and others, subjectivity, and the social construction of personhood and identity that are salient. These are probably oversimplified and abbreviated below.

Others provide the contrast that permits definition of self—the object (out there, not me) delineates the subject (in here, I, self). At the same time, we participate with others in what Crapanzano (1982, p. 192) calls a “conspiracy of ‘understanding’ ” about who we are and what categories we belong to, about the labels given and received. This is a fluid process, the pace and rhythm of which varies over time and by context or audience. There are periods of self/other agreement and confirmation, and contexts of convergence. Phases of renegotiation and change occur; signals from others that are discrepant with inner experience contribute to customary developmental processes as well as unexpected evolutions of self. In some contexts—for example, the family—we occupy permanent *roles*, even while our experienced selves change.

The levels or layers of person are divided typically into at least two facets. There is a private subject and a public person, a self known to self and the person known to and identified by others. Despite various schemes and labels promoted by contesting schools of thought, the principle is the same: inner and outer; secret and shared; individual and social; subjective and objective. While separable heuristically (and in some way separate actually), these layers must overlap to some extent. When they do not, the individual is likely to experience the “radical estrangement” or “hyperalienation” (Kovel 1987, p. 334) of self so characteristic of schizophrenia. This lack of agreement or constructive interaction between self and others *about* self may also result in an incomprehensibility of person, identified by Rosenberg (1984) as the hallmark of

psychosis.

Finally, there is the idea of reflexivity, the ability we have to consider ourselves as an object. Reflexive thought and speech include our observations of ourselves, our self-consciousness, our ability to refer to ourselves in the third person, and our ability to engage in a relationship with our selves. It is the capacity that allows us to write autobiographies and to engage in psychotherapy. With these principles in mind, we examine more closely some ideas of self, identity, and subjectivity applicable to schizophrenia.

What does a concept of subject, of self, of person entail? First there is the dimension of *time*, of personal history (Frankenberg 1987). There is a configuration of self that exists over time: an enduring entity that precedes, transcends, outlasts, and is more than an illness or diagnosis. While clinical accounts often document the course of an illness, they seldom provide a narrative of the person through time, in time—both personal and social. The “psychiatric history” is only a portion of personal history, yet it must be located, situated in the *lifetime* of the person now experiencing schizophrenia.

The individual and his or her relatives have a different notion of personal time and history than the clinician. Part of the agony of relatives must stem from their richer, longer, and rather different sense of history of the person who has schizophrenia. Clinicians meet and know patients after a disorder is present, when there is a disordered person. Unlike the friend or relative, clinicians did not have a different life course in mind, nor did they see or know the prior, perhaps more successful efforts to lead

a life, to be a different person than the one now encountered in a clinic or hospital ward. But, is that person so different, so altered, or so absent as we have thought? Is there a missing person associated with schizophrenia or is the person present but obscured from our recognition? Does schizophrenia alter that basic private biography, the developing but continuous logic of self, the privately known and lifelong embodiment of one's uniqueness? Brody (1987, p. x) describes this "dual nature of sickness—the way it can make us different persons while we still remain the same person." At present we lack information about what is the same and what is different about and within persons who have schizophrenia.

Considering time and personhood leads to the related topic of before and after. Who and what existed *before* the illness, and who and what endure *during and after*? Some do not accept that there is an "after" with schizophrenia, only before. This question seems to be rather crucial and may be answered most accurately by one seldom asked—the individual with schizophrenia. It is an area in which discrepancy abounds between clinician and patient, between relatives and diagnosed individual. We may see rather different changes than does the individual. Often referred to as "insight or denial" (see Greenfeld et al. 1989), the patient's protest or rejection of redefinition via diagnosis (or confinement) could signal something altogether different from pathology. It could be a cry for recognition of persisting, healthy, trying-to-survive self and personhood. In research in progress, we are finding that most of the patient-participants acknowl-

edge symptoms and disturbances of thought and emotion. What they resist and reject are notions that those signs mean they are incompetent, failed, or somehow revised individuals because of these problems. Many make what we call "normalizing statements" in order, we hypothesize, to stress and reassert their similarities with others and to retain claim to their persisting, unrecognized, not-disordered selves.

We know too little about conceptions and recollections of the self and time before voices were heard, and before thinking was derailed; before the "others" noticed and the interventions began. The articles by Cutting and Dunne (1989), Romme and Escher (1989), and Lally (1989) provide ample evidence that changes are felt and tracked, that losses and gains in function, relationships, and social situations are felt keenly. So often, when relatives tell their story, they begin with a description of their loved one *before*, when there were accomplishments and successes, a known, knowable, and welcomed presence. And then the narrative of loss begins—the tale of the new, strange, disturbed and disturbing, not-really-who-they-were-before-but-still-somehow-the-same person.

The stories of individuals who have schizophrenia vary on this topic. Jefferson describes clearly a loss and change of self. Others protest redefinition saying, "You are not your illness. Find another role besides mental patient" (*Lighthouse* 1988, p. 2). An essay in the same consumer newsletter asks, "Is there recognition and identity after mental illness?" (p. 3). "Is there identity after mental illness? That the question is asked at all illustrates the need for studies of the processes

and experiences of change, loss, and persistence of self accompanying schizophrenia.

Sickness in our culture implicitly alters the self (see Herzlich and Pierret 1987). We say, "I'm not feeling like myself," when we are ill. Others say, "You don't sound like or seem like yourself," when we are infirm or injured. We say, "I'm feeling much more like myself," on recovery. Others say, "You sound and seem much more like yourself these days." We are *not ourselves* in some profoundly cultural and symbolic way when we are sick or injured. Yet, of course, we are. The implication is that we reject the dysfunctional self of sickness as *not me*, as other than a familiar or claimed self. This is all well and good if illness or injury is temporary, and we can return to or reclaim ourselves. When sickness persists, when injury and resulting impairment linger, when others have in the meantime grieved the loss and perhaps buried the former self, what then? When sickness overtakes one's biography, what remains? French sociologists Herzlich and Pierret (1987, p. 178) explain:

By enforcing inactivity, illness thus prevents individuals from "playing their role," marginalizes them, and can even provoke a feeling of loss of identity. "Who am I?" the sick person wonders. These questions sometimes reveal a feeling of total annihilation of the personality . . .

There are two interrelated dilemmas here: First, when being "not myself" is my self, that is, illness persists. Second, when the most self-seeing, self-knowing, self-confirming others lose, alter, or put away the person's prior, not-sick self so that it is unverifiable to and

with them. And thus appears the double discrepancy, the double dilemma described in part by Erikson (1957):

... the patient has to seek definition as acutely sick and helpless in order to achieve a measure of public validation for his illness—and simultaneously has to use all his remaining strengths to struggle against that illness—a dilemma is posed which he may resolve by simply giving up the struggle altogether and *submerging himself* in the sick definition permanently. [p. 271, emphasis added]

This “struggle” for self and with self that may epitomize schizophrenia goes on on two fronts: privately and publicly, in terms of inner sense of self and in terms of social identity. The interaction of these two spheres may make a reclaimed and restored self, and an accepted, agreed-upon identity nearly impossible to achieve for the symptomatic or hospitalized individual. The individual may experience self as persisting, but with some new features or incapacities (symptoms). She or he may claim to be essentially “the same.” But if others acknowledge a revised person, shifting the terms of the conspiracy of understanding, an undermining conflict between self and others *about* self may arise. At present, we lack sufficient data and reflection on this aspect of the experience of schizophrenia to engage in more than informed speculation.

To continue with the inventory of self and person, we include also social place and space. We have roles, and we belong by virtue of kin ties, for example, to groups, usually at least a nuclear family. Sylvia Frumkin (Sheehan 1982) is a daughter and a sister. Lara Jefferson was someone’s child. These

kinship and other roles exist in the social world, and we fill them when we happen along with our own particular version of daughterhood or being a sibling. Belonging in a normative way to a larger group or groups both conveys and constitutes a sense of self, provides an identity in relation to others and by virtue of others’ acknowledgment of us. Each of us claims and is assigned membership in a variety of cultural categories and social roles. These contribute to what we experience, the meaning or significance of those events or emotions, with whom we validate or share those experiences, and among whom we come to know ourselves and become known to others.

Gender, age, and ethnicity are aspects of person, other categories to which we belong and from which we know who we are and what we are. Maleness and femaleness, youth and old age, blackness or whiteness, all contain and convey prescriptions and models for behavior and expected characteristics. They are part of the inventory of person. While kinship, gender, ethnic, and age categories transcend individual versions, our portrayal is expected to be unique. There may be others *like* us, but no one else is us. We are supposed to have exclusive claim on one such self for a lifetime.

Bolstering this expected uniqueness at the larger societal level, person-specific legal and administrative identities are created. We have Social Security numbers, drivers’ license numbers, and hospital identification numbers. These constitute so-called administrative selves (Douglas 1983) that accompany and mark us over a lifetime as the *same person*, at least in the political, legal, and bureaucratic arena.

There is also a core of meaning

and knowing in the person. By this I mean the ways in which we attach significance to events; the ways we learn and remember, hope or regret; the ways we know what is real, what we prefer or disdain. Each of us has (and in some way *is*) these belief and symbol systems; these enduring though evolving clusters of meaning, experience, and knowledge. These are, like other aspects of self and identity, derived over time, in and from culture, from the experiences we have alone and with others. Here, I am referring to the meaning-making, world-knowing, experience-having self that forms part of the core of each of us. For the person with schizophrenia, this part of the self is thought to be perhaps the most altered, most vulnerable, most hidden or obscured.

In this issue of the *Bulletin*, each of the articles seeks to retrieve this dimension of the person by asking, What is the meaning of this illness for this person? How profoundly and extensively is the person changed by having this illness? How can we best inquire about those meanings and learn from and about them? The subject, the person who experiences schizophrenia, may be more enduring than we have thought. The article by Bouricius (1989) presents a poignant and effective challenge in this regard. At the very least, these should be empirical questions deserving rigorous answers.

Perhaps different facets of self are more durable, if less visible or knowable, than others. If there are special vulnerabilities, special sensitivities of the self to destructive influences, clinical work needs to be informed and focused on self-protection and preservation. If there are special strengths and durabilities of self that can aid healing

and functioning, these require acknowledgment and encouragement—not engulfment in a patient role, label, or medication regimen, however well-intentioned. For example, Mann (1986, pp. 235–236) describes the treatment of a young man with schizophrenia as focused on filling in the “gaping maw of nonentity,” of healing the “lesion” of identity from which he suffered. This was accomplished by retrieving and re-creating an identity with and for the patient, within the therapeutic relationship. Pollack (1989) argues similarly that the quintessence of psychotherapy with persons who have schizophrenia is the construction (or reconstruction) of a coherent self first between therapist and patient, and eventually within the patient.

To sum up, schizophrenia is a disease, like others, that afflicts a person who has a history, an identity, kin and social roles, gender, age, hopes, ambitions, and these inner and outer selves. But because schizophrenia affects profoundly both how we present *and* experience ourselves, often the person and the disease or diagnosis become joined in scientific and social thinking in the realms of intervention and identity. To this point, I have outlined the more prominent aspects of self and personhood relevant to the study of individuals with schizophrenia. Next, we examine some proposed methods and concepts for a self-conscious, person-centered understanding of prognosis and the construction of chronicity.

Investigating Prognosis With Self-Conscious Concepts and Methods

Several questions arise here. Is it inevitable that a person who has

schizophrenia becomes schizophrenic? Is the self necessarily engulfed by the disease, identity taken hostage by the diagnosis? How does the individual view himself or herself in relation to the illness? Is good prognosis associated with a separation from self, a preserving of person who *has* but *is not* an illness? Or does the individual fare better by embracing and incorporating schizophrenia as within and of the self? Since we have paid so very little attention to subjective experiences and to the experiencing self of schizophrenia, we do not yet have empirically derived answers to these questions. We are apparently much more skilled at identifying evidence of illness than we are at recognizing and assessing the presence of person and condition of self.

Strauss (1989) suggests that individuals have a relationship with their disorders that influences course and outcome. Benjamin (1989), taking the hallucinated voice as a representative of the illness, describes the various coherent relationships individuals develop with those voices. These are significant contributions to the study of self and schizophrenia to which I wish to add, conceptually and methodologically.

Conceptually, we can posit two propositions about the relationship of self to sickness that apply in the Western World: (1) Loss or absence of self results in or constitutes an illness, and (2) sickness results in a loss of and change in self. Clinicians such as Kohut (Kohut and Wolf 1978; Wolf 1982) and others (Levin 1987) articulate the first position, suggesting that there is no formed or cohering self in schizophrenia. Social scientists such as Erikson (1957), Charmaz (1983), and Goffman (1963) tend, not coincidently,

to emphasize the second perspective, describing the transformation of self and identity that results from serious mental illness, especially that which is prolonged.

In clinical formulations, both psychological and biological pathology are located within the person, and they destroy or prevent the development of a self. In more social perspectives, external factors—such as responses to the individual by others and the individual's experiences with symptoms and treatment—erode, diminish, and otherwise alter the self and social identity. Neither approach ignores the contributions of factors emphasized by the other, but neither has been able to demonstrate empirically the relative influence of these various forces. Goffman, for example, persuades via elegant argument, compelling vignette, and logical precision that total institutions alter the internal selves and external identities of inmates. Yet, controversy continues in the research arena because empirical tests of this assumption have produced such equivocal results (Doherty 1975; Townsend 1976; Weinstein 1983).

These disputes will not be settled here. The point has been to highlight underlying assumptions about the relationship of illness to identity and of sickness to the self. In so doing, perhaps more direct inquiry can proceed to test these hidden but influential propositions.

The second conceptual proposal concerns how individuals locate or situate their illnesses and symptoms in relation to themselves. I find Kohut's object relations notion of a continuum between self → self-object → object helpful as a way of representing this dimension. It seems entirely possible that for some individuals, the illness is

experienced as an object, and for others it is more of a self-object, while for others it is inseparable from self. We would then seek some means for determining where a particular person fits along this dimension, investigating how or if prognosis was related.

Methodologically, there are several techniques for examining these dynamics. Several innovative means, such as Structural Analysis of Social Behavior (Benjamin 1989), Lally's (1989) scale and phases, and more conventional strategies such as Strauss' (1989) semistructured interview are promising. Careful analysis of first person accounts of schizophrenia (Sommer and Osmond 1983) or illness narratives (Kleinman 1988) that focus on the self-sickness dimension is long overdue. We lack rigorous inquiries into how individuals with schizophrenia represent themselves in these texts and in speech; whether they describe loss or persistence of self; how they remain apart from or join with their illnesses; and what others say and do that influences those processes.

In ongoing research, we are investigating what we call Illness-Identity Statements. We ask patient participants a series of open-ended questions about their explanations for and understandings of their problems; if they have names for the problem; how they think it works; what their doctors call it; and whether they consider this a mental illness. In response, many patients make *I have* statements, such as "I have a bipolar disorder." Others make *I am* statements, such "I'm crazy. I'm not crazy. They say I'm crazy. I don't know." We are also interested in *you have* or *you are* indications that come from others, especially clinicians, and the responses of patients to these.

These questions are repeated and the discussions are continued five times over 2 years.

Not only are we interested in how these individuals represent themselves in speech, but we use these data to locate them along the self-sickness continuum suggested above. As we track their functioning and experiences over time, we seek to establish whether prognosis or course bears any systematic relationship to this dimension.

Results from this investigation are far too preliminary to report, but the point has been to make a methodological contribution to the pursuit of subjectivity and subjects, and of self-schizophrenia relations. In that regard, two lessons are already apparent. First, on the basis of the obviously pained and sometimes forceful reactions of participants to these questions, we are convinced that these are not only crucial, but very private matters. The latter interviews in the sequence yield progressively richer, more detailed information. As the interviewer becomes better known to the participant, there is less hesitation and discomfort surrounding these topics. Second, the participants' formulations change over time: as they experience successes and failures in daily life, as they take or do not take medications, as they experience differing levels of symptoms, and as they respond to others' responses to them. As several articles in this issue demonstrate, there is a coherent process of reflexive assessment that occurs as individuals attempt to make sense of their symptoms, their lives, and their selves.

Chronicity as Loss of Self and Defeat of Person

Where, one might justifiably ask at

this juncture, does this leave and lead us? As promised, with more questions than answers. I have thus far suggested that our failure to identify and know the experiencing subject, their meanings, and the sense they make of schizophrenia represents a debilitating deficit in our understandings and responses via treatment. Ironically, the loss and disorder of person so characteristic of our conceptions of schizophrenia may be at least partly our own invention, and one of many ways in which we desert the person who has schizophrenia. We may both compound and create the isolation of inner and social self by failing to investigate and acknowledge the persistence of person.

In my view, the social and personal processes of having schizophrenia are not and need not be equivalent to the disease or having the disease. *Becoming a schizophrenic* is essentially a social and interpersonal process, not an inevitable consequence of primary symptoms and neurochemical abnormality. At the same time, I am not suggesting that schizophrenia is any sort of personal or cultural fiction. The point is that there are simultaneous, equally influential neurophysical, social, and personal processes at work. Within this conceptual framework, chronicity is a transformation of a prior, enduring, known, and valued self into a less known and knowable, relatively recent, devalued, and dysfunctional self. This process, I have argued, occurs among and in the eyes of others, and internally, within the person.

One of the ways that this occurs is through what we call progressive role constriction. As individuals cease to have a job, withdraw from school, and lose contact with friends and family, they also lose valued social roles, and the accept-

able identities compiled and derived from those roles. The patient role is often one of the few that remain. These cumulative experiences and situations result in necessary reformulations by the person, and can result in their becoming part of a new *category*, that is, schizophrenic. This category, which is as profoundly cultural and transcendent as the others identified above, carries implicit verification that the person is not who or how we may have thought the person was before. Instead of becoming *part* of the inventory of person, the category of schizophrenic engulfs or pervades the person.

Many parents and siblings wonder in agony where their son or brother went, once schizophrenia occurs. There is this partial stranger who is also their child, their sib. Perhaps it is this sometimes paradoxical persistence of the person, along with the person's symptoms and incomprehensible behaviors, that leads to confusion and wildly varying hope and despair about recovery. Our clinical and cultural conceptions of schizophrenia create the capacity to obscure and redefine individuals who have the disease, as surely as the primary symptoms alter their cognitions and perceptions. While it has been by no means established that preserving valued roles and retaining a positive personhood contribute to more positive outcome, it is difficult to imagine that the suffering and despair of individuals would not be lessened.

As Strauss (1989) has already noted, the idea that individuals have a relationship with their disorders, or representations of their disorders, poses some problems. This perspective presumes the existence of separate entities of self and sickness. Fabrega (1989) demon-

strates that this conception is culture-bound and of perhaps limited relevance to schizophrenia. Indeed, our cultural and clinical conceptions of schizophrenia lead to conflicting and contradictory positions. On the one hand, we suspect that the disease alters and even overtakes the self. On the other, we envision schizophrenia as a disease and biological entity, presumably separable from self, situated in the body.

The idea of fighting the disease, having distance from symptoms, making the separation between a sick or not sick self—all these require an intellectually unacceptable separation of symptoms from subject. Even if this is a scientifically or philosophically disquieting position, we must ask whether it is, however, realistic phenomenologically, and whether it is valid experientially and subjectively. In anthropological terms, we proceed ethnographically and inductively to learn the concepts, meanings, and experiences of our expert informants. At that point, our tasks as researchers are to seek associations, causal links, patterns, and implications.

To conclude, I have argued here that we have failed to pose and pursue several essential questions about the subjective experience of schizophrenia. How do the pervasive cultural, clinical, and personal symbols, metaphors, and meanings of schizophrenia influence prognosis? How do individuals with schizophrenia understand and locate themselves in relationship to the symptoms, labels, and responses? What contributes to a person's ability to separate himself or herself from this sickness, and does this facilitate or even constitute recovery? In some sense, I am wondering if loss of self, per-

sonal and social, to schizophrenia is *chronicity*. Is survival of the self to oneself and in the eyes of others a necessary condition of positive outcome and favorable course? Because we often fail to know, cannot comprehend, or irreversibly alter our own notions of the person with schizophrenia, we may be unnecessarily, wastefully contributing to chronicity and the construction of schizophrenic patients. Continued careful pursuit of the subject will, we hope, answer some of these questions.

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