

The Subjective Experience of People with Severe Mental Illness: A Potentially Crucial Piece of the Puzzle

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Abstract: Over the last two decades there has been growing interest in the subjective experiences of persons with severe mental illness (SMI). Despite this interest, little research has been carried out to understand whether and how such experiences are related to the course of SMI. In addition, few psychotherapeutic and rehabilitation interventions have been developed especially for persons with SMI that seriously take these persons' subjective experiences into account. In the present paper we discuss why the use and investigation of the subjective experience of people with SMI has been neglected, and we point out the potential importance of this experience. We then review the growing literature that focuses on the subjective experience of (1) the illness, (2) the self, and (3) the self as influenced by the social context of persons with SMI. Finally, the implications of this review for rehabilitation, recovery and research are discussed.

Introduction

During the last two decades, descriptive and biological approaches have contributed importantly to the classification and treatment of severe mental illness (SMI). Important achievements in these areas have earned such studies much status and research funding. Although standardized measures have contributed to the reliability of concepts and improved communication, they have also hindered readiness to consider other potentially important phenomena. The third and fourth editions of the Diagnostic and Statistical Manual (DSM) (1, 2), for instance, classify disorders phenomenologically, which emphasizes what can be observed and measured. It has been argued (3) that this sort of classification system, although very valuable at times, has had a "devastating impact on 'exploratory' psychotherapeutic approaches to treating mental illness" (p. 783) and has permitted the manifestation of a mental disorder to become "more impersonal and alien" (4). Frank and Frank (5) point out that descriptive psychiatry's "atheoretical" approach, as reflected in the DSM, suggests a theory in itself — that the meaning persons attach to their symptoms, their attitudes towards their behavior, and their social and historical context are all unimportant. Kleinman (6) emphasizes the importance of engaging in participant-ob-

servation to facilitate eliciting persons' exploratory models in order to understand their personal experience and its social source and consequences. Strauss (7) points out that focusing narrowly on the effort to meet a particular conception of science has generated an unscientific tendency to ignore large amounts of data that are difficult to measure reliably using standard methodological tools, but which might nonetheless be important. According to Strauss, these data often get lost in the process of systematically forcing individuals' experiences into questionnaire responses to be measured only by instruments designed to create neat preconceived static categories. Morstyn (3) argues that many concepts lose their essential meaning in the process of operationalizing them so they can be reliably coded and subjected to statistical analysis.

Moreover, a narrow focus on symptoms and pathology has oversimplified the complexity of mental illness, leading to the false conception that the person afflicted by the illness is "entirely ill." As a result, little attention has been given to the possibility of simultaneous presence of strengths and weaknesses, competence and dysfunction. This has discouraged paying attention to the healthy and restored parts of the person and his or her experience of living and coping with a severe mental disorder (8).

Recognizing the limitations of exclusively de-

scriptive and biological approaches, some researchers have generated a growing interest in the inner world of people with severe mental illness. In an editorial in *The Journal of Nervous and Mental Disease*, Brody (9) warns the profession about the danger "of losing the humane outlook that has characterized its development" (p. 195). Other major psychiatric journals such as the *Schizophrenia Bulletin* and *Psychiatric Services* now include first-person accounts of the experiences of people with severe mental illness. *Schizophrenia Bulletin* (10) published a special issue, focusing on first person accounts, subjective experience, and careful observation and description, illustrated how people with severe mental illness experienced and coped with their disorders. In their book, Hatfield and Lefly (11) provide a comprehensive summary of how mental illness feels to mentally ill individuals, relying primarily on patient-authored literature. In doing so, they convey their belief that at this point in the history of psychiatry, professionals are beginning to appreciate the strengths and inner resources some persons bring to managing their own illnesses. Recently, the *Israel Journal of Psychiatry* published an entire special issue (12) consisting only of articles, autobiographic accounts and personal experiences of clients.

Reviewing the available literature on the subjective experience of schizophrenia and related disorders reveals that personal accounts are considered important and that there has even been some discussion of narratives of SMI and recovery. However, these accounts and narratives have not been given significant professional and scientific status. Attempts to explore the subjective experience of persons with severe mental illness, and its relationship to course and outcome, have generally focused on (1) persons' subjective experience of their illness, (2) persons' subjective experience of self, and (3) persons' subjective experience of the self as influenced by the social context. Following is a review of these three topics.

Persons' Subjective Experience of Their Illnesses

The literature on persons' subjective experiencing of their illnesses falls into three central categories: (A) the persons' responses and attitudes towards their

illness, (B) the degree and nature of the persons' insight into or awareness of their illness, (C) persons' experience of illness as generating a full-blown, post-trauma syndrome.

Persons' responses and attitudes towards their illness

Mayer-Gross (13) was one of the first theoreticians to raise the issue of the significance of the expressions of persons with schizophrenia concerning their disorder. In his pioneering work, he identified modes of response that he viewed as a continuum of defenses designed to facilitate persons' adaptation to their illnesses. The categories Mayer-Gross identified were: 1) denial of the future, 2) creation of a new life after the onset of illness, 3) denial of the psychotic experience, and 4) molding of the psychotic experience into a new set of life experiences. Mayer-Gross observed that persons have relatively fixed attitudes about having been ill, and noted that these attitudes influence future course and outcome. In another study, Bowers (14) suggested that a patient's positive or tolerant attitude towards his or her own psychotic experience may facilitate coping and help resolve dynamic conflicts. Soskis and Bowers (15) conducted a retrospective study of 32 first-admission patients with schizophrenia to assess the relationship between their attitudes towards their psychosis and outcome. In their sample, persons who had a positive, integrated attitude toward their illness demonstrated lower levels of pathology and higher levels of functioning at follow-up. On the basis of interviews with 30 people with schizophrenia, McGlashan and Carpenter (16) uncovered further evidence of the influence of the personal experience of SMI on the course of the illness. Their results revealed that persons who were less negative about their futures had better outcomes. Interestingly, the relationship between attitude and outcome was stronger than that between any other prognostic variable and outcome. In another study, McGlashan and associates (17) conceptualized the subjective experience of SMI as a continuum of recovery styles. At one end of their continuum lies "integration," which is exemplified by persons who show an interest in their psychotic experiences and appear eager to discuss and learn more about them and to gain a meaningful perspective of them. At the other end of the

continuum is “sealing over,” exemplified by persons who deny the existence and/or severity of their illnesses and expect to return rapidly to normal functioning. These persons have difficulty recalling or describing the phase of acute psychosis. Individuals who demonstrate an “integration” style of recovery have been shown to have a better outcome in terms of relapse and social functioning than those using a “sealing over” style (18). An “integration” recovery style has also been related to fewer feelings of depression and more positive self-evaluations, as compared with a “sealing over” style (19).

Degree and nature of insight into or awareness of illness

The degree and nature of persons’ insight into or awareness of their illnesses is another important domain of the experience of illness. Although, as Greenfeld et al. point out (20), there is always the danger of viewing insight as synonymous with sharing the clinician’s perspective, there has been growing recognition regarding the complexity of the concept, its varied phenomena and the dimensions it encompasses (20-22), as well as the utility of understanding the concept as a process that exists and evolves within an interpersonal and social context (23). Whether lack of insight represents a psychological defense against the acceptance of the degrading status of “a schizophrenic,” or a symptom that should be considered part of the diagnostic criteria, is a source of debate (24). It is useful to note that, with few exceptions (25, 26), the lack of insight or awareness of illness has been found to be associated with an unfavorable course (26, 27) and has been described in the DSM-IV as “one of the best predictors of poor outcome”(2). At the same time, recent studies, which have investigated the impact of insight or the lack of it on a broader range of variables than symptomatology, take a critical view of past research and do not point to a positive relation between insight and positive outcome.

O’Mahony (28), in a study of 50 first-admission psychiatric patients, discovered that persons who actively rejected identification of self with the stereotype of mental illness and emphasized their own uniqueness showed the most favorable outcome. Moore et al. (29) investigated 46 individuals with schizophrenia and discovered that greater unaware-

ness of illness was related to less depressive symptomatology. This relationship was particularly strong for unawareness of the social consequences of having a mental disorder. Kravetz, Faust and David (30) found psychiatric self-labeling to be negatively related to quality of life in a number of significant areas of life. Schwartz (31), in a study of 223 outpatients with schizophrenia, reported that greater awareness was associated with more extreme symptoms of depression, and suggested that a linear insight-demoralization-depression-suicidality syndrome develops in many people suffering from schizophrenia. In another recent study, Pyne et al. (32) reported that 37% of their sample of 177 individuals with schizophrenia did not believe that they were mentally ill and showed fewer depressive symptoms, greater satisfaction with their current mental health, and less concern about mental illness stigma.

The accumulating evidence that lack of insight is not always associated with negative outcomes (33) led Roe and Kravetz (34) to propose a multi-functional narrative approach toward insight into mental disorder. They claim that such an approach is relatively free from a priori assumptions, because it conceptually disassociates the descriptive functions of accounts of mental disorder from their narrative functions and thus encourages the independent study of both kinds of functions. They argue that a primary question is whether the functions attributed to personal narratives of mental disorder and psychiatric disability can be reliably and validly identified. Once these functions are identified, it becomes possible to investigate narrative forms that lead to empathy, control and quality of life rather than to stigma and engulfment. Thus persons with psychiatric disabilities can be helped to use their awareness of their disability for psychological growth (35).

The disorder experienced as a traumatic event

Another important dimension of persons’ experience of their illness stems from recent observations that the experience of psychosis may generate symptoms of post-traumatic stress disorder (PTSD) (36-41).

The experience of terrifying delusions and hallucinations (36), along with their treatment which often includes involuntary hospitalization, contact with law enforcement agencies, forced sedation, re-

straint and seclusion, may result in a psychological trauma of considerable magnitude, influencing the course of the disorder. Studies of PTSD in persons with SMI indicate that these persons experience higher rates of PTSD. Eight studies of persons with SMI have examined the prevalence of PTSD in the SMI population. One study of first admissions for psychosis reported a PTSD rate of 14%, and the remaining seven studies reported PTSD rates ranging from 28% to 43% (36-41).

Mueser et al. (40) point out that the high rates of PTSD in persons with SMI are consistent both with these persons' increased exposure to trauma as compared to the general population, as well as to their elevated risk for developing PTSD due to this exposure. Furthermore, PTSD is related to poorer functioning in clients with SMI, including more severe psychiatric symptoms, worse health, and higher rates of psychiatric and medical hospitalization. Mueser et al. (40) argue that the high rate of PTSD and its correlation with poorer functioning are indicative of the need for treatment of this comorbid condition.

Persons' Experience of Self

Many distinguished theorists, including Kraepelin, Bleuler, Kohut and Sullivan, have maintained that the individual's experience of self is a central theoretical construct in the understanding and treatment of schizophrenia and related disorders. In fact, distortion in the sense of self is an essential phenomenological characteristic of schizophrenia, as described in the DSM-III-R (1). Despite its importance, there has been very little systematic study of the experience of self in people with severe mental illness and the impact of this experience on course has received relatively little attention.

Recent efforts to understand schizophrenia from the "inside" have drawn attention to the unique ways in which the disorder influences the person's core identity and sense of self over time. Based on this work it appears that the course of the disorder may be influenced at least as much by change in the "subjective" experience of self as by the "objective" disorder.

In a longitudinal study, Davidson and Strauss (41) described the possible relationship between

changes in the experience of self and improvement in terms of the following four basic aspects of recovery: 1) discovering the possibility of a more active sense of self, 2) taking stock of the strengths and the weaknesses of one's self and assessing possibilities for change, 3) putting into action some selected aspects of one's self and integrating the results of these actions into a revised sense of self, and 4) employing the enhanced sense of self to provide a refuge from the disorder, thereby creating additional resources for coping efforts. Similarly, Estroff (42) has related changes in the experience of self to the concept of chronicity. In her view, "a part-time or periodically psychotic person can become a full-time crazy person in identity and being" (p. 223). Indeed, change in level of self-esteem was found to be positively related to the course of disorder and improvement (43) and to emerge through ongoing interactions with the environment (44).

The Subjective Experience of Self as Influenced by Social Context

Schur (45) borrowed the term role engulfment from labeling theory. He used this term to illustrate how the person finds his or her behavior and identity increasingly organized around the deviant role, or in the present context, the sick role. Schur (45) conceptualized the process of role engulfment as a function of the continuous interaction between the labelers and the person. He emphasized the significance of the formal event of being diagnosed with and hospitalized for a mental illness. The interpersonal process of accepting the sick role is, according to Schur, an important component of role engulfment, as this role may become the primary identity of the individual. Maintaining a non-sick self-concept depends upon the individual's ability to separate him or her self from the sick role (45).

Estroff (46) described the transformation of a once-valued person into someone who is dysfunctional and devalued by self and others. She draws our attention to the frequency with which family members of persons with schizophrenia draw contrasts between the person they knew before the illness and the very changed person they now witness. It is as though schizophrenia is an "I am" phenomenon during which the self is engulfed by the disease and one's

identity taken hostage by the diagnosis. Persons often seem to “become” their illness. Such a person has lost his or her sense of self, or the self has been so altered that it seems as though a different identity has taken over. It has been suggested that a person undergoing a psychotic episode may be particularly vulnerable to incorporating the patient role in his or her own identity since any identity, however negative, serves to organize experience more effectively than does no identity at all (47).

The term role engulfment was modified by Lally (48) to “engulfment” to emphasize the subjective and intrapsychic aspect of the process. Using qualitative methodology, Lally (48) identified three stages of the engulfment process. In the early stage, persons with an SMI diagnosis deny and minimize their psychiatric problems, compare themselves with less fortunate individuals, and thus view themselves as better off than others. Important transitional events linking the early stage to the middle phase include the onset of hallucinations and repeated hospitalizations. In the middle stage, the latter persons accept that they have psychiatric problems, but minimize their potentially devastating implications and meaning by focusing primarily on normality and the commonality of mental illness. Transitional events leading to the final stage include hearing a diagnosis, applying for disability and resigning themselves to the permanence of the illness. In the final stage (“true” engulfment), an all-encompassing definition of self as “mentally ill” is established. Loss of hope, acceptance of a life with illness, and a deep sadness for the loss of a previous and future life without illness characterize this stage. Lally (48) identified various techniques that persons can use to avert the toxic consequences of engulfment. These are: (1) choosing a less stigmatizing label, (2) reducing the stigma of the label, (3) de-emphasizing incompetent aspects of the self by redefining one’s behavior and/or label, (4) emphasizing competent aspects of self, and (5) separating these two aspects of self.

Conclusions and Implications

The purpose of the present paper has been to discuss why investigating the subjective experience of people with SMI has been neglected, to review the grow-

ing body of research in this area, and to emphasize its potential contributions and importance.

The review of literature implies that if one is interested and willing to take the time and effort to listen, a “voice” may be heard. The importance of listening and taking into consideration the narratives of people with SMI is becoming more widely recognized and appreciated.

From a clinical perspective focusing on subjective experience offers a window into the uniqueness of each individual’s personal recovery narrative in conjunction with his or her strengths, weaknesses, wishes, activities and preferences. The personal meanings each person attributes to his or her illness within his or her life context is what constitutes the individual’s recovery process. By actively emphasizing the human context of subjective experience the clinician can most effectively understand and facilitate the process of a rediscovery of agency, sense of self, preferences and personal goals.

From a policy designing perspective, exploring the subjective experience of people with SMI emphasizes the value of the knowledge acquired by people who have learned much from their personal experience. The challenge then lies in incorporating this valuable perspective so that it will be sensitively and wisely integrated into policy development.

In terms of research, acknowledging that people are not only “disorders,” but rather these disorders are experienced by persons living and coping with them, implies that we cannot study the disorder in isolation from the person who is experiencing it. Appreciating the importance of subjective experience requires then a step towards shifting research to integrate qualitative approaches. Recent studies have demonstrated how subjective experience can provide the personal context which captures first person accounts, preserves subjectivity, and protects rather than reduces experiential data (49, 50). It requires not only a different approach on how to study but also on what to study by allowing for the consideration of data that are difficult to measure reliably using standard methodological tools, but which might, nonetheless, be important. It also requires of us the humility to admit that there is more than one kind of knowledge and to recognize that research will be enriched by carefully examining the depth and complexity of subjective experience.

As our review of the literature reveals, these trends have already begun to develop, and, in fact, though far from being enough, several advances have already been made. Local examples here in Israel include systematic efforts to incorporate consumer's perspective as part of the routine training of professionals. For instance, the program "du siach" ("dialogue") of the consumer service organization "benafshenu" ("in our souls") accompanies consumers through the process of becoming comfortable to tell one's personal story in front of a professional audience (51). Other examples are the course "Hafel" at the Magid Institute at the Hebrew University of Jerusalem and "Lahak" at Haifa University which, influenced by international trends (52), train consumers to become advocates, and a course titled "consumers as providers" which trains consumers to become providers of rehabilitation services. Finally, the growing opportunities for consumers of services and family members to share their voice and subjective experience is evident through the internet (www.voices.co.il, www.benefshenu.jerusalem.muni.il, www.ozma.org.il, www.behevratova.co.il). In addition, consumers and family members have a growing impact on policy and treatment issues as they participate in many committees such as the National Council for the Rehabilitation of the Psychiatrically Disabled in the Community, the advisory board of the Office for Populations with Special Needs at the Ministry of Justice and the Reform Committee for Mental Health Care in the Community. Finally, the growing influence of consumers is evident also through the internet, in particular the website "Kolot" (Voices) (www.voices.co.il), initiated and updated by consumers, offers an opportunity for consumers and their families to share their experiences in writing and through art.

The study of subjective experience requires moving beyond the use of traditional questionnaires and rating scales and incorporating a wider range of research methods and data sources. Examples include ethnography (49, 50), qualitative (51) and participatory research methods which elicit narratives (52, 53), observations (54), themes (55), case studies (56) and life histories (57). The use of such methods have already contributed to the goals, nature, and atmosphere of services — and this shift is hopefully only at its beginning. Future research focusing on the de-

velopment of creative methods to capture and productively use the findings of subjective experience are likely to further contribute to the study and treatment of severe mental illness.

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