

The Use of Personal Accounts in the Study of Severe Mental Illness

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This paper looks at the use of personal accounts in the education of medical students in psychiatry. It discusses the practice of giving students protected reading time to review case material that will prepare them for future clinical interactions. Much can be learned from personal accounts of severe mental illness that cannot be gleaned from shorter case studies. This paper discusses how personal accounts can uniquely shed light on the following aspects of a patient's subjective experience: breaks with reality, loss of sense of self, social isolation, the therapeutic relationship, stigma, coping, and recovery. Using

such narratives as a foundation, students can internalize a broader portrait of psychiatric patients, of their capacity for change, and of the discipline of psychiatry itself. This broader picture is useful because medical students' exposure to psychiatry is typically narrow, focusing largely on interaction with patients at their worst, when they require hospitalization. The narrow exposure in turn conveys a myopic picture of the individual patient experience and of the field of psychiatry as a whole. The use of personal accounts in the study of mental illness can counter this effect.

INTRODUCTION

The current Liaison Committee on Medical Education (LCME) accreditation standards require medical schools to "establish a system to specify the types of patients or clinical conditions that medical students must encounter" and to monitor their experiences. If a medical student does not encounter certain types of conditions, the training director can remedy the deficiency with a standardized patient experience: an online or paper case (Liaison Committee on Medical Education, 2013).

On psychiatry clerkships at Albert Einstein College of Medicine, students are given a list of required cases at the beginning of the rotation and paper cases are used to fill in deficiencies. In general, the paper cases are taken from standard texts, such as the casebook for the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR)* (Spitzer, Gibbon, Skodol, Williams, & First, 2002) and its treatment companion (Spitzer, First, Gibbon, & Williams, 2004). These cases are derived from clinical practice and are useful for teaching differential diagnosis and the diagnostic criteria outlined in the DSM-IV-TR (American Psychiatric Association, 2000) and the recently released DSM-5 (American Psychiatric Association 2013). They contain a psychiatric history and mental status features but often don't reveal the subjective experience of the patient, the fluidity of that experience, and the potential for change. Their intention is to portray symptomatology, not ego strengths and features of psychological health. The focus is not on coping strategies for living with mental illness, social support systems, or recovery.

Problem-based learning (PBL) cases are equally useful for teaching psychiatry (Guerrero & Piasecki, 2008). PBL is an active, student-centered form of learning in a group setting. Written cases are used to help students problem-solve with faculty facilitation. Ideally, a PBL case recreates

a patient narrative (MacLeod, 2011) and teaches "patient-centered care" (Bauman, Fardy, & Harris, 2003) by centering the patient and the illness within a social context. However, rarely does a PBL case contain the patient's own words, and in one study of PBL cases the inclusion of social factors was limited (MacLeod, 2011).

We would argue that the use of personal accounts in teaching is one way to provide the social context that is missing from some DSM and PBL cases. Personal accounts are written in the patient's own words and allow "glimpses into the subjective world of lived experience" (Kumagai, 2008). The patient's subjective experience has long been a concern of psychiatrists, as Strauss and Estroff (1989) noted two decades ago: "Patients' reports of their experiences have been the data base for descriptive psychiatry from the time of Kraepelin and Jaspers to DSM . . . and no doubt will continue to serve that role" (p. 177). More recently, Roberts (2000) has made a forceful argument for the role of patient narratives in an evidence-based world.

At least two psychiatry journals, *Schizophrenia Bulletin* and *Psychiatric Services*, continue to publish first-person and family accounts. Other mental-health professionals publish personal accounts in their journals (Frese, 2000) and as texts (Sattler, Shabatay, & Kramer, 1998; LeCroy & Holschuh, 2012), and personal accounts are also published as memoirs (Saks, 2007; Cockburn & Cockburn, 2011). These accounts reach a wide audience of patients, clients, and clinicians, and enable readers to better understand the illness experience and the process of recovery. They uniquely portray the loss of sense of self that occurs with severe mental illness; regaining or managing that loss can lead to recovery (Wisdom, Bruce, Saedi, Weis, & Green, 2008). They demonstrate the powerful role of the family and social factors in the recovery of the lost self.

Questions
What is the narrator experiencing?
What reactions/emotions did the account evoke in you?
What can you do to prepare for an interview with this person?
Do you see evidence of distorted reality? Other symptoms of schizophrenia?
Describe the role of the therapeutic alliance in severe mental illness.
What role does stigma play in mental illness?
What do we mean by "early warning signs"? How are they helpful?
What are some coping strategies used by people with severe mental illness?
What are signs of recovery?

WHY READ PERSONAL ACCOUNTS OF SEVERE MENTAL ILLNESS?

Medical students in the third-year psychiatry clerkship have been taught the DSM-IV definition of schizophrenia: a serious disorder with a minimum of six months of certain symptoms. For at least one month, the patient has two or more of the active-phase symptoms: delusions; hallucinations; disorganized speech, behavior, or both; and negative symptoms. The patient may experience prodromal or residual symptoms—negative symptoms or attenuated active-phase symptoms—within the six-month period. The patient’s social and occupational functioning is impaired (American Psychiatric Association, 2000).

Over time, these symptoms alter “the most basic functions that give the normal person a feeling of individuality, uniqueness, and self-direction” (Sadock & Sadock, 2005). The illness shatters multiple aspects of the self and can feel strange and incomprehensible to a medical student who encounters it for the first time. The patient with schizophrenia loses touch with reality as the student knows it, and the symptoms appear to replace the personality of the individual. The symptoms of paranoia and aggression can induce fear in the student, and the extreme isolation of the patient can be daunting for a beginning interviewer. There are also countertransference feelings to contend with: for example, the student may bring along stigmatizing attitudes from the larger culture (Rüsch, Angermeyer, & Corrigan, 2005).

The reading of personal accounts during the psychiatry clerkship can not only teach symptoms and diagnostic criteria but enable the student to gain some mastery over his or her preconceptions and emotional reactions.

THE ACTIVITY OF READING FOR MEDICAL STUDENTS

It is important to understand the activity of reading narratives from the medical student’s perspective. A medical student, when meeting a patient for the first time, can experience distractions that make it difficult to concentrate attention on the patient. There is the distraction of trying to recall all the questions students must learn to ask, concern about the supervisor’s assessments and grades, and anxiety about interacting with certain types of patients, who may be uncooperative, angry, or dismissive. There are also the distractions of the interview setting, such as those found in a noisy and crowded emergency room or on the psychiatric inpatient ward. Ultimately, it is essential to learn to tolerate and manage these kinds of distractions. However, a student can more easily adjust to and develop skills for the interview experience by reading beforehand.

For a medical student, reading a narrative account of an individual’s experience of illness can provide a quiet and protected space without any of the aforementioned distractions, a space in which the student can focus entirely on the

Narrative	Learning Objectives
“Henry’s Demons” (Cockburn)	Loss of touch with reality Ideas of influence Hallucinations Role of family and friends in treatment compliance
“Who Are ‘They’?” (Wilson)	Paranoia Ideas/delusions of reference Delusional system Loss of sense of self
“Schizophrenia and Socialization” (Fox)	Racing, intense thoughts Poor judgment Loss of social supports Resocialization
“More Magic Bullets?” (Neugeboren) “The Center Cannot Hold: My Journey through Madness” (Saks)	Importance of the therapeutic relationship
“First-Person Account: Landing a Mars Lander” (Parker) “Schizophrenia” (Ben-Dor)	The role of stigma in mental illness
“How I Perceive and Manage My Illness” (Leete)	Early warning signs Coping strategies
“Recovery as Discovery” (Scotti)	Signs of recovery

individual's experience of illness. The act of reading itself, and the relationship the reader develops in his or her mind with the narrator, can serve as a model for the kind of intellectual and emotional engagement that doctors develop with their patients. In the words of one eloquent academician, when students read fiction or nonfiction narratives of illness, "it allows them the possibility to step out of the professional space and meet the persona in his crisis" (Kleppe, 2006). The reader can concentrate exclusively on the narrator's experience and attend to whatever emotions that experience induces. It is important to do this prior to meeting the patient. Once the student enters the clinical setting, he or she will have to maintain proper personal boundaries and engage the analytical, non-emotional part of the mind in deriving the differential diagnosis and treatment plan.

If the student/reader experiences emotional reactions to a patient's raw emotions on the written page, he or she has a protected setting in which to deal with those emotions. "Protected reading" in a protected setting allows for increased reflection, as do follow-up discussions with the psychiatry instructor and other students. Examination of the affective or emotional domains is one of Epstein's steps in developing mindfulness or "mindful practice" (Epstein, 1999).

LEARNING FROM PERSONAL ACCOUNTS

On the psychiatry clerkship, excerpts from personal accounts can be given as class readings prior to meeting with patients with severe mental illness. The instructor summarizes the book or article and frames the context prior to introducing the reading. Some examples are excerpted below. They have been shortened for the purposes of this article, but the attached references will give the instructor and reader access to the full accounts.

These examples were culled from what is available in the literature: from *Schizophrenia Bulletin* and *Psychiatric Services*, which include articles written by members of the psychiatric consumer movement, and from memoirs. Personal accounts are not always available to demonstrate every symptom of schizophrenia. The goal is to present the student reader with the illness experience so the patient's story can reinforce the memory of the symptom (Roberts, 2000), coping skill, or sign of recovery, and the reading of the narrative can prepare the student to meet the patient. Using sample trigger questions (Table 1), faculty members can review observations from individual narratives (Table 2).

The Break with Reality

In a book-length memoir, *Henry's Demons*, a father and son give their individual perspectives on the son's illness (Cockburn & Cockburn, 2011). Henry, the elder of two sons, had his first psychotic break at the age of 20, during his first year of college in England. The book was written seven years later, after seven hospitalizations, when Henry was an outpatient.

At the time of his first psychotic break, his mother and brother visit him at college. Henry writes about the visit:

My brother, Alex, was coming down to Brighton to see me. I wanted to make a drum for him. I left college in search of clay for it. . . . I found myself walking on a road parallel to the train tracks. I felt I was going on a mission. . . . I sat under a big tree. . . . I felt the tree telling me to take off my shoes. I was scared, as I had been arrested previously for not wearing shoes. . . . A dog barked, and I held my breath for as long as I could until I soiled myself. I saw flashlights and people looking for me beside the railway track. The root of the tree moved as it touched me. . . . After talking to the tree, I had thrown away the pieces of wood and tin. . . . Everything seemed to want me to leave Brighton, but my brother was coming down for the weekend, and I felt I couldn't abandon him. . . . When I got back, my mother was furious with me for being three hours late. Eventually, she calmed down and let Alex spend the night with me. (pp. 39–41)

To the student/reader, the rhythm of the narrative sounds odd. The events occurring in his mind (such as the tree talking to him) and the events occurring externally (such as meeting with his mother and brother when they visit him in Brighton) are equally real to him and are woven seamlessly into one narrative. This juxtaposition reminds the reader how disorienting, difficult, and exhausting it is to be living in two parallel realities.

The Experience of Paranoia and Loss of Self

In her first-person account "Who Are 'They?'" Molly Wilson (2007) describes her paranoia and fears of others. She gives a vivid picture of her loss of sense of self as a result of being in "a terrible game."

Communications were totally confused. I thought conversations were all about me disguised only by different names people used. So if people hated someone or thought someone wasn't nice, they were really talking about me. I believed that the radio in my car was tapped and that the announcers were talking about me. I also thought movies were en-coded to send a message about what they thought of me. . . . I lost my opinions. I forgot who I was and what I believed in. I thought I was in a terrible game, a game where I was the victim and everyone else were players. (pp. 749–750)

The patient's account reveals the frightening experience of an idea of reference, where the simple act of listening to a radio leads to a sense that whatever is being said refers "to me." The account also reveals a loss of self ("I forgot who I was and what I believed in"). The extremity of this loss reminds the student/reader of what it would be like to lose identity—for example, the new identity of a medical student and healer.

A corollary view of the loss of the self is given by the mother of a son with schizophrenia (Ben-Dor, 2001). She describes the slow "death" of the son she once knew.

My son was already long gone, dying bit by bit over the 16 years of his battle with schizophrenia. . . . I had never had a real chance to say goodbye to David. He had disappeared into his illness so slowly, imperceptibly. (pp. 329, 332)

This is often a new realization for the student/reader: that parents grieve for the people they knew before their children were overcome by the illness. As with Alzheimer's disease, the family members watch and mourn as mental illness ravishes the minds and personalities of their loved ones but, with chronic schizophrenia, the loss occurs at a much younger age and proceeds for a long period of time. It is "mourning without end," as one parent/psychiatrist wrote (Willick, 1994).

The Experience of Social Isolation and the Need for Connection

In her first-person account "Schizophrenia and Socialization," Valerie Fox (2009) gives a painful description of her increasing isolation. After the onset of her "journey with schizophrenia" at age 21, she loses her one close friend, along with family members.

Today I think about when I left my family, which was my center; with no family around me, there was no distraction to my racing, intense thoughts—no distraction from schizophrenia's taking a firm hold. Once I grew out of the family unit and became independent, my thoughts were my guide to living, and they were ill; my judgment was not sound. I struggled for a few years until I realized that with schizophrenia I could not trust my thoughts alone and needed supports. (p. 430)

She loses her marriage and the relationships with her children before gaining another friend:

It had been about 35 years since I allowed myself the pleasure of a close friend, and I am enjoying having someone to share both the good and bad experiences in my life and to have someone who is always supportive. (p. 431)

The book *Henry's Demons* (Cockburn & Cockburn, 2011) reveals that, despite the fragmentation of consciousness and sense of self caused by schizophrenia, Henry retains an emotional connection to his family and friends. During his first hospitalization, when he is refusing medication, his mother cries and says: "I can't take this anymore. I can't face the fact, Henry, that you may never get well." At this moment, faced with his mother's emotional distress, Henry replies, "Well, all right, then, I will take the olanzapine" (p. 26). At another point, Henry describes how his best friend "persuaded me to take the pills, as it was the only way I could get any fresh air" (p. 90). These reactions allow the student/reader to see that hospitalized patients with schizophrenia seek human connections, no matter how unemotional and without affect they may appear.

The Therapeutic Relationship

In his family account, "More Magic Bullets?" Jay Neugeboren (2008) describes the treatment of his brother, Robert, who is hospitalized with psychosis, and what happens to Robert when he loses an important relationship.

Ten years ago, Robert was put on a new antipsychotic medication and responded so well that the staff at his hospital, who had previously thought Robert might have to spend the rest of his life behind locked doors, got him ready for discharge. Then one morning, in a total panic, Robert telephoned. "Alan's leaving!" he shouted. "Alan's leaving!" Alan was Robert's social worker, with whom he had had a good long-term relationship, and Alan had been transferred overnight to another hospital. The result? Robert decompensated completely, and it was another year before he would again be readied for discharge. The question, then: why did the medication that worked so well on Monday stop working on Tuesday? (p. 143)

Years later, for a book he is writing, the author interviews individuals in recovery. He asks them what made the difference: "In all instances, they said that the key had been a relationship—the presence in their lives of somebody—professional, family, or friend—who believed in them, who talked with them, and who was committed to staying with them for the duration" (p. 144).

This view is echoed in a memoir by Elyn Saks (2007), who suffers from severe schizophrenia with paranoia. She is highly intelligent and determined and comparatively lucid between bouts of auditory hallucinations and regressions into cognitive and emotional disorganization. After years of study, she graduates from law school and becomes a law professor. In her memoir, she describes her earlier treatment at a hospital in England:

I trusted Dr. Hamilton immediately. . . . He effortlessly made jokes; he spoke to me as though we were friends; he seemed to care about me. I looked forward to our appointments, no matter how difficult the conversations were. It was human contact, and I craved that. . . . I adored Dr. Hamilton, and I would have done anything to get better for him. Freud had picked up on this phenomenon in the early 1900s; he labeled it the "transference cure." (p. 70)

In Saks's book, the student/reader finds a model for the power of a successful therapeutic alliance. The student learns that, despite doing everything "according to the book," including the use of empathy, there might not be a connection. If the doctor is not emotionally awake, so to speak, an alliance may never form.

Stigma

The struggle to deal with stigma is ongoing for patients and families. A woman with schizophrenia talks about how difficult it is to make a friend—"it is like trying to land a Mars

lander on Mars”—and how difficult it would be to find a partner because of stigma (Parker, 2001).

If I ever found a potential life partner, I would eventually have to divulge my mental illness. I would, however, be in a quandary as to when to reveal that I have schizophrenia. A revelation that came too soon could cause the dissolution of the relationship because of fear and stigma. Would I ever be capable of “losing it” and endangering other people, especially people I love? . . . A revelation that came too late could also end the relationship because the partner might feel as if I had been lying throughout the relationship. (pp. 717–718)

A mother struggles for 16 years to find a way to help her schizophrenic son (Ben-Dor, 2001). She also has two young daughters.

My then 13-year-old daughter summed it up this way: “If David’s body were hurting, people would send gifts, but because it is his mind that’s hurting, they throw bricks.” And so we were thrust into the stigma/blame loop. “She’s the one with the crazy son. Maybe he’s crazy because she is?” My response? “I’m the one with the healthy daughters. Are they healthy because I am?” (p. 330)

When treating patients with medical illness, the student has little sense of the power of stigma; there is less prejudice toward medical illness than toward mental illness. In our culture, the seriously mentally ill are often feared and excluded (Rüsch et al., 2005); by reading personal accounts, the student/reader can begin to discern if he or she has stigmatizing attitudes toward these patients.

Coping

A number of first-person accounts provide coping strategies for persons with schizophrenia. In “How I Perceive and Manage My Illness” (Leete, 1989), the author writes, “Taking responsibility for my life and developing coping mechanisms has been crucial to my recovery” (p. 197). She summarizes her coping strategies as follows:

Many of us have learned to monitor symptoms to determine the status of our illness, using our coping mechanisms to prevent psychotic relapse or to seek treatment earlier, thereby reducing the number of acute episodes and hospitalizations. My own personal warning signs of decompensation include fatigue or decreased sleep; difficulty with concentration and memory; increased paranoia, delusions, and hallucinations; tenseness and irritability; agitation; and being more easily overwhelmed by my surroundings. Coping mechanisms may include withdrawing and being alone for a while; obtaining support from a friend; socializing or otherwise distracting myself from stressors; organizing my thoughts through lists; problem-solving around specific issues; or temporarily increasing my medication. (pp. 199–200)

On the psychiatry clerkship, the student is given an overview of coping skills that patients use. However, coping skills, like early warning signs, are individual. Elyn Saks and others (Saks, 2013) have been meeting with individuals like herself, with “high-functioning schizophrenia,” to understand how they succeed in their jobs and studies. What they do is identify triggers and develop techniques “to keep schizophrenia at bay.” First-person accounts help prepare the student/reader to discuss these specific strategies with patients.

Recovery

Recently, psychiatric approaches to treatment and rehabilitation have included the perspectives of people in recovery, including “the varying views of psychiatrists, psychologists and other highly trained persons who themselves have been diagnosed and treated for schizophrenia” (Frese, Knight, & Saks, 2009). According to a first-person account by Scotti (2009), recovery can lead to new meanings and possibilities. The author was a chemistry student studying for a master’s degree when he was hospitalized for schizophrenia, and his recovery was slow. He retrained as a dental technologist but was unable to keep a job. He retrained as a peer-support worker and found employment on a psychiatric Assertive Community Treatment team.

They say that recovery is knowing oneself under new circumstances, redefining one’s role, and reevaluating oneself to develop a new sense of respect of oneself. After living in darkness for many years and having died to my old self, thinking that my life was over and futile, a new birth emerged from within me that has made my life more meaningful and purposeful than before. Whereas before I was a “thing” person, I now discovered a part of me that is a “people” person. I treasure relationships. . . . All the pain and suffering of the past was not a waste because it has helped me to be more human in that now I feel I am a more compassionate and empathic person, and I can use that new enlightenment to help others. (p. 846)

On the psychiatry clerkship, students fear they will not be able to help patients or effect change in their chronic conditions. Students are taught that expectations are different for patients with serious mental illness, as there is currently no cure. First-person accounts reveal the possibility of recovery and teach the reader that every recovery—and every expectation for recovery—is different.

DISCUSSION

There are limitations to this paper. The narratives have been shortened to meet space requirements, but we have included all references, should instructors want to return to the original narratives. Ideally, on a psychiatry clerkship where most students do not choose psychiatry as a career path, narratives of other disorders, such as anxiety, mood, and psychosomatic disorders (LeCroy & Holschuh, 2012), would be helpful. The narratives reproduced here have been used on a state hospital clerkship, where schizophre-

nia is common, and many of the concepts could translate into work with other patients.

Another difficulty is the lack of evaluation. Possible avenues for evaluation include surveying the students on the effectiveness of individual narratives in teaching the objectives outlined in Table 2, and testing the effect of the early use of narratives on the clinical encounter with patients.

There has been an ongoing discussion in the literature about the value of using mental-illness narratives to train healthcare providers, and a movement has evolved to try to increase our understanding of the factors that shape the narratives. For example, Baldwin (2005) discusses the mental patient's loss of ability "to construct and articulate a coherent narrative" due to language and cognitive difficulties. Donohue-Smith (2011) has developed a conceptual model and checklist for evaluating the "influences" on the mental-illness narrative. This approach is beyond the scope of this paper.

CONCLUSION

While reading narratives written by persons with mental illness, the student can internalize a picture of each person he or she meets in a narrative. These people, in turn, become "touchstones" in the student's mind when encountering patients in the hospital. They become a source from which to extrapolate further meaning or understanding, much as a psychiatrist with twenty years of experience might draw on his or her knowledge from encounters with previous patients. Furthermore, by reading narratives, the student can move from the study of symptoms and differential diagnoses into the experiential realms of identity, relationships, recovery, and hope.

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The authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. No conflicts were noted.

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The authors had equal roles in writing the paper.

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