Recovery and Mental Illness: Analysis and Personal Reflections

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My strong desire to enter the helping profession has been fuelled by my experiences as a consumer-survivor of the mental health system who is recovered and is symptom-free. And yet, driven by concomitant hopes of changing the system under which I found my care and the care of those around me to be flawed at best, and in order to relate to both consumers and practitioners the need for a recovery paradigm and for empowerment and hope, I found that in the academic world, I “passed.” For fear of discrimination, tokenization, and the discreditation of my ideas, I took on the role of practitioner-in-training, never disclosing my identity as a consumer-survivor, no matter how much I felt this unique perspective could contribute to a discussion. I was torn. Had I not entered this field in order to bring about change and instill hope based on my story? Feeling hypocritical, I nonetheless decided that it would be best to delay self-disclosure until I achieved professional status.

My decision to explore recovery in mental illness has necessitated self-disclosure and an examination of my own recovery. The recovery movement belongs to consumers-survivors, not to practitioners. As someone who feels ownership of this by virtue of my identity, it would be wrong for me to situate myself as an outsider in my research. In writing about recovery, one must locate one’s identity as it relates to mental illness; it is called for. Further, the movement gives more legitimacy to lived experience than to academic theories; to approach this subject without using my own knowledge would betray this aspect of the movement, in which I firmly believe.

Finally, as someone who has been hiding her identity because of an ability to pass as someone without any experience of mental illness but for whom self-disclosure is key to my field, this paper affords me a safe place to reveal and discuss this part of myself.

In this article I explore recovery from mental illness. After offering an initial definition of recovery, I outline the history of the recovery movement, and discuss the role of consumer-professionals in recovery. I consider two key features of the recovery model: its psychosocial perspective and its humanistic ideology. Through contrasting the
rehabilitation and empowerment views of recovery and drawing on consumer definitions, I examine the question “what is recovery?” I explore thoughts on how people recover, analyzing my story from the perspective of Young and Ensing’s (1999) model of recovery. Finally, I consider the self, and how it is constantly being negotiated throughout illness and recovery.

**What is Recovery? An Initial Definition**
Definitions of recovery from mental illness are based on the experiences of consumer-survivors. Recovery is a highly personal and unique process, definable, and of living up to one’s full potential for the rights of people with mental illness (Chamberlin, 1990). Although it is previously thought to be degenerative, Harding showed in a longitudinal study (and other studies have since confirmed) that approximately two-thirds of patients diagnosed with schizophrenia recover (Harding, 2002). Harding and others have shown that “diagnosis and prognosis are two different dimensions of psychosis” (Vaillant in Harding et al., n.d., p. 1).

The movement began in the 1970s when small groups of ex-patients, fueled by a shared sense of anger and a hope that they could bring about change, organized throughout the United States. The struggle has always been political; its proponents have fought for the rights of people with mental illness (Chamberlin, 1995). These groups were influenced by the black, gay, and women’s liberation movements of the time. Non-patients were excluded from the organizations, as consumers found that their radical views on mental illness were not shared by practitioners or by the general public. These groups practiced consciousness-raising to combat the internalized stigma that they confronted. Traditional, medical model terminology, such as “patient,” was replaced with terms such as “consumer” (Chamberlin, 1990).

The major principles of the movement are empowerment, self-help, and advocacy. Empowerment refers to the transformation from “passive service recipient” (Chamberlin, 1990, p. 330) to taking an active role in one’s mental health care. The concept of self-help presents a means for empowerment through seeing oneself differently and interacting with the world in new ways. Advocacy is meant to address problems beyond the individual. It is to work for political change to benefit all those who face these issues (Chamberlin, 1990).

Courtenay Harding’s work in the 1980s provided an empirical basis for the concept of recovery from serious mental illness (Anthony, 2000). Although it was previously thought to be degenerative, Harding showed in a longitudinal study (and other studies have since confirmed) that approximately two-thirds of patients diagnosed with schizophrenia recover (Harding, 2002). Harding and others have shown that
be the only professional a consumer will trust, as the consumer movement values lived experience. "Prosumers be the only professional a consumer collaborators in their individual sign, delivery, and evaluation of mental health services" (Fresé & Davis, 1997, p. 245).

Several years ago I volunteered with a music therapist who worked with consumers in acute phases of illness. I did not disclose my identity as a survivor of the mental health system, taking on the role of the empathetic professional-to-be. The music therapist commented on my ease at being with these consumers in distress, and the calm that I projected. She also commented on my comfort in silence; I never felt I had to fill in the gaps with speech. While she may have attributed this to my personality or my sensitivity, I maintain that my behavior reflected my profound empathy. When I was ill and in hospital, I longed for calm. I hated it when eager staff would talk my ear off. I just wanted someone to sit with me and not to be afraid of me; to help me tune into someone else and to have someone tune into me. Who can do this better than someone who has been there?

The Recovery Model

Two key features of the recovery model are its psychosocial perspective on mental illness and its humanistic ideology.

A Psychosocial Perspective

The recovery model eschews the medical model of mental illness, in which the illness is defined, diagnosed, and treated by an expert, and is seen as "a defective chemical mechanism in the patient's brain that needs to be re-

paired" (Fisher, 1994, p. 913). In this model, the consumer is a passive recipient of expert care. Fisher (n.d.b) refers to this paradigm as a "machine model": the medical model promotes an ideology of resolving psychological problems in a similar fashion to that in which one would solve the problem of a broken down car. Further, the promotion of a pessimistic prognosis in the D.S.M.-IV is a "destructive social force," (Harding, 2002, p. 1) discouraging hope in consumers.

In contrast, the recovery model is based on a system of health promotion in which individuals actively define their needs and collaborate with others in their healing process. The individual is considered not in the context of an illness as such, but rather in the context of a unique psychosocial experience (Fisher, 1994).

From the psychosocial perspective, people with mental illness are recovering from many traumatic experiences, in addition to the illness itself. The way the individual is treated in the mental health system causes multiple traumas, as he or she faces negative professional attitudes; insufficient help; programs and professionals that disempower and devalue the individual; and side effects from psychopharmaceutical treatment. Further, consumers face discrimination within society, and are prone to both external and internalized stigma (Spaniol, Gagne & Koehler, 1999). These iatrogenic effects can be more difficult to recover from than the illness itself (Anthony, 2000).

The psychosocial model of mental illness highlights the importance of the individual's social role, and the extent to which it is interrupted by mental illness. Accordingly, recovery must include the development of supports to help in re-establishing one's social role, along with the development of self-management skills (Fisher, n.d.a).

Harding’s longitudinal study (mentioned earlier) followed patients treated at a Vermont hospital by George Brooks, who developed and implemented a psychosocial rehabilitation program in the mid-1950s (Harding, 2002). The great success of that program, reported in Harding’s study and others, testifies to the positive effects of considering mental illness from a psychosocial perspective.

A Humanistic Ideology

The humanistic approach to treatment emerged from existential philosophy. This ideological paradigm sees worker and consumer in a relationship that is above all human, and views the human condition that is common to everyone as what allows the two to connect. The worker and consumer engage in an I–Thou relationship, and not a subject–object relationship. In this state of humanization, the worker realizes that at another time, her/his role and that of the consumer could be reversed. The two work toward common goals, the worker never seeing her/himself as an expert of the consumer (Tropp, 1969). Anthony (2000) argues that consumers hold the key to their own recovery, and the role of professionals is one of facilitating this recovery. This deflation of the "expert" is a thoroughly humanistic notion.

Deegan (1996), an articulate and thoughtful consumer, practitioner, and advocate of recovery, contemplates the loss of hope that consumers experience that can appear as a lack of effort, and the reactions of those around them. The change in the person's behavior and presentation can be so profound, remarks Deegan, that one can question if the illness has eaten away the person's soul. It is in this state that consumers can be related to as their illness and not as themselves. Drawing on the existential philosophy of Martin Buber, Deegan argues that the I–Thou
relationship thus becomes an I—it relationship. She further suggests that in order to fulfill our own humanity, we must be compassionate and relate to others as Thou and not I. "I become I by saying Thou," (Buber in Deegan, 1996). The notion that not only do consumers deserve respect and compassion, but that by treating them this way workers can realize their own humanity is of utmost importance during times of distress; they are not divorced from their "illness." The focus remains on the person.

Finally, Spaniol, Gagne, and Koehler (1999) assert, "the goal of recovery is to become more deeply human" (p. 410). They argue that "one of the main benefits of utilizing recovery...is that it allows us to look at the whole person, in all of his or her humanity, instead of just at their illness" (p. 410). This notion of humanity that is so intrinsic to recovery is inextricably linked to the humanistic ideology.

**Recovery—What Is It?**

What does it mean to be in recovery or to be recovered? Within the recovery paradigm, there are competing views of what recovery means. The rehabilitation view suggests that mental illness is a permanent disability, and that recovery comes from learning to negotiate life and regain functioning in light of this impairment (Fisher, n.d.a).

Proponents of the rehabilitation view consider themselves to be permanently in recovery once they have successfully learned to live with their illness. Joseph Rogers, a consumer and activist in the consumer movement, considers his recovery to be analogous to recovery from alcoholism. He asserts that recovery must be continually maintained in order to avoid a relapse, and considers himself to be currently in recovery from his illness (Szegedy-Maszak, 2002).

In contrast, the empowerment vision of recovery challenges the notion of permanent mental illness. Currently promoted by Daniel Fisher and the National Empowerment Center, it suggests that mental illness can be overcome completely. Proponents of the empowerment vision see themselves as having recovered from their illness. Once they have gone through the process of recovery, they are no longer still recovering from the disorder (Szegedy-Maszak, 2002).

**Consumer Definitions of Recovery**

To me, being recovered means feeling at peace, being happy, feeling comfortable in the world and with others, and feeling hope for the future. It involves drawing on all my negative experiences to make me a better person. It means not being afraid of who I am and what I feel. It is about being able to take positive risks in life. It means not being afraid to live in the present. It is about knowing and being able to be who I am.

Through analyzing the consumer definitions of recovery from the National Summit of Mental Health Consumers and Survivors Recovery Plank (1999), I found three major themes in their definitions of recovery.

1. Recovery involves one's internal self. Consumers noted that knowing oneself, believing in oneself, being able to help oneself and others, acceptance of self, loving oneself, spiritual wholeness, integrating mind, body, and spirit, and gaining self-confidence are all important to recovery.

2. Recovery involves one's social role. Consumers commented that being able to use one's gifts and talents, to be needed, and to be productive are all part of recovery.

3. Recovery involves the way one interacts with one's environment and lives one's life. Consumers reported that enjoying life, taking responsibility, not giving up, having freedom, feeling safe, living a fulfilled and meaningful life, living with hope, and making connections with others and with the world are all parts of recovery.

**How Do People Recover?**

Many years ago, with more diagnoses than I care to remember (ranging from major depression to schizoaffective disorder) and as many prognoses, with more hospitalizations than I'd like to list, I was trapped in the ache of mental illness. Although I have many ideas about how I got there, what is of concern here is how I got out. There are several factors that I can identify that aided me in my recovery process.

First and foremost was what kept me wanting to get better. I can attribute this desire to two factors: the need to be out of a state of constant ache and torment, and the passion I had to pursue a music career. I was in so much
emotional pain that I spent most of my time alternately sobbing, numb, or sleeping. Much like the way our bodies aid us in our physical recovery, I think that somewhere within me an involuntary mechanism kicked in in an attempt to release me from my state of pain. This provided me, I think, with part of my drive to end this experience. The easiest thing for me to do to satisfy this primitive need to avoid pain would have been to settle into a state of numbness, which I might have done, but other circumstances, such as my recovery. Not only did it push me to release me from my state of pain. The doctors' lingo and could speak it with them, and was thereby able to advocate for myself. At one point I read my hospital chart, in which an admitting doctor commented on my extensive use of medical terminology. I was always receptive to this. But the times that I was able to get over the depths of my illness to begin recovery were the times that I chose my own medication. The doctors who would allow me to direct the course of my treatment saw me as a person, even if they did not believe in the possibility of recovery. My relationship with them was essential; they reminded me of who I was and who I might become.

As I grew stronger I went off to university, where I was able to develop parts of myself that I did not associate with illness. I made friends tentatively and allowed myself to develop my identity as a person, and not as a sufferer of illness.

Young and Ensing (1999) have developed a tri-phase model of recovery, whose phases reflect my own journey. The first phase, initiating recovery, comprises acknowledgment and acceptance of illness, desire and motivation for change, and finding a source of hope and inspiration. As I described for me this process was facilitated by my desire to pursue my music career, by the inspiration music brought me, and by my stark realization that I was ill and could remain that way for many years. Smith (2000) notes the role of a strong desire for change in the initial phase of recovery, something that was very strong in me and that I deem to have been essential in my recovery. I remember sitting in the smoking room in one hospital, surrounded by people doing the same, trying desperately to pass the time from one sleep to the next. Some had spent most of their lives like this: in constant fear of the present, resorting to smoking and watching television. While I, too, spent much time staring at the television in the common room, at a certain point I was desperate for it to end, and believed it could.

The middle phase of recovery involves regaining what has been lost and moving forward (Young & Ensing, 1999). Self-empowerment is important in this phase. I developed self-empowerment as I took responsibility for my recovery by researching illnesses and treatments and advocating for myself with my doctors. The other aspect of self-empowerment is believing in oneself and being able to take risks, which I did by going to university, unsure whether or not I'd manage. This phase of recovery is also one of learning and self-redefinition. I went through this process as I went to university and realized there was more to me than illness, and as I learned to reintegrate myself with my peers. At first, I felt like I had a big secret that I was keeping from everyone I met. No one knew my past, and assumed my teenage years were similar to theirs. I have never lost this feeling, although it has dulled significantly with time.

As I began to feel more and more like illness was something in my past that I was recovering from, and that illness was no longer part of my identity (although being a consumer-survivor always will be), I began the process of being comfortable in my own skin, which was something I had never felt.
What kept me so determined to remain well was my commitment to my music. I put it above everything else, using it as an excuse not to go out with people (the smoke would bother my throat) and as an excuse with myself: I told myself I was fulfilled with my music. But as other things in life started to become important to me, I realized the role that music was playing in my life. It had helped me to recover thus far, giving me hope, inspiration, discipline, and even spirituality, but I no longer needed it; it was no longer me. As my recovery became more and more stable, I began to want to change careers; I wanted to help consumers. And hence my career change, my entry into social work.

Young and Ensing (1999) define the final phase of recovery as improving the quality of one’s life. One of the behaviors of this stage involves striving to attain an overall sense of well-being, which happened to me as I became more comfortable in myself and began to care about things more and more. Another behavior characteristic of this phase is striving to reach new potentials of higher functioning. By taking a risk and acknowledging that music was a crutch, giving it up, and being able to change career paths, I have achieved a much higher level of functioning. Worth mentioning is that this phase of the model specifically includes the desire to help other consumers, something that was abundantly present in my recovery.

Renegotiations of the Self
There are many times in the course of illness and recovery during which our sense of self is contested. When we are first diagnosed, we must come to terms with the prevailing ideologies regarding people with mental illness. These ideologies segregate people with mental illness from the rest of the population through the enforcement of an “us—them” mentality. Consequently, our identity is challenged as we are placed in the “them” category by virtue of a diagnosis. Because the popular conception of people with mental illness is of the mad deteriorating in backwards, we begin to imagine that this may very well be the prognosis to which we are destined. This first negotiation of the self, then, involves fitting our diagnosis into our identity and challenging our preconceived notions of what mental illness means.

Another way in which the self is challenged is when we emerge from acute periods of illness. I found that in times of acute illness I did not look in the mirror, and when I did, I did not really recognize myself. When I emerged from these periods I was changed, but I had been functioning as though I was not a part of myself. Consequently, I had to become reacquainted with myself. This becomes more complicated when our physical appearance has changed. In my case, the drugs I was taking caused enormous weight gain, and I was incredibly uncomfortable with my physical self.

As we recover, we come to terms with the self that we have lost. For some, it is a self of innocence. For others, it is a self that was on a path to a successful career. The self that we were, and thought that we would become, changes paths when we become ill. For me, my self of teenage-hood is lost. My teenage years were spent with doctors and consumers, fighting illness and side effects. I was never a teenager in the typical sense.

Spaniol, Gagne, and Koehler (1999) argue that “sickness in our culture alters the sense of self” (p. 411). Instead of accepting the self who we are when we are ill as our self, we reject it, as in “I am not feeling like myself.” When illness becomes chronic, the person must negotiate this ill self as the self.

The self plays a mediating role among many areas of functioning. A lower-functioning self will produce an overall lower level of functioning. Consequently, when we are disconnected from our selves, we are unable to move forward with our lives. The self is thus the agent of recovery (Spaniol, Gagne & Koehler, 1999).

It is clear that illness brings with it a trauma to the sense of self. The self, then, needs to recover. There are four steps in the recovery of the self (Strauss, 1992, in Spaniol, Gagne & Koehler, 1999). The first step is to discover a more active self. This involves the awareness that our actions influence our lives, and that we can act in our own interests. The next step involves taking stock of our selves. We begin to test out our strengths and feel more comfortable in our selves through our actions. The third step is to put the self into action. At this stage we reclaim our social roles, and confront harmful discourses. The final step is to appeal to the self. At this stage, we feel empowered, and can count on the self when needed. Throughout these four stages, the fragility and vulnerability of the self gives way to a stronger, more secure self.

Conclusion
This article has been an attempt for me to process my own recovery while discovering and integrating the existing recovery literature. It is my hope that in understanding my own recovery, and in having the courage to draw on this experience as legitimate knowledge, I can advocate for the recovery model of mental illness as a member of the consumer community, uniquely situated as both a consumer and a professional.
References


