

Recovery as a Self-Directed Process of Healing and Transformation

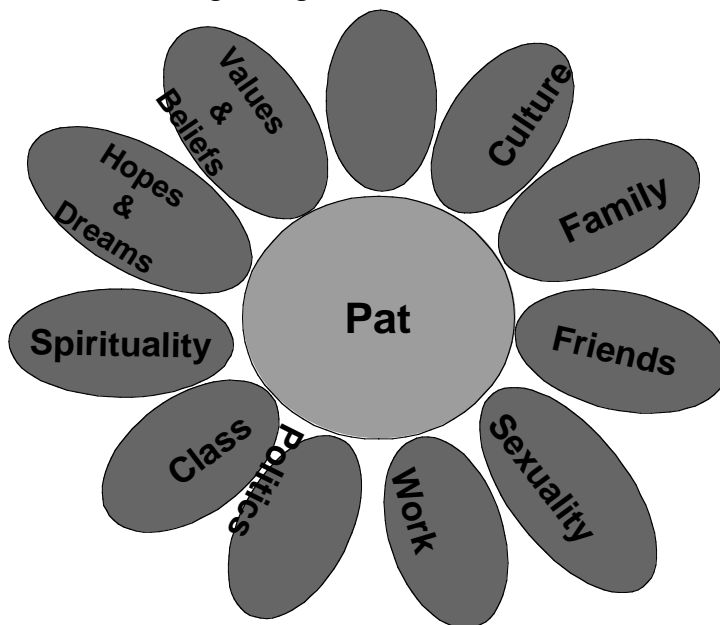
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Recovery is often defined conservatively as returning to a stable baseline or former level of functioning. However many people, including myself, have experienced recovery as a transformative process in which the old self is gradually let go of and a new sense of self emerges. In this paper I will share my personal experience of recovery as a self-directed process of healing and transformation and offer some suggestions as to how professionals can support the recovery process.

When I was seventeen years old and a senior in high school, I began to have experiences of severe emotional distress that eventually were labeled as mental illness. The illustration below symbolizes how I experienced myself and how others perceived me, before I was diagnosed with schizophrenia.

Illustration 1

How I am Seen By Others And Understand Myself Before Being Diagnosed with Mental Illness



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The most immediate impression of this symbolic flower is its integrity and wholeness. This represents the fact that before being diagnosed with mental illness there was a basic congruity between how I understood myself and how others perceived me. In addition, each of the petals on the flower represent aspects of who I was. I was the oldest child in a large working-class Irish Catholic family. My friends, my social role as a worker and student, my spirituality, values and beliefs, culture, family and socio-economic class all converged to form the unique individual I was at seventeen years old.

Notice that one of the petals on the flower is empty. This empty petal symbolizes the idea that my life opened onto a future. That future was unknown and ambiguous. It was

precisely because my future was unknown that I could project my hopes, dreams and aspirations into it. That is, hope arises in relation to an open, ambiguous and uncertain future. As a teenager, I remember my dream was to become a coach for women's athletic teams. I was a gifted athlete and did just enough academic work to get passing grades so I could continue to compete on varsity teams. At seventeen I could not have imagined that someday I would have a doctorate in clinical psychology and be writing a chapter for a book!

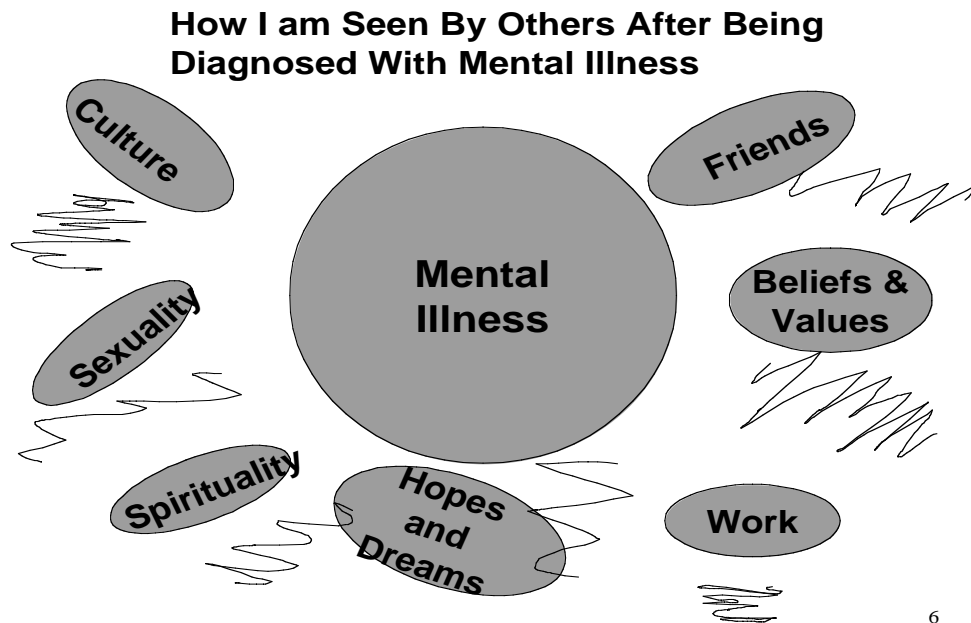
The image of me as a whole, unique and promising young person began to crumble during the winter of my seventeenth year. Even now I can vividly recall some aspects of the emotional distress I began to experience. For instance, during basketball practice it became harder and harder to catch a ball. My depth perception and coordination seemed strangely impaired and I found myself being hit in the head with passes rather than catching the ball. Objects around me also began to look very different. Countertops, chairs and tables had a threatening, ominous physiognomy. Everything was thrown into a sharp, angular and frightening geometry. The sense that things had utilitarian value escaped me. For instance, a table was no longer something to rest objects upon. Instead a table became a series of right angles pointing at me in a threatening way.

A similar shift in my perception and understanding occurred when people spoke to me. Language became hard to understand. Gradually I could not understand what people were saying at all. Instead of focusing on words, I focused on the mechanical ways that mouths moved and the way that screw drivers had taken the place of proper teeth. It

became difficult to believe that people were really who they said they were. What I remember most was the extraordinary fear that kept me awake for days and the terrible conviction I was being killed and needed to defend myself.

The adults around me eventually decided that I had “gone crazy,” and I soon found myself being escorted up a hospital elevator by two men in white uniforms. Once in the mental hospital, I was diagnosed with schizophrenia. The illustration below represents the way I was viewed by those around me once I had been diagnosed:

Illustration 2



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Whereas before being diagnosed I was seen as a whole person, after being diagnosed it was as if professionals put on a pair of distorted glasses through which they viewed me as

fundamentally ill and broken. The jagged lines represent the distorted lens through which I was viewed. It seemed that everything I did was interpreted through the lens of psychopathology. For instance, when growing up my grandmother used to say I had ants-in-my-pants. Now, in a mental hospital, I was agitated. I never cried very much while growing up, but after diagnosis I was told I had flat affect. I was always quiet, shy, and introverted. Now I was guarded, suspicious and had autistic features. And in a classic double-bind, if I protested these pathologized interpretations of myself then that was further proof I was schizophrenic because I lacked insight!

Notice also in the first illustration there was congruity between how I viewed myself and how others viewed me but after being diagnosed there was a lack of congruity. That is, although I was severely distressed, I still felt that deep down I was myself – Pat. However, the professionals and later my family and friends, seemed to forget about Pat and were now more interested in “the schizophrenic”. This is symbolized by the substitution of a diagnosis for my name in the center circle.

After being diagnosed, mental illness took on a master status in terms of how others viewed me. The fact that I was a unique person with my own spirituality, culture, sexuality, work history, and values and beliefs was secondary – one might even say perfunctory. This is symbolized by the petals being broken off, and even missing altogether. What mattered most to psychiatrists, social workers, nurses, psychologists and occupational therapists was that I *was* a schizophrenic. My identity had been reduced to

an illness in the eyes of those who worked with me. It was only a matter of time before I began to internalize this stigmatized and dehumanized view of myself.

Dehumanization is an act of violence, and treating people as if they were illnesses is dehumanizing. Everyone loses when this happens. People, especially people who are feeling very vulnerable, internalize what professionals tell them. People learn to say what professionals say; “I am a schizophrenic, a bi-polar, a borderline, etc.”. Yet instead of weeping at such a capitulation of personhood, most professionals applaud these rote utterances as “insight”. Of course the great danger of reducing a person to an illness is that there is no one left to do the work of recovery. If all professionals see are schizophrenics, borderlines, bi-polars, etc., then the resilient strengths and gifts of the individual are ignored and sacrificed to the gods of the DSM IV.

Notice that the empty petal is missing from Illustration 2. This symbolizes the fact that because of my diagnosis professionals lost hope that I could have a meaningful future. Recall how in the Illustration 1 the empty petal symbolized the unknown, ambiguous future into which I projected my hopes, dreams and aspirations. Once diagnosed with schizophrenia, professionals acted as if my future and my fate were sealed. I recall the day this happened for me: I asked my psychiatrist what my diagnosis was. He looked at me from behind his desk and said, “Miss Deegan, you have a disease called schizophrenia. Schizophrenia is a disease like diabetes. Just like diabetics have to take medications for the rest of their lives, you will have to take medications for the rest of your life. If you go into this halfway house, I think you will be able to cope.”

Coping is definitely not what a teenager wants to do on a Friday night! I was not at all inspired by the thought of a life spent coping. I remember feeling like I had been hit by a truck upon hearing his words. Then I remember my mind racing, trying to think of one famous person who was diagnosed with schizophrenia. I instinctively needed to identify someone who had beat the odds but nobody came to mind. As the psychiatrist continued to babble on, I felt a surge of anger rising up within me. Although I knew better than to get too angry in a psychiatrist's office, I found the words forming silently inside me: "You are wrong. I'm not a schizophrenic. You are wrong!"

Today I understand that this psychiatrist did not give me a diagnosis. He gave me a prognosis of doom. Essentially this psychiatrist was telling me that by virtue of the diagnosis of schizophrenia, my future was fait accompli. He was telling me the best I could hope for was to cope and remain on medications for the rest of my life. He was saying my life did not open upon a future that was ambiguous and unknown. He was saying my future was sealed and the book of my life had already been written nearly 100 years earlier by Emil Kraepelin (1912), the psychiatrist who wrote a pessimistic account of schizophrenia that influences psychiatrists even to this day. According to Kraepelin my life, like the life of all schizophrenics, would be a chronic deteriorating course ending in dementia (Kruger 2000).

It was this prognosis of doom, this life sentence, this death before death that I instinctively rejected when the words "You are wrong" formed silently within me. With

the wisdom of hindsight I understand why this moment in the psychiatrist's office was a major turning point in my recovery process. When I rejected the prognosis of doom I simultaneously affirmed my worth and dignity. Through my angry indignation I was affirming that "I am more than that, more than a schizophrenic." Importantly, it was my anger that announced the resurrection of my dignity after it had been so battered down during hospitalizations. My angry indignation was a sign I was alive and well and resilient and intent on fighting for a life that had meaning and hope. What some would have seen as denial and a lack of insight into my illness, I experienced as a turning point in my recovery process.

Rejecting the hopeless prognosis through angry indignation happened almost like a reflex. And just as quickly as I turned away from the prophecy of doom, I found myself asking – so now what? In other words, I turned away from a hopeless path but also, at the same time, had to turn toward something. What I remember was that when I left the psychiatrist's office, I stood in the hallway and had an image in my mind's eye of a big heavy key chain – the type carried by the most important and powerful professionals who have the keys to all the hospital doors. I found myself thinking, "I'll become Dr. Deegan and I'll make the mental health system work the right way so no one else ever gets hurt in it again." And this plan became what I have come to call my survivor's mission. Yes, it was a grand dream that would have to be molded and modified with time and maturity. But it was my dream nonetheless and it became the project around which I organized my recovery.

I did not tell anyone about my dream. In hindsight this was very wise. Imagine if I had gone to my treatment team as an 18 year old girl diagnosed with chronic schizophrenia, having had three hospitalizations, barely graduating from high school with combined SAT scores of under 800 – and announcing that my plan was to become Dr. Deegan and transform the mental health system so it helped instead of hurt people. Delusions of grandeur! Clearly it was better to keep my dream to myself.

I wish I could say that having found a survivor’s mission I resolutely marched forward in my recovery. But recovery does not strike like a bolt of lightning wherein one is suddenly and miraculously cured. The truth is, when I returned home after that transformative experience, I proceeded to sit and chain smoke in the same chair I had been sitting and smoking in for months. In other words, although everything had changed within me, nothing had changed on the outside yet. Here is what people would have seen me doing at that time in my life:

“I turn my gaze back over the years. I can see her yellow, nicotine-stained fingers. I can see her shuffled, stiff, drugged walk. Her eyes do not dance. The dancer has collapsed and her eyes are dark and they stare endlessly into nowhere...She forces herself out of bed at 8 o’clock in the morning. In a drugged haze she sits in a chair, the same chair every day. She is smoking cigarettes. Cigarette after cigarette. Cigarettes mark the passing of time. Cigarettes are proof that time is passing and that fact, at least, is a relief. From 9 a.m. to noon she sits and smokes and stares. Then she has lunch. At 1 p.m. she goes back to

bed to sleep until 3 p.m. At that time she returns to the chair and sits and smokes and stares. Then she has dinner. She returns to the chair at 6 p.m. Finally, it is 8 o'clock in the evening, the long-awaited hour, the time to go back to bed and to collapse into a drugged and dreamless sleep.

The same scenario unfolds the next day, and then the next, and then the next, until the months pass by in numbing succession marked only by the next cigarette and then the next..." (Deegan 1993, p.8)

For many months I lived in what I came to call the coke and smoke syndrome. The first truly proactive step I took in my recovery process occurred at the prompting of my grandmother. Each day she would come into the living room as I smoked cigarettes. She would ask me if I would like to go food shopping with her and each day I would say "No". She asked only once a day and that made it feel like a real invitation rather than nagging. For reasons I cannot account for, one day after months of sitting and smoking, I said "Yes" to her invitation. I now understand that "yes" and the subsequent trip to the market where I would only push the cart, was the first active step I took in my recovery. Other small steps followed such as making an effort to talk to a friend who had come to visit or going for a short walk.

Eventually it was suggested I take a course in English Composition at the local community college and I agreed. Going to college presented me with a whole new set of challenges such as managing anxiety, distressing voices and suspicions during class time as well as finding ways to concentrate in order to do homework. At the time there were no organized self-help and mutual support groups for ex-patients so I was very much on

my own in terms of developing coping strategies. Table 1 lists some of the most important self-care strategies I developed.

Table 1

Some of My Recovery Strategies

- No drugs or alcohol
- Finding tolerant environments
- Relationships
- Spirituality and finding meaning in my suffering
- A sense of purpose and direction; survivor's mission around which to organize my recovery
- Routine
- Day at a time, hour at a time, minutes at a time
- Study, learn, and work
- A willingness to take responsibility for myself and accepting that no one could do the work of recovery for me
- Willingness to do psychotherapy to work through trauma history
- Meeting others in recovery and learning not to be ashamed
- Development of self-care skills:
 - How to avoid delusional thinking
 - How to cope with voices
 - How to cope with anxiety
 - How to rest, pace myself, sleep
 - Prayer, meditation
 - Sensory diet

Through a process of trial and error I discovered self-care strategies that worked for me. For instance, I learned at a young age that street drugs, alcohol and even some over-the-counter drugs such as certain types of cold medications were not good for me. I avoided these and am certain this helped my recovery.

Relationships – especially learning to balance time alone and time with people - have always been an important self-care strategy for me. In the beginning my relationships were quite limited and lopsided in the sense that people tended to care more for me than I did for them. Over time I learned to become more intimate with people and to develop more mutually reciprocal relationships.

Routines were important to me, especially in the early years of my recovery. Sometimes when everything was falling apart inside of me, it was good to be able to rely on routines that would give form and structure to the chaos I was experiencing. Having a sense of purpose, a reason to get up in the morning and a goal to organize my recovery around were important. Studying a wide range of subjects, especially world religions, philosophy and archetypal psychology were helpful in my efforts to make sense of the experiences I was having. My spirituality and faith tradition had always been a resource for me. Spiritual practices and making an effort to have conscious contact with my God became integral to my recovery. My spirituality offered me a way of finding meaning in my suffering and that in turn helped me through feelings of anguished futility, self pity and the inevitable “why me” questions that come with difficult passages.

I find that tolerant environments have always been helpful in my recovery. I discovered this quite accidentally when I moved from a single rented room, into an apartment I shared with a group of ex-hippies. In that environment my roommates were quite open to all sorts of unusual experiences and their world-view included experiences like auras, astral travel, etc. In such a tolerant atmosphere my psychotic experiences were not

viewed as terribly deviant and nobody overreacted. Instead, people were non-intrusive, generally kind and supportive, and they gave me the room I needed to experience my madness. In this tolerant environment I learned that although psychosis does not come with directional signs and maps, it does have a certain terrain and topography. I found that if one returns to the psychotic landscape over time, one can come to know it, to learn not to fear it, and to master ways to navigate through it. Had I been in a halfway house where one must be almost more normal than normal, I fear I may never have learned these important lessons in my self-care and my recovery may have been slowed or prevented.

Learning to tolerate discomfort, anxiety and symptoms meant developing a new relationship to time. I can remember trying to make it through a one hour class and sometimes watching the clock, repeating to myself, "I can make it just one more minute." Each success built my sense of self-efficacy and confidence in my skills to endure and persevere. Also, I learned to tell myself that "tomorrow will come". This phrase took on great significance for me in my recovery. Tomorrow will come meant that if today was too painful, it too would pass. The assurance that a new day would dawn - and with it new possibilities - became a great comfort in my recovery.

People often ask me if medications were a significant part of my recovery. I did not find psychiatric drugs to be particularly helpful except for their capacity to help me sleep during very stressful times. I found the emotional numbing, sexual dysfunction, and overall sluggishness caused by the drugs to be more disabling at times than psychotic

symptoms. The key for me was learning to use medications in conjunction with self-help strategies and overall self-care practices. The more skilled I became in using self-help, the less I relied on medications.

Later in my recovery I became willing to do psychotherapy in order to work through a history of child abuse. This was long and difficult work and I am glad I embarked on it after I had established myself in a meaningful career and had a strong network of friends. I needed to be firmly planted in the present as an adult, in order to look back at the trauma in my childhood. In the course of doing the trauma work I sought out the help of an occupational therapist who specialized in sensory defensiveness in adults. She helped me learn a myriad of coping strategies including use of a sand blanket, joint compression, tactile brushing, and the use of a sensory diet to help me modulate sensory input and affective arousal. These strategies have proved tremendously helpful and are a part of my everyday recovery “toolkit”.

I developed many self-help strategies that made it possible to cope with a myriad of symptoms. For instance, I learned to use headphones and ear plugs to stop the distressing voices I heard. I learned to avoid certain types of situations and subjects that would lead me into the vortex of delusional thinking. Physical exercise, especially daily walks in the woods, remain an important self-help strategy for me. Overall physical health, a good diet, a willingness to pace myself and to get sleep were all important strategies that I learned and refined over time.

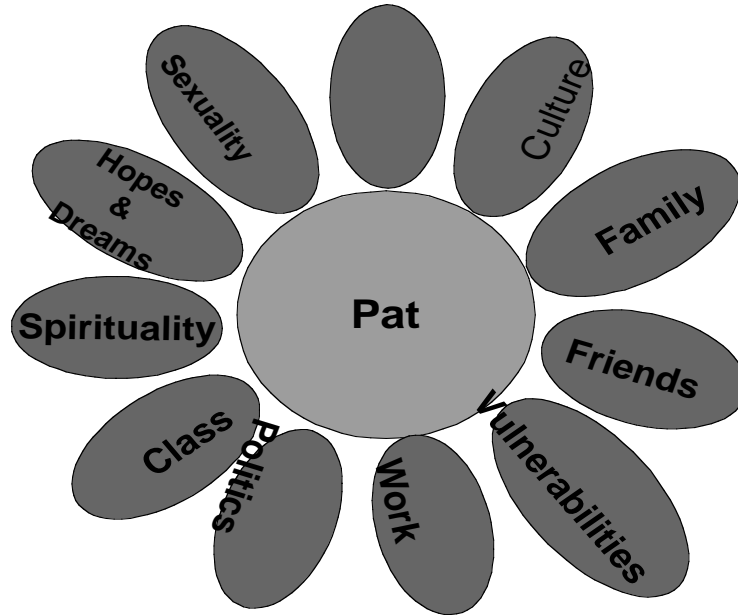
For me recovery meant learning to overcome the shame and stigma I had internalized. Like many people in the early stages of recovery, I saw becoming normal as a goal. I remember going through a phase where I measured my wellness by how little medication I took and how few mental patients I was associated with. In fact, there was a time when I refused to be around people with psychiatric histories. I thought the further I could get away from them, the further I could distance myself from my own history. For many years I settled for simply “passing” as a normal person.

The pressure to remain in the closet about my psychiatric history did not come just from me. There was a good deal of social pressure to keep my psychiatric history a secret. For instance as a student in graduate school there was the unspoken rule that if you had a psychiatric history there was no way professors would allow you to become a clinical psychologist. In the 1980’s, before passage of the Americans With Disabilities Act, I knew of no professionals who were out about having a psychiatric history and I did not feel comfortable being the first. Therefore I hid my psychiatric history and that meant re-living many traumatic memories with no support. For instance, I remember doing my first internship in a state hospital and on the first day having a panic attack when the heavy metal door slammed shut behind me. I can remember freezing in a type of flashback when I witnessed a person being dragged into restraints. Only a few years ago that had been me! Living in the closet meant I had to work through this part of my professional development alone.

I found living in the closet was the same as living a lie. I grew tired of being ashamed. By the time I had finished my doctorate I began to meet psychiatric survivors and activists who had recovered. Meeting these friends was an epiphany for me. They taught me it was not my problem the world insisted I be either a clinical psychologist *or* a mental patient. It was not my problem people insisted I wear one hat or the other in order to make them comfortable. I was a whole person. I was a person with a psychiatric history who was also a clinical psychologist. If the world did not have a category for that, then that was the world's problem, not mine. I did not have to live in the closet so others would feel comfortable. And importantly, I was not alone. There were others like me and if we supported one another, we could lead our lives with pride. Thus, rejecting internalized stigma and learning not to be ashamed of myself was a big step in my recovery process. The illustration below symbolically captures the transformed sense of self I now experience.

Illustration 3

Recovery: I am a Person, Not an Illness



This illustration symbolizes how I have been transformed through the recovery process. The flower is no longer broken as in Illustration 2. My name rather than my diagnosis has resumed its rightful place at the center of who I am. The empty petal has been restored because I have a future that remains ambiguous and unknown and into which I can project my dreams and aspirations. I have used all of the gifts and resources at my disposal to achieve my recovery and so the petals have been restored to the flower.

Notice that one new petal has been added to the flower, vulnerabilities. I do not feel I have a residual mental illness that is in remission and that may get activated at some later time. However, like most people, I live with certain vulnerabilities. I still use my self-

care strategies on a daily basis in order to stay well. I am a person, not an illness. I can use what I have learned through my recovery to continue to lead a whole and vibrant life.

Recovery has been a process of healing and transformation for me. I am not the same person I was before I went crazy. My madness has been a kind of fire through which I have walked and through which I have been changed. There were times in the early years when all I wanted was to go back to who I had been. I wanted to go back to high school and pursue that dream of becoming an athletic coach. I wanted to go back and “feel like myself again”.

This wish to return to the former self is understandable and is called a restitution narrative by Frank (1995). The restitution narrative is a story that some people tell about their recovery. Its basic storyline is: “Yesterday I was healthy, today I am sick, but tomorrow I will be healthy again.” The phrases “good as new” and “I feel like myself again” capture the essence of the restitution narrative. Frank notes that restitution narratives are most often told by people were recently ill and least often by those with long term conditions.

The restitution narrative does not tell the story of the struggling self, but rather is a testament to the expertise of professionals and their technologies that have “fixed” the problem. This type of narrative is the preferred narrative of the medical professions, as well as the powerful interest groups/industries behind medicine. The restitution narrative permeates our culture in a myriad of ways. TV advertisements, infomercials, brochures

in doctors' offices, and drug advertisements in magazines, newspapers and professional journals all tell of the restorative wonders of medications. For instance, in a mainstream psychiatric journal a 1996 advertisement for an anti-depressant drug shows a little girl with a big smile, racing her energetic mom up the stairs in their home. In bright crayon colors, a note from the child reads: "I got my mommy back". Then comes the name of the drug with the middle letter in bright crayon color. The restitution storyline is clear: Depression came, the medicine worked and then this mom was restored to her family as good as new. Through the power of such images and advertising, the restitution narrative has become a cultural expectation of how all illness should end happily ever after.

For those of us who have struggled for years, the restitution storyline does not hold true. For us, recovery is not about going back to who we were. It is a process of becoming new. It is a process of discovering our limits but it is also a process of discovering how these limits open upon new possibilities. Transformation rather than restoration becomes our path.

Transformation narratives emphasize the agency of the self in the healing process as opposed to crediting professionals with curative powers. In this light, the task of mental health professionals becomes one of supporting people and helping them build skills and a sense of agency. Helping people learn to become self-directing as opposed to compliant, is a goal of the recovery process.

Because recovery is a unique journey for each individual, there is no cookbook approach. Mental health professionals must explore the special gifts and resources of each individual and help them mobilize these resources in the service of recovery. Begin with asking people what they already do to cope with various distressing symptoms. In this respect the research of Vaughn Carr (1988) is instructive. He asked 200 people diagnosed with schizophrenia to respond to a questionnaire about how they coped with various symptoms. In addition to the coping strategies identified in the questionnaire, nearly half (n=92) identified other strategies they used. In all, 350 individual coping strategies were identified. Carr concludes that:

“From the foregoing it should appear obvious that schizophrenic patients are not simply passive victims of their illness. On the contrary, these results together with the literature reviewed suggest that in schizophrenia patients can play an active role in the management of their illness, particularly in the containment of its symptoms...The experiences of schizophrenia is evidently a learning process in which patients make active attempts to master the illness and not have it dominate them.” (p.350)

People are more than their diagnoses. People diagnosed with mental illness are resilient and are more than passive victims of disease processes. Professionals who learn to collaborate with the active, resilient, adaptive self of the client will find themselves collaborating in new and rewarding ways with people who may have been viewed as hopeless by others who reify diagnoses and related prophecies of doom.

There is hope for recovery. We can no longer justify the pessimism and prophecies of doom that surround diagnoses like schizophrenia. We now have seven long-term studies that ground our hope for recovery in empirical findings (Bleuler 1968, 1974; Tsuang, M.T., Woolson, R.F. and Fleming, J.A. 1979; Ciompi 1980; Huber, Gross, Schuttler and Linz 1980; Harding, C.M., Brooks, G.W. Ashikaga, T., Strauss, J.S., and Breier, A. 1987a, b; Ogawa, K., Miya, M., Watarai, A., Nakazawa, M., Yuasa, S., and Utena H. 1987; DeSisto M.J., Harding C.M. McCormick, R.V., Ashikaga, T. and Gautum, S. 1995a, b) . The seven studies were conducted in different countries including the United States, Japan, Switzerland, and Germany. Each of the seven long term studies have large cohorts of between 140 – 502 research participants diagnosed with major mental illnesses. The length of study during which the research participants were studied ranged from 22 years – 37 years. The recovery rate in these seven long term studies ranged from 46% to 68%. That is, half to two thirds of people diagnosed with major mental illnesses including schizophrenia were found to show significant or complete recovery over time. Even in the second or third decade after being diagnosed, people still go on to significant or full recovery. We should never lose hope (Harding and Zahniser 1994).

Recovery is not the privilege of a few exceptional clients. We can now tell people the good news that empirical data indicate most people do recover. Since there is no way to predict who will or will not recover, we should approach each person as being able to recover if given sufficient opportunity to build skills and supports. In this way professionals can stop the iatrogenic wounding of hopelessness and begin working with clients on that the transformative journey of recovery.

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