SPEAKING OUT

The Role of Self-Determination in Mental Health Recovery

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Topic: This contribution describes a personal recovery journey and highlights the importance of growth and renewal of self-determination as a critical part of recovery from mental health challenges. Purpose: Five factors that foster the development of self-determination are highlighted and include access to information about treatment and rehabilitation options and resources, support from trusted others, exposure to mentors or coaches who have the lived experience of mental health challenges, willingness to experiment with various interventions and recovery strategies, and opportunities to be engaged in personally meaningful activities such as work, parenting, or teaching. Sources Used: Personal life experiences are shared and resource information is provided as a guide for readers. Conclusions and Implications for Practice: Attention to these factors that foster self-determination by service users, peers, clinicians, teachers, and loved ones may help cultivate self-determination and contribute to the process of recovery.

Keywords: mental health, recovery, self-determination, psychiatric rehabilitation

As a public health professional with the lived experience of mental health challenges, I have often wondered how self-determination contributes to recovery and how it can be promoted within the recovery process. The simplest definition of self-determination is the ability to make your own decisions (Microsoft Corporation, 1998-2007). That includes, but is not limited to, decisions about where to live, what to do with your time, who your caregivers will be, and what intervention strategies they will employ.

Self-determination is linked to self-confidence. The more control you have over the decisions in your life, the more confident you feel in your ability to achieve your goals. The consumer movement has encouraged people to demand that their service providers share decision making with them rather than operating in the traditional “Doctor knows best” fashion. Both physical and mental health challenges, especially the latter, have challenged my self-determination by undermining my confidence in my ability to make sound decisions.

So what fosters self-determination in those of us who face mental health challenges? In reflecting on my own experiences and those of others in the peer community, I have identified five factors that have contributed to the growth of my self-determination:

- Access to accurate and balanced information about potential services and resources
- Support (emotional, physical and/or financial) from others whom I trust
- Exposure to potential mentors/coaches who have the lived experience of mental health challenges
- Willingness to experiment with various interventions and recovery strategies
- Opportunities to be engaged in meaningful activities (e.g., work, parenting, volunteer positions) that can boost self-confidence

An integrated understanding of the importance of these five factors can be provided in terms of Ryan and Deci’s (2000) theory of self-determination. Ryan and Deci posit three innate psychological needs that are the basis for self-determination and optimal functioning: autonomy, competence, and relatedness. As alterations in one’s feelings, thoughts, and behaviors that define the nature of mental illness can impair one’s decision making and lead to reduced autonomy when others step in and take over, minimizing episodes of mental illness and symptom severity is critical to regaining autonomy. Three of the factors listed above address the need to learn effective illness self-management, including having accurate information about interventions and resources, exposure to peer mentors who can serve as role models, and being willing to try different services and recovery strategies.

Just as experiencing the consequences of poor decisions related to mental illness can erode one’s self-confidence, it can also contribute to feelings of incompetence. The fifth factor listed above that facilitates the regrowth of self-determination, access to opportunities to engage in personally meaningful activities, reflects the need to establish a sense of competence in some spheres of one’s life. Finally, aside from the value of social connection, including the need for acceptance and connection with others, in contributing to one’s self-worth and belief in the right to self-determination, the support of others (second factor) is vital to seeking and exploring effective illness self-management strategies, and establishing areas of competence in one’s life. Below, I

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describe my experiences with mental health recovery and self-determination as they relate to the five factors listed above.

Information and Support

I have experienced debilitating depression on two occasions, with each episode robbing me of my self-worth, energy, and hope, and requiring a psychiatric hospitalization. With my first episode, I tried psychotherapy and 12 different medications, all of which failed to help me. I was terrified that I would never get better. Several years before, while working as a mental health worker in a local hospital, I had the good fortune of seeing electroconvulsive therapy (ECT) bring the life back to a woman with profound depression and catatonia. With the hope that ECT might help me, I mustered up my courage to ask my clinical team for it. My clinicians were resistant to my request because they were concerned about the possible side effects of ECT (e.g., memory loss). I asked my husband to advocate with me. Together we succeeded in convincing the team to give me ECT. I had 14 ECT treatments, which successfully eliminated my depression and enabled me to leave the hospital and resume my life with enthusiasm.

Fifteen years later, with the onset of menopause and the death of my beloved mother, I had a second profound depressive episode which came on quickly and led to another hospitalization. Unlike the first time, I felt confident in advocating for ECT myself because I had seen it work before on me. I was pleasantly surprised when the staff immediately agreed to my request. Like the first time, I improved rapidly and was discharged from the hospital after only eight ECT treatments.

When I look back at my two hospitalizations, I realize how lucky I was to have seen someone receive and benefit from ECT. During my first depression, although I had failed to respond to multiple psychotherapeutic approaches and medications, no clinician ever mentioned ECT to me, despite research supporting its effectiveness (Greenhalgh, Knight, Hind, Beverley, & Walters, 2005), and its inclusion in guidelines for the treatment of severe depression (Gelenberg et al., 2010). I believe that mental health professionals have a responsibility to inform people with mental health challenges about the range of intervention options, especially those for which there is scientific support, including biological-based ones such as medication and ECT, and psychosocial interventions such as supported employment, family psychoeducation, illness self-management, cognitive–behavioral therapy, and skills training (Mueser, Deavers, Penn, & Cassisi, 2013). Were it not for my good fortune of having witnessed someone benefit from ECT, and the support and advocacy of my husband, I might never have learned about ECT during my first episode of depression, and may have never experienced the recovery I did.

I had initially thought that my first episode of depression would also be my last. But after recovering from my second episode, I realized that I needed to accept its recurrent nature and learn more about the challenges and other peoples’ experiences using ECT. My first step was to read an influential book on ECT by Dukakis and Tye (2007). This book exposed me to the courageous public figure of Kitty Dukakis who has been very open about her mental health challenges and intervention approaches. I reached out to Kitty to express my interest in meeting other people who had been helped by ECT. She encouraged me to join a support group that she was forming to help ECT patients and their families. I joined ECT: A Light in the Darkness, and for several years I have been an active board member. In the hopes of redesigning negative stereotypes about ECT and expanding peoples’ access to it, this organization provides community education about ECT (see www.ecttreatment.org for more information) and individual support to people undergoing it. Belonging to this “can do” advocacy and support group has enabled me to support others, build meaningful connections of mutual support, and use my lived experience in a valuable way to encourage the self-determination of others.

Access to Peer Mentors

During my second hospitalization for depression, I learned that I had two mental health diagnoses (posttraumatic stress disorder and bipolar disorder 2) that I needed to somehow integrate into my sense of self without having them become my identity (Davidson & Strauss, 1992). Deep inside, I believed that if I had been strong enough, I would have never developed these mental health challenges and hence I thought they were signs of weakness. At the same time, I also felt a strong urge to be more open about my lived experience with others both in and outside the mental health community, but I was worried about how people would react to me.

Fortunately, I learned about and then enrolled at the Recovery Education Program at Boston University’s Center for Psychiatric Rehabilitation which provides rehabilitation services to persons with mental health challenges, and “students,” using an educational approach. Some of the teachers are peers, which gives students the
Willingness to Keep Trying Various Approaches

I have tried many different approaches to managing my health and wellbeing. I have succeeded in finding a number of wellness strategies that I use to complement the medical interventions of ECT and medication. Over the years, I have developed a personal “toolbox” of strategies to keep me well. My toolbox includes adequate sleep, daily exercise, Reiki, meditation, cognitive–behavioral and talk therapies, yoga, and acupuncture.

In reflecting on my wellness tools, I realize that I would never have developed such a variety of wellness strategies without my willingness to try new things. My list includes several alternative/complementary therapeutic modalities, including Reiki, which is the one I think helps me the most. Although I was skeptical about Reiki when someone told me about it 20 years ago, my attitude changed when it brought me substantial pain relief from tendinitis in both my arms. Reiki is an ancient Japanese energetic healing approach, in which a practitioner places hands on a person’s seven energy centers (i.e., chakras) to enhance the flow of energy in the body. Like acupuncture and healing touch, Reiki supports both mental and physical healing, with growing evidence supporting its beneficial effects (Anderson & Taylor, 2011; Joyce & Herbison, 2015; Rosada, Rubik, Mainguy, Plummer, & Mehl-Madrona, 2015; Thrane & Cohen, 2014). After one treatment, I was determined to learn it, and subsequently I became a Reiki student, then a practitioner, and finally a teacher.

Reiki has helped mitigate my physical injuries and pain (e.g., tendinitis, back, knee, and neck) and my emotional challenges (e.g., fear, sadness, anger). Hence, I have worked to bring Reiki to other people with physical and/or emotional challenges. Four years ago, I began teaching Reiki courses at the Recovery Center. As part of their training, my students have held Reiki Clinics for people in the Recovery Center and for the general population. They have spoken passionately about how doing self-Reiki and participating as practitioners in Reiki Clinics has helped their self-confidence and feeling of competence. My experience teaching Reiki at the Recovery Center has strengthened my own self-determination to seek ways to make Reiki accessible to more people with mental health challenges.

Opportunities for Personally Meaningful Activities

The recovery movement emphasizes the value of having supportive social roles (e.g., parent, partner, friend, worker, etc.) for the healing process, especially with people who are flexible in their expectations of those of us in the recovery process (Davidson et al., 2004). In my case, because my mental health challenges and related matters such as stigma came when I was a middle-aged adult, I had already experienced a number of personally meaningful roles and activities. For instance, besides my role as a wife to my husband, I have been helped (and challenged) enormously by my roles as mother and Reiki teacher. My daughter was 12 years old when I was hospitalized with my second depression and I remember how challenging it was to tell her I needed to go to the hospital for depression. Her difficulty believing that I was depressed because of my cheerful manner gave me hope that I would one day again be the cheerful person she imagined. Her counting on me to be there for her got me to fight even harder for my recovery.

In addition to my roles as a wife and mother, my role as a teacher at the Recovery Center (of Reiki and other wellness tools) has been very meaningful for me. Teaching has enabled me to “give back” to others with mental health challenges. Helping others learn how to use Reiki to ground and support themselves and others has helped me find meaning in my own experiences and has contributed to my feelings of competence, value by others, and self-determination.

Conclusions

The growth of my self-determination has been fostered by a combination of supportive relationships, access to accurate information about a broad range of intervention options, a willingness to experiment with different strategies for getting and maintaining wellness, and involvement in meaningful roles and activities. Mental health challenges are an assault on one’s self-esteem and self-confidence. I believe that these can be restored through the growth of one’s self-determination. Attention to these factors by service users such as myself, as well as the clinicians, peers, teachers, and loved ones in our lives can play an invaluable role in supporting our recovery and cultivating our self-determination.

References
