Recovery Through the Perspective of a Service User Researcher

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KEYWORDS
Recovery, Service Users

Service user researchers are equipped with theoretical and experiential knowledge with mental ill health. As a service user researcher who focuses on recovery, my lived experience with mental illness provides me with a unique lens with which I can use to critically reflect on recovery theory; and my theoretical knowledge gained through education provides me with a unique lens through which I can reflect on my recovery journey. Service user researchers have a comprehensive perspective with which they can reflect on theory and their personal recovery stories.

In my role as a service user researcher at a tertiary mental healthcare facility, I have recently become acquainted with a recovery journey framework: The Ladder of Change¹ which is based on the Transtheoretical Model of Change². I was immediately struck with the relevance of this model to my own recovery journey. The Ladder of Change is a framework that breaks down recovery journeys into five stages: 1) Stuck, 2) Accepting help, 3) Believing, 4) Learning, 5) Self reliant³. While on my recovery journey, I progressed through these phases.

When I was eight years old, I was not functioning well. I did not sleep, and if I did, I would wake up screaming. I did not eat, and if I did, I would throw up whatever I was able to ingest. I was not attending school. My life was consumed by the thought of death. ‘What ifs’ overwhelmed me. What if I die? What if my family dies? What if this is it? What if there is no life after death? These unknowns devastated me. My parents watched me as my quality of life declined. My mother says if I had gone another couple of months like that my body would have shut down. Ironic, isn’t it? How my fear of death was slowly killing me? At this point, I was in the ‘stuck’ phase on The Ladder of Change¹ as neither my family nor I knew what to do or why this was happening to me. My family and I felt helpless and did not know where to turn, but my mother knew something had to be done. She felt like she was out of options so she took me to the emergency room. It was at this point that I moved into the ‘accepting help’ phase on The Ladder of
Change as my family and I knew that I could not go on in this state of active crisis and acknowledged the need for professional help. I was then admitted to an adolescent inpatient unit at a local hospital. I stayed there for two nights. I was assessed and then was diagnosed with Generalized Anxiety Disorder. At least this gave us a place to start. I transitioned into the 'learning' phase, where I underwent intensive Cognitive Behavioral Therapy and was put on medication for one year. I worked with a team of social workers, psychologists, and psychiatrists. I also attended group therapy sessions with my parents. This group was called 'Brave Bears' and was for youth undergoing challenges with mental health. The youth were taught strategies on how to deal with mood disorders while their parents learned how to best care for their children with mental health challenges.

After the year of intensive therapy, I was taken off medication as I had acquired sufficient skills to function despite my illness. I continued therapy on a regular basis. My anxiety has never gone away, but I have become an expert at managing it. Since that time, my anxiety has taken many forms. Sometimes it manifests itself as social anxiety, obsessive compulsive thoughts and behaviours, or as cyclical and damaging thoughts. I have had to learn to adapt to these challenges as they arise. Once a year, I would have what I call a blip, which is when I return to the dysfunctional state that I was in prior to my diagnosis. These blips have persisted for years but have become less severe and less frequent as time goes on.

By the age of 17, I believe I had undergone clinical recovery but not personal recovery. Personal recovery from mental illness differs from clinical recovery in that it focuses on hope, purpose, and a meaningful life ‘despite’ the symptoms and challenges associated with the illness. Personal recovery occurs in the context of one’s life; and although my symptoms were managed, I lacked two things essential for personal recovery: hope and identity. Although I was effectively managing my symptoms and functioning, I lacked hope for the future as I felt that re-admission to a psychiatric ward was inevitable. Also, I lacked a sense of identity as mental health challenges during adolescence had disrupted my healthy development. Reflecting now on my journey, I realize that I had not engaged in the 'believing' phase on The Ladder of Change. This is the phase in which individuals with mental illness start to hold hope for personal recovery. This lack of personal recovery is what I feel led to my next challenge, depression.

When I was 18, I was working in a labour-intensive job where I was alone most of the time and not intellectually challenged or stimulated. Combined with social challenges and life transitions, I began to lose my lust for life. My self-esteem was very low and I felt worthless. My life felt pointless. I lost interest in my favourite activities and no longer wanted to get out of bed. It was at this point that I was diagnosed with depression. Depression and anxiety interact in a challenging fashion. On one hand, I had no motivation to do anything; but on the other hand, my fear of death made me feel as though I was wasting the precious time I have on this earth. This internal conflict resulted in a vicious cycle where more depression led to more anxiety and vice versa. I was put back on medication and continued working with my care team to tackle this new challenge.
I am confident to report that I am now, at the age of 22, in a state of personal and clinical recovery. There are multiple things to which I attribute my recovery. Reflecting on my recovery through a research lens has helped me identify and make sense of the components of my journey that have led me to my current state. The CHIME framework is a recovery model that I have found to be particularly relevant to my personal experience. The CHIME model was developed based on a systematic review of the personal recovery literature and includes the following domains: 1) Connectedness; 2) Hope and Optimism for the Future; 3) Identity; 4) Meaning and Purpose in life; and 5) Empowerment. I am well versed in the application of this theory in that I have intimately experienced it firsthand.

The 'connections' that make up my support system have been integral to my personal recovery. My support system includes the social workers, psychologists, and psychiatrists I have worked with over the 14 years I have been in treatment. They have taught me strategies that I can use so that I can function and thrive despite my illness. In addition, they have taught me to challenge my anxiety and depression and think in new ways. My family is also an integral part of my care team. They educated themselves by reading books, attending support groups, and consulting others on how to best cope with having a child that is struggling with mental illness and how to best support me. They held hope for me when I could not hold it for myself. I used to think that re-hospitalization was inevitable. My family helped me identify goals and supported me in achieving them which allowed me to see the possibility of recovery. Finally, my 'connections' within my community have supported my recovery. I have been and continue to be involved in a variety of extra-curricular activities including horseback riding, the Youth Advisory Council at a local hospital, and volleyball leagues just to name a few. The connections that I have made through these activities have helped me develop a sense of 'identity' as the roles I play in all of my relationships have allowed me to become the engaged, caring, active, and intelligent young woman that I feel I am today. These ‘connections’ have also given me a sense of belonging and helped me to realize that I am not alone. Specifically, horseback riding had played a significant role in aiding my recovery. It has allowed me to 'connect' with animals, other people, and nature. I developed 'meaning' in my life as I was responsible for the horse’s care and wellbeing.

More recently, taking my care into my own hands has been an ‘empowering’ development in my recovery journey. By doing independent research, I have been able to identify therapeutic avenues and interventions that are best suited to my needs. This has ‘empowered’ me to take my illness into my own hands. My new-found control has given me the 'hope' of recovery and allowed me to identify recovery related goals.

I am now graduating university and was captain of the university equestrian team, I worked as a Youth Advisor for the Canadian Armed Forces, received a Commanding Officer’s Commendation, was awarded university equestrian rookie of the year and most valuable player, am a prospective Master’s student; and I am currently a Lived Experience Co-Investigator/Research Assistant. My 'identity' is shaped by this role, and
it has provided my life with 'meaning' as I am fulfilled by the work that I do and the positive impact that it has on others with mental illness. I have achieved the final phase on The Ladder of Change which is 'self reliance'\textsuperscript{1}. Despite challenges with my mental health, I now see myself as a thriving young woman with a bright future.

I have undergone post-traumatic growth in that my mental illnesses may have held me back temporarily when I was in active crisis, but now I consider it a blessing in disguise. The help that I received along my recovery journey has inspired me to dedicate my life to working to improve the mental healthcare system through research pursuits. I am currently using my lived experience, passion for mental health, and research skills in my role as a Lived Experience Co-Investigator/Research Assistant.

In my current role, I am very willing to disclose my lived experience. Since entering my state of recovery, I have felt as though it is my duty to break down stigma and show people that individuals with mental illness can be successful and that recovery is possible. I have had positive experiences sharing my lived experience with colleagues and patients as I am shown respect for leveraging my lived experience in a professional setting. I have found that I am afforded instant credibility due to my experiential knowledge; and people appreciate the unique blended perspective I bring to the table.

It is becoming increasingly evident that academic research in mental health represents a single perspective on mental healthcare\textsuperscript{7,8}. As a result, service user researchers have been increasingly involved in collaborative research in the past two decades\textsuperscript{9,10}. This shift has allowed for the development of new knowledge and research methods\textsuperscript{10}. Service user researchers are increasingly being involved in the design, development, implementation, delivery, and evaluation of mental healthcare services\textsuperscript{11}. I have been invited to work on a variety of multi-disciplinary teams because, as a service user researcher, I am in a position to influence and enhance the quality of the research by improving the relevance and the significance of the research through the inclusion of a lived experience perspective\textsuperscript{9,11,12}. This dual perspective that is comprised of theoretical and experiential knowledge is extremely valuable as both perspectives play an integral role in determining the quality and effectiveness of mental healthcare services\textsuperscript{11}.

Service user researchers contribute to the quality of the research in many ways throughout the research process. When planning research, service user researchers have a unique perspective that allows them to assess the relevance and practicality of research\textsuperscript{12}. Service user researchers can also enhance the quality of the research by heightening consciousness around how the methodological choices being made will affect service users and practice\textsuperscript{12}. When service users are involved in research from the outset and are seen as partners in co-production, they can improve the relevance, generalizability, reliability, and overall quality of the study\textsuperscript{13}. In the data collection phase, previous studies have shown that participants being interviewed by service user researchers feel more relaxed and feel that they are able to divulge more information\textsuperscript{14}. Service user researchers can also create a shared language between researchers and service users and promote an increased understanding of the research project for
participants and an increased understanding of participants responses for researchers\textsuperscript{12}. In addition, service user researchers are increasingly being used to inform methodology and as data collectors but are less likely to be involved in the data analysis phase of research projects\textsuperscript{9}. Research has shown that service user researchers can enhance the quality of data analysis through multiple coding which involves individual analysts discussing their interpretations of the data to understand the similarities and differences between their perspectives\textsuperscript{9}.

Although the value of service user researchers is becoming increasingly evident, there is still a significant amount of work to be done in integrating them into the mental healthcare workforce. For example, I am the first and only identified service user researcher employed by the tertiary mental healthcare facility where I currently work; and this facility is known as an international leader in the implementation of recovery oriented practice. Despite the evidence of the value that service user researchers add to the quality of mental healthcare research, there are still many barriers to fully integrating and accepting them into the research process\textsuperscript{11}. Barriers include stigma that is held by mental healthcare professionals\textsuperscript{15} and beliefs that experiential knowledge lacks the perceived objectivity and rigour of academic knowledge and research\textsuperscript{11,16}. In addition, large power imbalances are prevalent between the academic researchers and service user researchers, which makes equitable collaborations difficult to achieve\textsuperscript{11}.

There are many ways to facilitate the integration of service user researchers into mental healthcare research. A practice that has been found to break down barriers associated with the full integration of service user researchers is allyship\textsuperscript{11}. Allyship occurs when an individual in a position of power facilitates the implementation of opportunities for service user researchers to become actively involved in research and serves as an advocate for service user researchers\textsuperscript{11}. Allies can influence their peers and spark a culture change to one that leverages lived experience\textsuperscript{11}. Also, connecting service user researchers to each other is a powerful way to counter professional isolation and facilitate the development of new collaborations\textsuperscript{11}. Finally, co-production is a way to dismantle power differentials and give those with less power in the relationship the opportunity to have more influence\textsuperscript{13}. When engaging a service-user researcher, co-production should involve this individual by using their perspective to enrich mental health services and their outcomes\textsuperscript{13}. I propose that mental health research could be enhanced through the further integration of service user researchers. Researchers in mental health who have undisclosed lived experience, could openly, and voluntarily leverage their lived experience to enhance the quality of their work by providing two perspectives, that of the researcher and that of a service user.

I am excited to be a part of the early shift toward service-user researcher integration in Canada. Meaningful integration of a lived experience perspective into research has the potential to increase applicability of research to service, ultimately enabling shifts in mental health services that better address the needs of service users and improve service delivery and outcomes in a timely manner.
Acknowledgements

The author declares no conflict of interest.

References