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UMI

Recovery from Mental Illness – The Experiential Perspective

by

Jean Laforge

A Thesis

Submitted to the Faculty of Graduate Studies

through the School of Social Work

In Partial Fulfillment of the Requirements

for the Degree of Master of Social Work

at the University of Windsor

Windsor, Ontario, Canada

2009

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Abstract

The purpose of this study is to explore what recovery means to people who have had personal experiences with mental illness. A qualitative design using exploratory and descriptive approaches was used. Two focus groups consisting of seventeen participants were asked questions about their recovery process. The data were categorized and themes emerged from the analysis.

This thesis will discuss the four themes that emerged: recovery means stability and growth in a meaningful way; recovery includes a process of self-actualization supported by both natural and professional supports; barriers to recovery; and, facing barriers using steps towards recovery. The findings elaborate on what stability and growth mean to people with a mental illness, the barriers they face, and the steps they believe are necessary to live a meaningful life. This study also discusses the implications for social work practice.

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CHAPTER 1

Introduction

In the mental health system, recovery is a term that has many meanings. Anthony (1993) envisions the 1990s as the decade of recovery and indicates that people with mental illness require more than symptom relief. Some people may be satisfied with symptom relief while others are not. People require opportunities to live a meaningful life. The primary goal of this study is to understand recovery from the perspectives of people who have lived with mental illness.

Based on information from this study, people struggle with stabilization and self-actualization; they face challenging barriers that prevent them from moving forward; and they have to find resources and take steps to overcome the barriers. This study focuses on the self-reported ways in which people can live a meaningful and fulfilled life while living with a mental illness. From the data analysis, four main themes emerged and will be presented in this study.

To understand the magnitude of mental illness, it is estimated that one in five people in the province of Ontario live with a mental illness (Bay, 2003). According to reports from Statistics Canada (2006), the population in Ontario is more than twelve million people where most people live in a society where opportunities such as a healthy lifestyle, employment, and family and friends can be enjoyed. However, for the one fifth of the population who live with a mental illness, those opportunities may not be their reality. Their daily reality may be social isolation, poverty, and social and self-stigma. According to Crosse (2003), the majority of those living with a mental illness may have lost essential life roles that normally provide self-esteem and meaning. It may be

challenging, however, with the appropriate supports and services, people can try to regain what was lost.

History

People living with a mental illness have suffered severe consequences as a result of their illness. With the introduction of psychotropic medications in the early 1960s, people became deinstitutionalized from psychiatric hospitals (Newman, 1998). While medications did not provide a cure, symptoms were reduced or controlled as people moved back into the community.

Since the 1990s, the Ministry of Health and Long Term Care has placed a priority on transforming the mental health system which included enhancing the provision of services in the community. Although much has been done in the area of mental health, much more remains to be done to improve the system and provide a more meaningful life to people living with a mental illness.

As well, further research is needed in the area of mental illness and the lived experience. This area of research is important to the researcher for reasons listed below.

Epistemological Positioning

Epistemological positioning attempts to explore linkages and helps us to determine how we know what we know (Patton, 2002). Our individual life experiences, values, education and biases combine to help shape our personal views and eventually impact on how we know what we know.

My epistemological positioning comes from two different perspectives. One is the personal experience of being a family member of a person who had a severe and persistent mental illness, which has made me aware of the losses that can take place in

the life of a person living with mental illness, even the loss of their own life. People can live a tormented life without knowing how to change it. Instead of accepting support, some tend to push people away when it appears that they need help the most. Family members also suffer in silence when they can't access resources to help their loved ones.

The other perspective is that of Executive Director of an agency that provides psychosocial services to those with mental illnesses. The ability to provide services that are effective and supportive may mean the difference in whether people can live a meaningful life. The organization approaches support from a person-centered perspective building on members' existing strengths and helping to maximize their potential. The information from this research will be helpful in this regard.

In some agencies, service provision comes with minimal risks. In mental health agencies, however, service provision may come with huge risks, because agencies are dealing with fragile lives. The imperative of minimizing the risk, and maximizing the potential of people living with a mental illness cannot be overstated. The individuals who come for services are someone's husband, wife, son, daughter, mother, father or someone else who has significant meaning in their lives. They are people with feelings and emotions who once had meaningful lives with people who loved them and are now trying to rebuild that kind of life. Learning to look beyond the behaviour to find the essence of a person with a mental illness can help bring meaning back into their lives. Every life is sacred and deserves respect and dignity no matter how far the person falls into the depths of despair.

About The Study

The goal of this research paper is to better understand recovery from mental illness based on the experiential perspectives of people who live with a mental illness.

The paper will begin with the theoretical framework used in this study and a literature review focusing on relevant topics regarding mental health and recovery. The next chapter will cover the methodology section, including design, sampling, data collection and data analysis. The results will be presented in the chapter following which will discuss the four themes that emerged from the analyses of the data. The final chapter will include the discussion section which elaborates on the results and concludes with Implications for Social Work, Practice and Policy, Future Research and Conclusions. The Chapters will be followed by a list of references.

It is hoped that this study will be of interest to other mental health professionals (in particular, the profession of Social Work) and be instrumental in providing people with a mental illness opportunities to live a more meaningful life. It may also be of interest to other consumers who can understand what recovery means to their peers and how the information contained in this study may impact on their own lives.

CHAPTER 2

LITERATURE REVIEW

Theoretical Framework

The theoretical framework used for this qualitative study is based on the holistic (mind/body) bio-psychosocial (biological/psychological/social) understanding of mental health and recovery perspectives. According to Domback (2006):

the biological theory helps understand how the body and brain are constructed and affected by disease and medicine; the psychology theory helps understand how minds develop and operate, how thoughts and feelings work and how behaviours and attitudes can be changed; and the sociology/social work theories helps people develop an appreciation for the social systems in which people live and the impact these systems have on their group and individual health.

In this study, the researcher's goal is to explore the meaning of recovery from the lived experience. According to Dilthey (1985), a lived experience is a subjective experience and in its most basic form "involves our immediate, pre-reflective consciousness of life." The word "experience" has been observed by Gadamer (1975) as meaning: "If something is called or considered an experience, its meaning rounds it into the unity of a significant whole" (p. 60). What makes the experience unique so it can be reflected on and talked about is what gives the experience its central idea or dominant theme (Dilthey, 1985). In other words, people assign their own meaning to their own experiences.

Understanding the literature from the “learned experience” to the “lived experience” should provide a specific level of knowledge. According to Charmaz (2006), theorizing allows theory to flow from the data collected. Reviewing the literature and becoming aware of the perspectives from the “learned experience” to include the “lived experience” may add another dimension to the perspective of recovery from mental illness as discussed in this chapter.

The interrelationship of the biological, psychological and social aspects of developmental psychology forms the essence of the holistic biopsychosocial perspective. This perspective attributes complex phenomenon to multiple causes which is in contrast to the reductionistic perspective which reduces complex phenomenon to a single cause (Borrell-Carrio, Suchman & Epstein, 2004). These perspectives could be related to the holistic approach comprised of numerous methods of recovery which help people to live a meaningful life versus the medical approach which is based on the single approach of symptom relief.

Background

The purpose of this study is to understand the meaning of recovery from mental illness based on the perspectives of people who have experienced mental illness. According to the literature reviewed on recovery from mental illness, recovery is generally based on two different models, the medical model and the holistic model. Although much has been written about recovery from many different perspectives, there is not a lot of consensus about the nature of this phenomenon (Young & Ensing, 1999).

Medical Model

The medical model focuses on symptoms, medication and managed care (Brown, Rempfer & Hamera, 2008). Fisher (2008) views this model as seeing mental illness as a primary, permanent impairment. The goal in the medical model, according to Anthony (1993), is relief of symptoms treated solely with medication prescribed by the doctor with a goal of lifelong treatment and maintenance of the condition and minimal possibilities for recovery. According to Deegan (2007), much of the treatment and support delivered by service providers is based on the medical model, which means to her that the doctor is considered to be the expert and the patient complies with the directives from the doctor to relieve symptoms.

Personal Experiences - the Medical Model

When Patricia Deegan was first diagnosed with schizophrenia at seventeen years of age, she was told by her psychiatrist that she would not recover from her illness and would have to take medication for the rest of her life. "I was given a diagnosis of doom and gloom" (Deegan, 2007, p. 62).

In Mead and Copeland (2000), Mary Ellen Copeland discusses how she was told that she would have to live with the symptoms and take medication for the rest of her life.

Holistic Model

The holistic model focuses on the whole person, both mind and body, based on the lived experiences of people with a mental illness (Brown et al. 2008). It understands the goal of recovery as living a full and meaningful life. Based on the holistic view, clients have expertise by virtue of the lived experience of their disorder and their own intimate knowledge of what gives meaning, purpose and quality to their lives (Deegan,

2007). As an example, Deegan explains that in spite of her diagnosis and the barriers she had to overcome, she found ways to cope and supports that helped her live a meaningful life. She eventually went back to school and obtained a Ph.D in Clinical Psychology.

In Mead and Copeland (2000), Copeland states that she complied with medication as a sole method of treatment and after ten years, she developed severe stomach problems from the medication and could no longer take the medication. She reported having to learn new ways to cope in order to find relief from her symptoms in order to live a meaningful life. As she started to find relief from new coping mechanisms, she wondered why she had to wait ten years for that effective medication that never came.

According to Sullivan (1994), in order to enhance the holistic model of recovery, personal experiences are crucial in order to guide the vision of mental health professionals into the twenty-first century. Bassman (2000) believes that the unique insights and experiential accounts of persons with a mental illness are usually outside the realm of academically trained staff. Therefore, it is necessary for the system to work together with people and their personal experiences to assist them to lead full and meaningful lives.

The newer recovery models are challenging the older, pessimistic view of psychiatric disabilities through the use of experiential accounts and empirical evidence (Brown et al. 2008). Throughout history, under the pessimistic view, people with mental illness were confronted with many challenges.

History of Mental Illness

Sue, Sue and Sue (1990) discuss some of the history of mental illness going back 2,500 years when Hippocrates, a Greek physician, discussed disorders and imbalances of

the brain. His philosophy about treating people with a mental illness was very humane. However, during the middle and dark ages (thirteenth to fifteenth centuries), people with mental illnesses experienced devastating consequences because it was believed that mental illness was caused by supernatural forces. Witch hunts occurred and people were tortured, burned at the stake and murdered.

The seventeenth to the nineteenth centuries focused on more humane treatment and reform when some key people tried to implement change in the system; however, only minor improvement occurred. Conditions were still deplorable and people were warehoused in insane asylums and there was little understanding about the persons or the illnesses (Sue et al. 1990). These deplorable conditions desperately needed to change in order to allow people to have more control over their care and treatment. It took more than a century for those changes to finally happen.

Changes to Policy and Legislation

According to Newman (1998), the first asylum in Ontario was opened in 1850 and housed people with a mental illness. Under this system, patients had very few rights. They did as they were told and those who didn't suffered severe consequences. This system continued until the mid 1930s (Bay, 2003). As a result of this type of treatment, public pressure and the media brought attention to the predicament of people in institutions. Finally, it was acknowledged that treatment in institutions was not meeting the needs of people with mental illnesses (Anthony, 1993; Rapp, Shera & Kisthardt, 1993).

In the late 1960s, deinstitutionalization started to occur in Ontario and, in 1968, the Province of Ontario finally approved revisions to the Mental Health Act, giving more

rights to people with a mental illness (Bay 2003). This was a major step forward in the transition of the mental health system, but more changes were still needed.

Another major development occurred in the mental health system with the introduction of the Ontario Hospital Insurance Plan in 1972, as more people started to have access to health care coverage (Newman, 1998).

As people began to live in the community, thought had to be given to how services would be organized and delivered to meet these new needs through community support (Anthony, 1993). With community support systems in place, drastic changes started to occur and it appeared that social adjustment improved and there were fewer rehospitalizations (Test, 1984).

When the Canadian Charter of Rights and Freedoms became law in 1982, it was the beginning of a whole new era for people with a mental illness. A mechanism was put in place to address the long standing injustice and discrimination against people with a mental illness. Discrimination for any reason was prohibited and people had a right to participate in their own treatment (Dykeman, 2003).

Continued changes included the Patients' Bill of Rights which was introduced in 1983. Its purpose was to serve as one of the checks and balances to help equalize the imbalance of power that existed between the mental health system and the person with mental illness (Simpson, 2003). This was a small part of the broader change that was finally happening.

In the 1990s, a series of reports were requisitioned by the Ministry of Health and Long Term Care (MOHLTC). Action on these reports further enhanced mental health reform in Ontario by creating a system that was supposed to be accessible, integrated,

comprehensive and accountable (MOHLTC, 1999). The MOHLTC believed itself to be on a clear path of providing optimum community support.

As transformation of the mental health system in Ontario continued, patients and their families were supposed to be placed at the centre of the transformed system. People with a mental illness would now have a right to the same quality of health care as anyone else in the province (Wilson 2003).

Although changes were occurring, it took time for people to become aware of their rights and options for treatment under the transformed system and for service providers to change along with the philosophical changes. When people become aware of their rights, they know what to expect from the system (VanKruistum, 2003).

Recovery was shifting from relief of symptoms to being able to live a meaningful life.

Recovery Model

The 1990s became known as the decade of recovery, which signified a paradigm shift from a predictable and deteriorating illness to a potential for recovery (Anthony, 1993; McGrath & Jarrett, 2004). Under the old paradigm, the expectation was lifelong treatment and maintenance of the condition. With the transformation of the mental health system, it is now being recognized that persons with a mental illness can live a meaningful life with adequate resources (VanKruistum 2003).

As the concept of recovery began to further evolve, a more balanced, comprehensive recovery service based more on community treatment started to be delivered by community agencies (Prowse & Carpenter, 2003). The recovery model has made great strides in the movement toward client self-determination, empowerment and independence despite the fact that the medical model is still actively used (Walker, 2006).

As the holistic model continues to evolve, it is important to focus on the perspectives of people who have lived with mental illness who can share their view of recovery which is the purpose of this study.

Definitions and Views of Recovery

Many different versions of recovery soon emerged (Anthony, 1993). Some people view recovery as medically focused, (i.e. relief of symptoms), others view it in a more holistic view (i.e. focus on the whole person). In reviewing the literature, many views and concepts of recovery were found. Anthony (1993) defines his vision of recovery as:

a deeply personal, unique process of changing one's attitudes, values, feelings, and goals, skills, and/or roles. It is a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life (p. 15).

Although Anthony does not focus on symptom relief, he does note that recovery does not necessarily mean that people will return to their previous level of functioning.

This vision of recovery is also shared by Deegan (1995) who defined recovery as a self-directed process of reclaiming meaning and purpose in life, rather than meaning a cure or stabilization. She believes that recovery can be a slow, ongoing process which involves a transformation of the self where one can accept the realities of the illness and discover a new self-understanding.

Walsh (1996) defined recovery as "a deeply personal and unique process of changing one's attitudes, values, self-concept and goals - it is finding ways to live a hopeful, satisfying, active and contributing life" (p. 87). He believes that in difficult

times it is easier for people to give up and blame themselves. However, through participating in the holistic approach to recovery, he reports that he found the hope and encouragement to maximize his potential and returned to school to work on his doctorate. Walsh states that accepting his limitations gave him the power to live a more satisfied and successful life and, he states, although he is not a finished product yet, he has the ability to move toward wholeness.

Hatfield and Lefley (1993) view recovery as “a process of adaptation at increasingly higher levels of personal satisfaction and interpersonal functioning” (p. 141). However, Mead and Copeland (2000) view recovery as a personal choice which may have different meanings to each person experiencing it. Some may take a medical view focusing on symptoms and medication, others may take a more holistic view, focusing on their strengths and potential.

The World Health Organization deems insight as one of the important components of recovery and defines it as “the patient’s capacity to acknowledge some awareness of having an emotional illness” (Greenfield, Strauss, Bowers & Mandelkern, 1989, p. 246. Amador, Strauss, Yale, Flaum, Endicott & Gorman (1993) also stress the importance of insight and note that poor insight relates to poor treatment compliance which affects the course of the illness. Podvoll (1985) also argues that gaining insight is important but conceptualizes it as a series of stages that are characterized by moments of clarity and insight into one’s psychopathology.

Concepts of Recovery

Some central concepts of recovery reviewed in the literature and elaborated further include empowerment and personal responsibility.

Empowerment

Corrigan (2004) describes empowerment as a measure of control people with experience of mental illness have over all areas of their lives. Corrigan states that this measure includes two components – one involves positive self-regard and the other involves the desire to have a positive effect on one's community.

This concept is viewed by Fisher (1994) and Lawson (1994) as increased self-confidence, self-reliance, sense of personal control and self-esteem. Their belief is that empowerment can help people to develop positive coping skills, reduce stigma and give people the motivation and the willingness to take more personal risks.

Jacobson and Greenley (2001) state that a sense of empowerment includes both internal and external factors and has three components. The first is autonomy or the ability to act independently which would mean having knowledge, self-confidence and being able to make meaningful choices. The second is having courage including a willingness to take risks, speak out and step outside of the comfort zones. The third is personal responsibility. External factors are referred to which include recovery oriented services and a positive environment in which people can heal. The results from their study suggest that a combination of both internal and external factors is necessary for recovery.

Jacobson (2001) discusses empowerment as a similar four part process of recovery, consisting of recognizing the problem, transforming the self, reconciling the system and reaching out to others. In a study by Piat, Sabetti and Couture (2009), consumer-survivors refer to empowerment as resourcefulness and resilience. Ahern and

Fisher (1999, 2001) also assert that through empowerment, full emotional recovery is possible for everyone.

There seems to be agreement in the literature that empowerment includes both internal and external factors and is instrumental in recovery.

Personal Responsibility

Another concept discussed in the literature and considered by some to be a component of empowerment is personal responsibility. Mead and Copeland (2000) indicate that it is up to each individual to take responsibility for their wellness. If necessary, they state, it is helpful to work with health care professionals to achieve this goal. Young and Ensing (1999) state that reports from participants in one of their studies indicate that taking responsibility for one's own behaviour and problems was part of taking control of one's life. This meant "recognizing self-defeating behaviours and making a commitment towards growth and self-accountability" (p. 8).

In a personal account by Leete (1989, p. 1), she also states that "taking responsibility for my life and developing coping mechanisms has been crucial to my recovery." This concept is also postulated by Breier & Strauss (1983).

Processes of Recovery

Some processes of recovery that have been found in the literature regarding recovery and elaborated on in this literature review include: awareness, forgiveness, belief in oneself, hope, and seeking support of others.

Awareness

Breier and Strauss (1983) discuss awareness and support the idea that some people can take control over their symptoms which they claim is done in a three phase

process of self-monitoring. This three phase process includes awareness of symptoms and behaviour; self-evaluation which includes the implications of the behaviour; and the ability to use self-control. Leete (1989) and Lovejoy (1984) also support the idea of self-monitoring as a state of awareness.

A study by Young and Ensing (1999) seems to have similar findings where, although participants reported that acknowledging and accepting the illness is admitting the need for help which could mean a loss of control and independence in their lives, they reported having to make peace with their condition and accept the illness as a fact of life before moving forward. Considering the idea that the future can be different, one first has to develop the awareness that change is possible (Onken, Dumont, Ridgeway, Dorman & Ralph 2002).

Mead and Copeland (2000) state that once people become aware of their illness, they work at their own pace and consider the options available to them for change.

Forgiveness

Because of low self-esteem, hurt can be experienced and the other person may not even be aware there is an issue. Walsh (1996) states that during difficult times, it is easier to blame oneself and give up because of low self-worth.

Worthington, Berry and Parrott (2001) believe that the comprehensive nature of forgiveness involves both health and mental health and has both direct and indirect effects. The direct effects deal with the ability to forgive and involve feelings and emotions of resentment, bitterness, hatred, residual anger and fear. The ability to forgive is thought to be associated with personal control in one's life (Benson, 1992). The indirect effects involve mental health through such variables as social support,

interpersonal functioning and health behaviour (Temoshok & Chandra, 2000; Worthington et al. 2001). In further studies by Toussaint, Williams, Musick, and Everson (2001) forgiveness of self and others was shown to be associated with less distress and a greater sense of well being.

According to Richmond (2009), bitterness acts like a mental poison that only hurts oneself. If issues in a relationship cannot be resolved, whether intentional or not, if there is no forgiveness, it will drain one's strength and prevent or slow down growth and healing. While the review of the literature supports forgiveness as having a positive outcome from the ability and willingness to forgive, the inability to forgive can lead to resentment within the person and affect relationships with others, preventing people from moving forward to have a meaningful life.

Belief in Oneself

Belief in oneself was supported in the literature by Chamberlin (2008, p. 3) who stated that "one of the elements that make recovery possible is the regaining of one's belief in oneself." This was also supported by Borg and Davidson (2008) who found that in addition to believing in oneself, having the belief and faith of other people was valuable and meaningful.

Hope

Jacobson and Greenley (2001) indicate that hope is a frame of mind that colours every perception and it is hope that leads to recovery. They state that the first step to recovery is when individuals believe that recovery is possible because hope creates its own possibilities and can begin the healing process.

In a study done by Young and Ensing (1999), participants report that seeking out a source of hope helped motivate them to change. Prayer and spirituality were reported to be among the sources of help for people to survive even in severe crises. Deegan (1996) states that hope is the alternative to despair and discusses the importance of creating environments that are filled with hope which will nurture growth and recovery. She further discusses (2001) how prayer and spirituality, as components of hope, offered her a way to find meaning in her suffering. Mead and Copeland (2000) state that many people become victims of mental illness because of internalized messages of hopelessness. They believe that “a vision of hope includes no limits” (p. 4)

Seeking Support

Seeking support from others is a process of recovery agreed upon by many (Breier & Strauss, 1983; Cohen & Berk, 1985; Deegan, 1988; Leete, 1989; Lovejoy, 1984; Walker, 1986). Leete (1987) also believes that while hospitals and medicine have a place in treatment and stabilization, community based programs are more successful in the long term because of the flexible environment in which people can rebuild their lives. This is supported in a study done by Young and Ensing (1999), where one of the findings reported by the majority was that relationships with other peers were more meaningful and supportive than relationships with family members. This supports the belief of Davidson, Chinman, Sells and Rows (2006a, p. 443) that people who “have faced, endured, and overcome adversity can offer useful support, encouragement, hope and perhaps mentorship to others facing similar situations.”

Social support systems as defined by Caplan (1974) reported in a study by Hatfield and Lefley (1993, p. 80) are “attachments between and among individuals that

promote mastery of emotions, offer guidance, provide feedback, validate identity and foster competence.” Anthony and Blanche (1989) relate social support to psychosocial rehabilitation and clubhouse programs which reduce rates of hospitalization. Greenley (1984) argues that research findings consistently indicate a link between higher levels of social support and lower levels of psychological distress.

This would also be supported by VanKruistum (2003) who concludes that with the transformation of the mental health system, it is now being recognized that persons with a mental illness can live a meaningful life with adequate resources.

Recovery Using Combined Treatment

Medication in the recovery process was discussed and the literature on holistic approach to recovery supports a combination of medication and other supports. This combination is the personal choice of the person during a shared decision making process. According to Fisher (2008), the goal in the holistic view of recovery is a combined treatment approach aimed at regaining a greater sense of well being either with or without medication. Fisher further states that this approach is based on the decision of the individual depending on the nature of the illness, to assist people to regain control of their lives and to have valued roles in society.

Mead and Copeland (2000) indicate that taking medication is a choice and do not recommend it as the only form of treatment. Deegan (2001) states that she learned to use medication in conjunction with self-help and self-care strategies and says the more skilled she became in using self-help, the less dependant she became on medications. She refers to medication as “pill medicine” and self-help as “personal medicine” and indicates that

pill medicine must complement and support personal medicine which is what gives purpose and meaning to one's life (Deegan, 2007).

Barriers to Recovery

Social Stigma

According to Webster's Dictionary (1991), stigma is defined as a mark of disgrace. Stigma exists because of ignorance, prejudice and discrimination (Martin & Johnson, 2007). Many studies have found that the public views people with mental illness as being responsible for their illness because of character flaws or lack of moral backbone (Corrigan and Watson, 2004). Weiner (1995) argues that the stigma of blaming someone for having a mental illness, which is a negative life condition, leads to anger and social avoidance. The effects of stigma limit opportunities for people with a mental illness in areas such as: income, housing, employment, education and medical care. These factors are considered to be social determinants of health for all people by the World Health Organization (2008) who refers to them as conditions in which people are born, live, work, grow old and participate in the health care system.

According to Raphael (2004), social determinants of health can influence people's ability to cope with their environment, fulfill their needs, identify and achieve their goals. As a result of the inability to obtain the basic necessities of life, people's self-esteem can be lowered. This point is consistent with a view from Link and Phelan (2001) who states that stigma attached to mental illness can have lasting effects and result in low self-esteem.

According to Clausen (1981), the uncertainty of a person's ability to function on a daily basis and their fear of rejection creates a significant barrier to social participation.

While people's tendency to cope with stigma through avoidance, withdrawal and secrecy is common, it may result in lost opportunities for education, employment and housing (Link, Mirotznik, and Cullen, 1991).

In a discussion paper (MOHLTC, 2009), the Ministry of Health and Long Term Care suggests that the same opportunities for income, employment, housing, education and lifestyles should be available to people with a mental illness. However, often times stigma, poverty and other barriers in society over which people have no control create inequities for people with a mental illness. This may cause people to isolate and lose hope, thereby being deprived of the opportunity to live a meaningful life. As quoted by Deegan (1995, p. 7), "Healing from mental illness is the easy part, it is healing from the effects of poverty and second class citizenship which is more difficult."

Self-Stigma

While social stigma is indicated as a barrier to recovery so is self-stigma. Self-stigma as presented by Martin and Johnson (2007) is described as internalizing negative attitudes regarding one's own situation leading to the belief they are only worthy of poor treatment and rejection which is coped with by secrecy and withdrawal.

Another study by Watson and Corrigan (2001) states that the primary effect of self-stigma among people with a mental illness is reduced self-esteem and self-efficacy. They further state that people with self-stigma are less likely to seek treatment for symptoms than people without self-stigma. Therefore, according to Bromley and Cunningham (2004), they are less likely to receive support when needed.

Watson and Corrigan (2001) argue that education helps to reduce and prevent self-stigma. They further state that if people with a mental illness had better information

about the structural causes of stigma and discrimination, they might be less likely to internalize stigma. As a means of combating self-stigma, enhancing empowerment is mentioned as being helpful and cognitive reframing therapies may help build empowerment and reduce self-stigma (Watson & Corrigan, 2001). Corrigan (2004) describes empowerment “as a measure of the control people with the experience of mental illness have over all areas of their lives” which include internalizing the principles of recovery, using cognitive restructuring to challenge self-stigmatizing thoughts, supporting consumer operated health initiatives, consumer conducted research, supported employment and education, clubhouses, lodges and increasing mental health service accountability to consumers. Shih (2004) also supports the view of Corrigan that empowerment helps people with mental illness to develop feelings of mastery and self-efficacy which may help to avoid internalizing stigma.

People internalize negative emotions either due to self-stigma or previous life situations, and Peterson, Barnes and Duncan (2008) state that self-stigma can have a greater negative impact on an individual’s health and well-being than social stigma.

As stigma is a barrier with multidimensional challenges, it is one of the barriers to be faced while working through recovery.

Conclusion

While the literature on recovery seems to support the biopsychosocial approach to recovery, further research based on this approach is necessary in order to provide further clarification of recovery based on experiential perspectives.

In light of the fact that one in five people lives with some type of mental illness (Wilson, 2003) combined with the high cost of service (Prowse and Carpenter, 2003), it

is important for service providers to better understand the experiential perspective of mental illness. This understanding could provide a recovery process based on a personal choice in which people may enhance the quality of their lives and possibly reduce the financial burden on the acute care system.

Deegan (2001, p. 20) argues that “people with a mental illness are more resilient than the myths about mental illness would suggest.” Deegan (2005, p. 5) further states that “professionals must ask what we need” and “listen to what we say” because “help isn’t help, if it is not helpful.” If the concept of recovery is to further guide service providers, it is important to understand the personal experiences of individuals living with a mental illness (Sullivan, 1994).

CHAPTER 3

METHODOLOGY

Design

From the results of this study, it is hoped that we will gain a deeper understanding of the meaning of recovery based on the experiential perspectives of people with a mental illness.

The research is a qualitative, descriptive and exploratory study based on data collected from two focus groups with a total of seventeen adult participants. Documenting responses to interview questions in focus groups based on personal experiences was an effective way to find out what recovery from mental illness means to the participants.

The qualitative approach contributes to our profession's knowledge base and favours open and in-depth data collection and analytical approaches which help to better understand the personal experiences of individuals (Tutty, Rothery & Grinnell, 1996).

The purpose of descriptive research is "to increase precision in the definition of knowledge in a problem area where less is known than at the explanatory level" (Grinnell, 1993, p. 441). Grinnell also defines exploratory research as "the gathering of data in an area of inquiry where very little is already known" (p. 442). The research used for this study incorporates both descriptive and exploratory types.

In order to obtain data for this study, interview questions were prepared by the researcher and participants responded to the questions in a focus group. The data collected in the form of personal experiences was documented and analyzed in an effort to better understand the recovery process from the experiential perspective.

Sample

In this experiential study, the sample was made up of willing participants who met specific criteria including: having experienced some type of self-identified mental illness and, according to them, being currently in a stable mental condition, over the age of eighteen and of any gender, race or religion. The reason for requiring stability is that stable individuals are more likely able to articulate their responses accurately because their cognitive ability is not impaired by symptoms.

The different types of sampling include nonprobability sampling which is a type of sampling that doesn't support the claim that the sample is representative of the population from which it is taken (Grinnell, 1997). A combination of two types of nonprobability sampling was used for this study.

One type is purposive sampling, where, according to Grinnell (1997), participants are sought out who are known to be good sources of information and can yield considerable data, particularly when used within qualitative research studies where representativeness is not the central goal.

Since having experienced a mental illness was one of the criteria, mental health agencies seemed like a place to find participants who would meet the criteria and be good sources of information as discussed by Grinnell (1997) and the small sample was considered to be adequate for the research. There were eight participants in one group and nine in the other, eight of whom were male and nine were female. The groups were not segregated by gender. From observation, they ranged in age from early twenties to mid sixties and a variety of different diagnoses was reported.

The other type of sampling is convenience sampling, also referred to as availability sampling. This type of sampling is commonly used in social work research and relies on the closest and most available subjects to make up the sample (Grinnell, 1997). Participants from mental health agencies were convenient and available. Because they responded to a flyer, the participants self-selected.

Participants were recruited following their response to a flyer posted at Mental Health Connections or they may have been referred by community support workers in other mental health agencies in response to the flyer.

The researcher did not know for certain how many participants would be present until the evening of the focus groups when people showed up and read and signed the consent forms. The researcher was hoping to have approximately eight to ten participants in each focus group. However, if more had come, they would not have been turned away.

No intervention was provided in this research; however, if any person in either of the groups had experienced any type of negative impact, they would have been referred to their community support worker or the crisis centre. Participants were offered refreshments, fresh fruit and vegetables at the focus group location.

Data Collection Procedures

According to Unrau (1997), data collection consists of a detailed plan of procedures that aims to gather data for a specific purpose. Since the purpose of this study was to gather data from an experiential perspective, two focus groups were held to gather first hand information. The focus groups were approximately three hours in duration with a total of seventeen persons in attendance at both groups. Each group was comprised of different participants but both were held at the same location at Mental Health

Connections, a local mental health agency which provides psychosocial rehabilitation services. The same interview questions were asked of both groups and documented in the same manner. A list of the questions is attached to the thesis as Appendix A.

The help of a research assistant was obtained to assist with the data collection process. The role of the research assistant, who was a Master's student in the Social Work Program at the University of Windsor, was to facilitate each group. The role of the researcher was to document the responses on a flip chart and to ensure they reflected the ideas and exact words reported by each participant. The research assistant was briefed on the format and procedures by the researcher and given a copy of the interview questions.

Each participant signed a written consent form and handed it in. When each focus group started, the researcher introduced herself and the research assistant and explained that the research assistant would facilitate the group and the researcher would document the responses.

The research assistant then began to facilitate and explained the requirements of the research and the procedures for the focus groups to the participants and ensured that everyone understood the process. Information contained in the consent form was then reviewed with each group and the research assistant asked if anyone required further clarification. Participants were informed that any information collected would be analyzed collectively rather than individually in order to protect the confidentiality of each participant.

Confidentiality in the group was emphasized, as well. Although participants agreed to keep all information in the group confidential, it is still difficult to guarantee total confidentiality in a focus group because it is a group event. While confidentiality of

the information given by the participants will be protected by the researchers themselves, this information was heard by all the participants and therefore was not strictly confidential. All participants were aware of this information.

The voluntary nature of participation was emphasized and participants were told they could withdraw at any time, without penalty. A list of specific interview questions had been prepared by the researcher and was presented to the participants by the research assistant for response. The responses were documented on flip charts by the researcher and verified by the participants. The facilitator used prompting questions in order to gain as much information as possible.

The purpose for having a research assistant facilitate this process was to keep the participants on track when documenting on flip charts. This was to ensure that one participant responded at a time and that everyone who did want to respond was provided an opportunity to ensure that some participants didn't dominate the group. The research assistant also ensured that any valuable information was not missed as a result of participants talking together when the researcher was writing responses on the flip chart. This allowed the researcher to focus on writing the responses of the participants to guarantee their accurate documentation.

It was important for the researcher to be present during the focus groups. Without being privy to the more in-depth information obtained when documenting and verifying the responses and doing it accurately, analyzing the data would have posed some difficulty.

When the facilitator completed the focus groups, the data collected and documented on flip charts were stored in a secured place and later typed as written by the

researcher. Typing the information onto 8 1/2 x 11 inch paper made the analyses a little less difficult because working with the large flip chart paper would have been cumbersome to keep flipping through. Any raw data collected were locked in a file cabinet inside a locked office after it was typed. Any typed data had no reference to individual names. When that process was complete, the typed data were ready for analyses.

After successful completion of the defense, the raw data collected will be shredded by a criss-cross shredder.

Data Analysis Procedures

Because the researcher wanted to gain a deeper understanding of recovery from the experiential perspective of mental illness, interview questions were designed to collect data based solely on the experiences of the participants. Understanding participants' experiences and nuanced meanings of recovery was critical to the study. The data analysis of this research can be described as an understanding of what recovery means to people who have experienced a mental illness rather than an explanation (Charmaz, 2006).

Data analysis is the process of creating structure and meaning to the data that were collected (Harris, 1991). The data from the focus groups were organized into codes and sorted into categories. The data were then analyzed using thematic analysis, which according to Tutty et al. (1996) is a type of analysis which describes the major themes. Four main themes emerged from the analysis and descriptions of those main themes are presented in the Results chapter. The time consuming process of sifting through the large amount of data collected was tedious, but necessary.

The responses that were documented in the focus groups were typed word for word, then put into a table and formatted as codes. In order to capture all the input from the participants, the codes were then placed in categories. Some codes fit into more than one category. From the categories, themes emerged as the qualitative data collected were analyzed (Harris, 1991).

The researcher had a minimal amount of familiarity with some of the participants and none with others, but no therapeutic relationship existed with any of the participants. The research assistant did not know any of the participants. In spite of the unfamiliarity, the researcher would describe the participants as being open, candid and very informative with their responses.

Responses were a little slow at the start; however, as some participants openly shared personal experiences, others related and the open sharing became contagious. Sharing was encouraged and the groups took an hour longer than originally intended. Participants were told they could leave after the indicated time frame; however, they chose to stay until the groups were completed.

Approvals

The researcher presented a request to the Board of Directors at Mental Health Connections to perform two focus groups on the premises after regular business hours if the research was approved by the Ethics Committee at the University of Windsor. Since the topic of the focus groups was learning about recovery from the perspectives of people who experienced mental illness, it was also of interest to the Board members. The Board supported the work and the Chair of the Board of Directors wrote a letter to the Ethics

Committee at the University of Windsor indicating that the focus groups were approved to be held at Mental Health Connections after hours, as requested.

An application was then submitted to the Ethics Committee by the researcher, including the letter prepared by the Board of Directors, requesting review and ethical approval to perform the research. The Ethics Committee reviewed and approved the proposal for this research. A copy of the Approval by the Ethics Committee is attached to the Thesis as Appendix C.

A point of interest should be noted here. As the researcher is also the Executive Director of the agency where some of the participants receive services, concerns could be raised about the power dynamic in this process. If this were an evaluation of the agency, the presence of the Executive Director would likely have an impact on the results. However, in this particular research, the discussions related to people's general experiences about their illness, rather than experiences regarding the agency. The researcher had no previous therapeutic relationship with any of the participants.

Limitations

One of the limitations of the study was the small sample size of less than 25 participants. In qualitative research, however, this sample size is not unusual. Findings are targeted more towards depth rather than breadth.

Another limitation was that because the focus groups were not audio or video taped, the data collected is not as rich with detailed information. Also, the data were collected in the form of focus groups only and no individual interviewing took place which could have provided more in-depth information.

Summary

Overall, each individual group was very cohesive, and there appeared to be a bonding of group members even though most of the participants did not know each other prior to the focus group. The researcher was moved by the amount of open sharing that occurred, which indicated a strong level of trust which developed among the participants as well as with the research assistant and the researcher in a very short time frame.

Through the use of a qualitative research design using purposive and convenience sampling techniques, seventeen people were available to participate in two focus groups. With the help of a research assistant, the open sharing contributed to the data collection. The researcher was amazed by the similarities in each group as participants provided input through their own personal stories and experiences. Through this process, the researcher is hoping to gain a better understanding of the meaning of recovery based on the experiential perspective.

As the data collected from the two focus groups was analyzed, the four main themes that emerged will be presented in the next chapter.

CHAPTER 4

Results

As a result of the data collected from the two focus groups and the analysis which followed, four main themes emerged: recovery means stability and growth in a meaningful way; recovery includes a process of self-actualization supported by both professional and natural supports; barriers to recovery; and, facing barriers using steps leading to wellness. A description of these themes is presented as follows.

Recovery Means Stability and Growth in a Meaningful Way

In order to have a meaningful life, some of the steps towards stability and growth were described as: stability; regaining what was lost; rebuilding relationships; and living in a healthy way. These topics will be covered under the subheadings in this section.

Becoming Stable on Medications

Since stability was one of the criteria for participation in the focus groups, all participants had comments to contribute regarding this topic. Participants discussed the challenging situations in their lives that finally led to stability. They reported that stability was an important factor in their recovery and stated that they had to become serious about turning their lives around, which meant accepting their illness and taking medication before stability could occur. Although the use of medication was believed to be an important factor in becoming stable, it was reported that other factors included in the holistic (mind/body) approach were important and contributed to recovery, as well. This section; however, will focus on medication.

Participants discussed positive responses to the medication when taken as prescribed, some of which were “mood stability, better sleep habits, more balance in life, increased energy level, less anxiety, better reasoning abilities and ways to cope with life.”

Although medication was seen to be important, some participants talked about going off medication. Discussion took place regarding the reasons why people stopped taking medication. One person reported that he stopped taking medication because of “the negative side effects.” Others agreed and stated various reasons which included “severe headaches, weight gain, dry mouth, fatigue, decreased libido, gastrointestinal problems, tremors, difficulty concentrating, memory loss,” as well as other physical discomforts.

All participants acknowledged having had a negative experience with medication and reported “[they] didn’t work closely with [their] psychiatrist” at the time. Some participants reported they found “the trial and error process of finding the right medication was frustrating,” especially because they didn’t always report their symptoms accurately or report they were drinking or taking street drugs in combination with the medications, so it was difficult for the doctors to prescribe more accurately.

Some also reported “self-medicating” with alcohol and street drugs and discussed the consequences which were detrimental to their lives. One person indicated that “being sober is also a key to recovery.” Some participants said their lives had become “a mere existence” living in poverty and isolation without family or friends. They described how they searched unsuccessfully for a “quick fix or a magic pill” to make all the bad feelings go away. One woman said she “wanted to be in control of her own life,” and now admitted she would require help to do it.

One person reported that out of the desperation came the recognition that it was necessary to “stop the denial” and “accept the mental illness” in order to survive. This meant trusting and working with their psychiatrists to find the right dosage of medications and taking them as prescribed. Others agreed with this statement and interactively discussed how difficult it was to make the choice to take the steps necessary to turn their lives around in order to create the life they wanted. They discussed the “strength and courage” it took to overcome the embarrassment and shame of their behaviour when they were not taking medications.

One woman discussed how the medications made her feel “very lethargic” and she reported that because she was too tired to do much, it gave her time to think about her life and what she wanted to do with it. As a result, her life is now “less complicated” and she has a better understanding of what is important to her.

Another man stated that “medications work when taken as prescribed” and another described how the medications brought “normalcy” to his life. Participants openly agreed that “taking medication as prescribed” was important in their recovery except for one person who stated that he “takes medication,” but if he “could find a good therapist,” he “might not have to take any.”

Regain What's Been Lost

Participants reported major losses in their lives due to their inability to accept their mental illness. These losses included: family, friends, jobs, homes, cars, lifetime savings, as well as other emotional losses, such as their dignity, pride and self-confidence. One person reported that in order to regain what was lost from his life, he

had to “accept the fact of having a mental illness” before he could make changes in his life, both mentally and physically.

One woman indicated she felt she had “slipped so far down” that she might never be able to get back up again and said the only thing she had to hold onto was hope. Others reported feeling this way as well. Another woman stated that for her, recovery meant getting back to where she was, prior to her “spiraling out of control,” when she had a life with a job, family and friends. Another person agreed, saying she just wanted to “feel normal again” and also “have a job and people in [her] life who care for [her].” Another person wanted the “chaos out of [her] life” so she could have some “peace and tranquility”. She stated that “knowing it is okay to be alone and not be lonely, is being at peace with yourself.”

As participants discussed the losses as mentioned above, they wondered whether they could attain a similar quality of life as prior to the losses. Another woman reported that just thinking about the changes she would have to make and the effort it would take would send her on a drug or drinking binge. She indicated that the harder she tried to move forward with her life, the harder it became until she finally recognized that her full life had been reduced to “merely surviving.” Another stated that if you can “accept what you can’t change,” moving forward can be less difficult. Others reported having similar experiences with the challenges of moving forward and expressed the importance of “moving forward with courage.”

Another person reported that after so many crises had happened she felt as though she had “lost all control” of her life. She reported that if she was going to have any type of productive life again that she would have to recognize the state her life was in and “the

realization that you can change your life.” Another person said that “learning who I am and what I stand for is like being reborn.” Others discussed their life after crises and one person said that life “is like starting over again.”

This brought up the topic of setting and working on goals. Others agreed with the importance of goal setting and discussed the importance of taking small steps gradually in that process because “taking back control” of their lives appeared to be overwhelming. Another stated that it was important to “keep trying because setbacks are not failures.” Others shared their setbacks and discussed similar difficulties they encountered in the process of trying to regain what they had lost in their lives and noted the importance of having supports in their lives to help with transforming their lives.

Rebuild Relationships

Rebuilding a life was described as having family, friends and possibly a job in their lives. Not everyone reported being ready to have a job at this time in their lives, but they did report being ready to reestablish a healthy relationship with family and friends. Participants discussed previously severing relationships with family members, friends, employers, psychiatrists, caseworkers, and other supports in their lives. They thought they didn’t need people when they were not well and didn’t want help from anyone and exhibited argumentative and aggressive behaviour that “pushed people away.” One participant said he felt “so alone and lonely” without any supports in his life and commented on the importance of “not giving up hope.”

It was reported that socialization was an issue and one woman stated that developing more effective ways of socializing was important, because if they were to move forward, it was necessary “to avoid the self-destructive people and things” and

instead “choose actions that you would not be ashamed of.” Finding new friends was reported to be difficult due to the lack of necessary coping and social skills to maintain new relationships with positive people. Others agreed that they experienced similar feelings regarding lack of socialization and loneliness.

Trust was stated to be a major factor in rebuilding relationships - trust in themselves and trust in the other persons with whom they would be building relationships. One woman stated that “trust would be necessary in order to share [her] personal experiences with others.” Another man reported that he found it was important to trust because it was too difficult to recover without the support of others and regaining their trust wouldn’t be easy because of all the emotional hurt he had caused them. Others expressed challenges with trust and discussed the importance of learning how “to open [their] hearts to trust again” which they thought would be difficult, but necessary for growth.

Living in a Healthy Way

Participants reported that they understood the importance of “changing to a healthier lifestyle” in order to get well. There were discussions regarding irregular sleep patterns, unhealthy eating, lack of exercise, and lack of structure and routine in their lives. Some reported feeling more tired and depressed after staying up late at night and sleeping until late in the day. Participants also reported that due to their irregular sleep habits, they developed poor hygiene, and irregular eating times. They also experienced weight gain because they did not have enough energy to exercise or enough money to buy healthy foods.

Some participants said they now recognize “the importance of healthy eating and regular exercise to lose weight” which was caused either by medication side effects or unhealthy eating and irregular sleep patterns. One participant stated that it is important to have “good physical health in order to work on having good mental health.”

Some discussed accessing food banks and co-ops where they could get extra food to bring home and finding places where they could get a hot meal during the day. Not everyone expressed a wish to visit some of these places, because of overcrowding, unhygienic odors, or loud and vulgar discussions. However, there was agreement that people do what they have to do when they are desperate and have no food.

There were reports of having to get money from working odd jobs, from family members or borrowing from friends. Others reported previously getting money from illicit means such as stealing, prostitution or selling drugs. Some reported having no money at all and sleeping at the Salvation Army, on someone’s couch, or on a park bench. They all reported now having an income through the Ontario Disability Support Program, Ontario Works or Employment Insurance. Some shared that they previously refused to apply for such programs because they “denied having a mental illness.”

Participants discussed the benefits of “accessing available services that don’t cost money” and expressed the difficulty in sometimes finding such services. One man reported that he “feels much better after finishing a workout at the gym which doesn’t cost any money” when he goes with the psychosocial rehabilitation group.

Participants said that when they have some type of an income and a place to sleep and food to eat, they are in a better frame of mind to focus on changing their lifestyles and working on their recovery. There was discussion about how difficult it is to work on

improving one's life when there is no money, no food and no place to sleep. All participants said they are grateful to now have an income which allows them the opportunity to concentrate on their growth and potential.

Based on the discussions, recovery had different meanings for different participants. However, many similarities were noted as they discussed their personal experiences. It was clear from the documentation that the most important thing about recovery is that everyone wants to live a more meaningful life with family, friends and an income, in spite of the limitations encountered through the experience of living with a mental illness. In addition to describing what recovery means, participants also identified the processes they thought are important to recovery.

Recovery Includes A Process of Self-Actualization Supported by Both Natural and Professional Supports

Participants discussed the importance of coming to understand themselves with the support of natural and professional services.

Self-Actualization

Participants talked about self-actualization which to them, meant becoming the best person they could be. Various processes were identified as being important in self-actualization according to each person's definition of what recovery means for them. Some of these processes include: awareness, trust, forgiveness, courage, belief in oneself, hope, determination, patience and understanding.

Participants discussed being aware that change could occur in their lives and acknowledged that help and support from others is necessary. Others discussed the importance of knowing their symptoms and triggers. One participant said that it was

important for her to be aware of “how far down” she had slipped and how frightening it was to think that she might never have what it takes to move forward. One person stated that when he “recognized the limitations and was able to accept them,” he was able to “have a purpose” in his life. Another stated that it was important for him to “accept what you can’t change” and “realize that you can change your life” by “acknowledging the illness and making a commitment to recovery.” Others agreed with these statements.

Participants also discussed the importance of recognizing “how far [they] have come” and of being “aware of how much further [they] can go,” in spite of the limitations associated with the illness, the medications and/or relapses.

One woman stated that she felt a lot of shame and embarrassment about the type of behaviour she displayed when she was ill and not taking medications. She stated that looking back she didn’t understand why she behaved the way she did and said she would “have to stop beating up” on herself. Another person spoke of the negative effects on others of his aggressive behaviour and the difficulty he had dealing with that. Other participants reported they were working on “forgiveness of themselves and others” but, because of guilt and shame, it would be a lengthy process and would take a lot of courage. They noted that shame and guilt reduce one’s self-worth. It was viewed that “without realizing you are worthwhile,” it is difficult to move forward.

Other statements regarding forgiveness included “be less angry because of the illness,” “be more willing to let go of the past,” and one man stated that he wanted “revenge and justice” for what he has experienced (losses due to mental illness). Others confirmed the challenges with shame and guilt in the growth process and referred to forgiveness as a way to “move forward.”

Participants discussed the importance of “believing in oneself.” One man stated that it was really hard to do when he had lost everything that was important in his life and he held himself responsible for it. Another person talked about “determination and the need to understand that setbacks are not failures” and that it was important to continue “to believe in [himself], in spite of the slips.”

Participants discussed the difficulty getting started with their recovery and the persistence required to stay on track when it would have been easier to quit. However, they stated that determination to have a better life gave them the strength and courage to continue. One person reported he felt like “a stronger person” with more faith in himself and more self-confidence because of the determination and strength it took to move forward after a relapse. He shared the importance of “participating in educational programs to learn about personal growth” and using both the professional and natural supports in his life when working to turn his life around.

Participants shared the results of some of their destructive behaviour when they were not in a recovery process and said it would take time to work out some of those long standing issues because many people developed hurt feelings along the way, including themselves. One participant stated the importance of patience and understanding when working on long term resolutions such as “learning to trust others and regaining the trust of others.” Another person described that patience and understanding is necessary when having to accept “the long struggle to surrender to the fact of having to be on meds for the rest of your life.”

There was a discussion regarding the courage it took to overcome of the challenges to “get through some of the obstacles” before they could see a change in their

lives. Some reported finding courage through prayer, others through determination and others through the encouragement of others and discussed “the courage it took to reach out for help.”

Participants also stressed the importance of holding firmly on to hope and not giving in to the despair that can be associated with mental illness. One participant reported that “not giving up hope” when dealing with challenging situations can make the difference between survival or not. One man reported that when times were very difficult, “holding on to hope,” even though he thought it might be in vain, was the only way he got through.

These processes identified by participants are an important factor in achieving self-actualization. As participants noted, when they had adequate housing, food and medical attention, it was easier to concentrate on self-actualization. In addition to processes, participants discussed the necessity of having both professional and natural supports in their lives to assist with the self-actualization process. Participants indicated that having a meaningful life would not have been possible without “reaching out for help.”

Natural Supports

Natural Supports are referred to as supports in an unpaid capacity, such as family members, friends, peers, group members, church groups, pets, etc. Many of the participants emphasized how important it was to have natural supports in their lives. Family members of all types were identified and documented as being important – mothers, fathers, sisters, brothers, husbands, wives, sons, daughters, aunts and uncles.

Some statements reported by participants regarding family included “acceptance

by family and friends,” having a relationship with family,” “good rapport with family” and “having a family connection and understanding.” One participant discussed how she missed the family get-togethers and the fun they had before the family excluded her because of her behaviour. She stated she would work towards being accepted by them again because the “love and caring of family” was important in her life. Another woman said she was able to keep going because she “knew that [her] children needed [her].”

Another man said it is difficult to recover “without the support of [his] family” and discussed how he was willing to try harder to keep his family in his life. Some participants reported having good family support, others reported having some family support and others reported having none. One woman reported the relief she felt because her mother was always there for her no matter what she did. Not everyone said they were as fortunate.

The importance of having friends was shared. Friends were referred to as people who listen and understand and not judge or look down upon them. One woman said it was important for her “to have friends who understand and listen, but not friends who tell you what to do.” Others discussed liking the camaraderie of friendships and having someone to go places and do things with and being able to meet new people. Participants believed that having friends made life less lonely, even if it was only one friend.

Another person commented on the positive experience of having peers in her life. Peers were described as people who have experienced a mental illness. One woman stated that they can share feelings and emotions or assist with the experiences of working through the health care system. One individual explained that “peers can understand the

experiences of others without being judgmental.” There was discussion about the importance of meeting peers and gradually learning to trust each other. While some participants reported the importance of having peers in their lives, not everyone agreed that peers were important to them, but all reported seeing the value of having trusted peers in their lives. Those who believed peer support to be important said that often times they met people through participating in the educational sessions when there was group sharing with people who had similar experiences. They reported making the connection in the group and connecting again outside of the group.

Animals were also reported as being an important part of people’s lives. One woman reported that her “dog loves [her] unconditionally and doesn’t get upset when [she] slips up.” Several others shared stories about their dogs and cats and agreed with the importance of animals in their lives. Another woman agreed and stated that she couldn’t afford to have a real animal, but her “stuffed animals meant a lot to [her].” Not everyone had an animal, but all could relate to their importance.

Some people discussed their experiences with faith in God and that without God “protecting [them] and giving [them] courage,” they may not be alive. Many related to this experience, but not everyone did. Another person reported the importance of “belonging to a church” as it provided a sense of belonging and offered activities, especially on weekends when professional services are not available. Another reported the “satisfaction of doing volunteer work.” She stated that the self-satisfaction of being able to give back when she had received so much meant a lot to her.

Many said that natural supports are usually available and needed when professional supports are not, such as evenings and weekends. Participants reported that

evenings and weekends can seem very long and lonely and when people often need help the most.

Professional Supports

Participants discussed various types of professional supports they found helpful in their recovery process. Professional supports were described by participants as “good clinical support – psychiatrists, psychologists, social workers, case managers, crisis workers, psychosocial rehabilitation workers, as well as other workers in the helping profession.” Regarding professional help, participants made statements such as “trusting the doctor,” “taking meds as prescribed,” “networking into mental health agencies,” and taking all available programs.

Participants commented on their various experiences with psychiatrists. Some reported having positive experiences while others reported having negative experiences, but all participants reported they are receiving the services of a psychiatrist.

Some reported that they believe their “psychiatrist always listens” to them, while others reported they believe their “psychiatrist doesn’t listen.” Others thought the psychiatrist didn’t spend enough time with them while others reported having adequate time. Some reported changing their psychiatrist to find one they could feel comfortable with. Others said they didn’t have a psychiatrist for a long time and now feel fortunate to have one.

Another person said she preferred to see her psychiatrist in the morning when he is not “grumpy.” Another person stated that since he started to comply with his treatment, his psychiatrist doesn’t get upset with him as much. Others agreed that when

they became serious about getting well, and “taking the medications as prescribed,” they developed a better relationship with their psychiatrist.

Participants also shared their experiences with other professional supports. Some discussed having “a case manager” and others reported not having one due to the waiting list, saying “more case managers are needed.” One man stated that he liked meeting with his case manager because she helps him stay on track with his goals and will even go to the psychiatrist appointment if he has difficulty explaining something.

Participants reported that the “psychosocial rehabilitation program was helpful because there are so many things to do, the staff is supportive and the education sessions are helpful with personal growth.” Positive aspects include: “doing physical fitness,” “learn about healthy eating,” “get involved in groups,” “learn about budgeting,” “participate in positive activities,” “safe place,” “socializing with positive people,” “meet other peers,” and “take the WRAP program.”

One person stated that the peer led Wellness Recovery Action Plan (WRAP) Program really helped him learn about his triggers and relapses. He reported that when emotions flared from learning about triggers he could see the social worker and she would help him to get his emotions into a perspective he could feel better about.

Another man talked about how much the ceramics program helped him to relax and also helped with his tremors. Yet another person stated that going to the gym and working out with the group helped him both physically and mentally. Another reported that he couldn’t afford a membership of his own but when he goes with the group it doesn’t cost him any money. He has a trainer to help him, other peers to provide support

and encouragement and he “can feel better by doing the exercise.” Others discussed the importance of learning about “nutrition,” “budgeting,” and other classes that are held.

Others appreciated being able to obtain services at “the crisis centre with staff on duty, twenty-four hours a day, seven days a week.” One person reported when he felt troubled and had no one to talk to in the middle of the night, he could call or go to the crisis centre and talk to a crisis worker who would help him feel better. Another shared feeling supported knowing that services are available after hours if she needs them. Someone else reported she liked “the convenience of the crisis mobile team,” who would visit in the home or other locations in the community, if necessary. She stated that this can reduce the anxiety of going to the hospital when support is needed.

The advantages and disadvantages of counselors were also discussed. Everyone agreed on the effectiveness of counseling; however, the main disadvantage reported was “the limited number of visits allowed at no cost” in some agencies. The other option would be expensive visits by private counselors which the participants said are unaffordable on a disability benefit. All participants explained that they would use counseling if there was “better access and affordability.”

Another person emphasized the importance of the pharmacist when not being able to reach the psychiatrist. Participants agreed that the pharmacist was very knowledgeable regarding medications and a good resource when there were questions about the medication or the side effects.

The general consensus was that it is important to have both professional and natural supports during the recovery process. Participants believed that it is necessary to have a psychiatrist who listens and cares, as well as various other professional sources to

provide personal growth opportunities to help them move forward with their lives. It was also reported that professional supports are important to assist with removing or reducing barriers such as stigma that hold people back from achieving self-actualization.

Participants also agreed on the importance of family, friends, peers, clergy, animals and other types of natural supports.

Barriers to Recovery

Social Stigma

Stigma was reported as one of the barriers to recovery. The definition of stigma found in Webster's Dictionary is "a mark of disgrace." Participants reported that it is hard to deal with stigma when they have done nothing wrong to deserve the way they are viewed and treated by society. One person said "when someone knows you have a mental illness, they treat you differently." Another woman reported that she is well into her recovery process, dresses nicely and can attract nice men in her life. However, when she tells them she has a mental illness, she doesn't see them again. Others reported similar situations regarding dating.

Another reported that stigma was a problem for him when he was trying to rent an apartment. When the landlord found out he had a mental illness, he was told the apartment was already rented. Others reported having similar problems with housing, employment, education and health care. One participant stated that he didn't bother filling out applications for jobs anymore, because he knows he won't get them.

As the barriers of social stigma were reported to prevent people from moving forward in their lives, participants began to explain other areas of their lives, unrelated to the social context that were holding them back from being the best person they can be.

Self-Stigma

While social stigma appears to be a barrier to the recovery process, according to the discussions, self-stigma can also be a factor in slowing down recovery.

Some barriers reported as self-stigma were: fear, anger, guilt and shame.

Participants discussed how fear holds them back. One person spoke about not trying to do things because he said he failed at so many things when he wasn't being treated, now he is "afraid of letting people down." Others agreed that fear of failure is a fundamental aspect of recovery they are still working on. Other participants discussed the "fear and uncertainty" their lives had taken on because of the mental illness, including their lost employment and the fear of living on a disability pension for the rest of their lives.

Others discussed the fear of abandonment by their families and those with children talked about the "fear of passing the illness on to their children." Another woman reported the fear of losing her children if she had a relapse and the guilt she would feel if she couldn't look after them. Participants reported that "removing or reducing fear" would help them move forward. However, they discussed the difficulty in moving forward when they focused on their past experiences and their inability to keep a job, maintain family commitments, attend medical appointments, stay sober, or make other personal commitments related to their ability to function on a daily basis. All participants shared experiences with fear and its ability to hold them back.

Participants expressed their frustration with having a mental illness and what it has taken from their lives with one man saying he was so upset with all the losses in his life that he wanted "revenge and justice." Other participants also spoke about the unfairness of having a mental illness. For some, "anger only created more negativity" in

their lives. There was unanimous agreement that once there was acceptance of the illness, the anger was reduced.

Guilt was another emotion that was identified as a barrier to recovery and participants discussed how guilt affected their lives. One woman expressed the guilt she felt about her inappropriate behaviour when she wasn't well and now she believes she has to compensate by doing everything she is asked, even when she doesn't want to. She said she "learned [she] had the right to say no, without feeling guilty." Others shared similar experiences with feelings of guilt because of their behaviour when they were either having a manic or psychotic episode or under the influence of substance. Another person discussed how it was important for him to realize he was not "damaged goods" even though that was how he felt.

Others reported believing their mental illness was caused by "a weakness or character flaw." One woman viewed the inability to concentrate as a weakness and reported she felt like a failure because she could not finish her post secondary education and dropped out before completion. People discussed the importance of "having to change the perspective from which they viewed their life and illness" and be able to "learn and use new coping strategies." One woman reported that her "recovery was based on a combination of factors" and said she was "grateful for the illness because of what [she] has learned and the people that have now come into [her] life." Others agreed that their lives had taken on a new meaning which was fulfilling to them.

As the sharing continued, there was agreement among the participants regarding the negative thoughts, emotions and behaviours that were preventing them from having a productive and fulfilling life. One person expressed his surprise by stating how their

lives are so different but experiences are so similar. He talked about how he could relate with everything being discussed and felt relieved to know he was not the only one who had all those “negative things happening in his life.” Others expressed similar feelings about their experiences. Although the barriers to wellness were discussed, participants also described having to face those barriers and put effort into changing the things that were preventing them from having a meaningful and fulfilled life.

Facing Barriers Using Steps Toward Wellness

Facing barriers was reported to be challenging; however, participants realized that in order to have a meaningful life, it would take effort on their part.

Wellness Takes Effort

According to the data collected, participants’ goal of having a more meaningful and productive life included family, friends and jobs if they chose to have one. One person stated that wellness didn’t just happen, it had to be worked on and another stated if she was going to get well that it would require effort on her part and she would have to “stop looking for a quick fix.” If a more meaningful life is the goal, steps to achieve the goal would have to be put in place. There was discussion about “the over reliance on medication” without putting personal effort into doing the personal growth work. It was reported that doing the personal growth work was not easy and while having to face the difficulty of dealing with the unpleasant experiences that had been suppressed in their lives, processing these experiences was reported to be necessary in order to “find peace in [their] lives.”

Participants reported that although being on medication to control the symptoms had “reduced the frequency and duration of relapses” which reduced the number of

hospitalizations, “it was only a partial answer to wellness.” There were discussions about dealing with negative emotions and the importance of finding the professional and natural supports to assist in that process. The importance of being positive and “spending time with positive people” was stressed by others. Participants discussed the benefits of “taking one day at a time and learning as much as possible about the illness and [themselves].” It was also reported that in order for that to happen, it was important to be “committed to the process” and work hard to put their lives back together.

Planning and Seeking Assistance

Participants explained that recovery would mean attending educational programs to learn about feelings and emotions. To do this, it would be necessary to “network with mental health agencies” or “addictions’ agencies” to find out what programs are available and appropriate. Peers were also noted as being a good source of information regarding wellness.

Participants also said that due to their irrational behaviour without treatment they would not have survived without making an effort to change their lives. At the point they decided to turn around their lives, everyone reported that they knew they couldn’t do it alone. Some sought the help of a crisis worker, others worked with a community support worker who helped with goal setting and referrals to other agencies to obtain additional help.

Others who were unable to have the immediate assistance of a community support worker reported being referred to short term counseling or psychosocial rehabilitation services where there were a variety of programs to choose from. Participants reported “taking part in educational sessions” to learn about their feelings and emotions,

particularly how to deal with negative emotions. Some people found this difficult and one person reported “spending time alone for days at a time to find the strength to continue to face the challenges.” Others stressed the importance of “being persistent and not giving up.” Some reported finding support through social workers, family doctors, clergy, instructors of programs, peer support, families, physical exercise, healthy eating, journalling and having a daily plan to stay on track.

Some participants reported finding it challenging to discuss intimate issues with new people in a group setting. One woman reported that it was difficult for her to deal with the shame of things that happened in her life and she would rather work on this in an individual session with a professional. Participants agreed that each person needs to find supports and services that work for them because what works for some, may not work for others. One person reported that the “journey to wellness” has not been easy, but the efforts to recover were driven by “determination and persistence.”

The steps to wellness were based on participants’ experiences in their search for meaning in their own lives which they reported only comes with considerable effort and support from many people, both natural and professional, as well as a commitment to the process of recovery. One participant said it is also important to have “fun and flirt with life” during the recovery process. Another stated that “a good cry and a little belly laughter” also helps, but it is so vitally important to “never give up hope” and to “keep committed to the process.” There seemed to be a consensus about this statement.

Summary

According to the data, participants explained that in order to achieve self-actualization, recovery based on the holistic approach to wellness along with a

commitment to the process is important. It was reported that stability and sobriety, a safe and affordable place to live and healthy food to eat are key ingredients to that process. They also reported the need to have both professional and natural supports to help them move forward. Participants shared their feelings of trepidation along the way, not knowing whether they would continue to have the strength, courage and resilience required to achieve recovery because of the continuous effort that had to be made. One person's advice of "taking it one day at a time" was emphasized as being an important part of recovery.

Facing the barriers and working hard to overcome them was reported to be challenging. However, most people stated they think they are now in recovery and although some days are still difficult they believe they can eventually have a meaningful and fulfilled life.

CHAPTER 5

Discussion

The purpose of the study is to explore the meaning of recovery based on the experiences of people with a mental illness. The data collected were provided by people who live with a mental illness and who, thus, have firsthand knowledge about this topic. The findings of this study, as discussed in the previous chapter, support the concept of recovery based on the interrelationship of the biological, psychological and social aspects of recovery. These biopsychosocial perspectives are comprised of numerous methods of recovery which help people to live a meaningful life versus the medical approach which is based on the single approach of symptom relief (Borrell-Carrio, Suchman & Epstein, 2004).

According to the literature, recovery has been referred to as a process (Anthony, 1993; Deegan, 2001; Walsh, 1996), a vision (Anthony, 1993; McLean, 2003; Anthony, Cohen and Farkas, 1990) or a guiding principle (Chamberlin, 1987). This study refers to recovery as a process.

In this study, participants reported wanting to live a meaningful life. This concept emerged into four main themes. First, participants described recovery: recovery means stability and growth and recovery includes a process of self-actualization supported by both professional and natural supports. In addition, barriers to recovery were identified as well as methods for facing barriers.

Stability and Growth

Although medication was reported to be helpful in gaining stability, it was determined that full recovery was much more broadly based and that medication was

only a partial answer to wellness. Anthony (2005, p. 1) supports that finding, by stating that “people with a severe mental illness, want and need more than just symptom relief.” As participants discussed positive and negative effects of medication and the assistance of medication in the process of gaining stability, it was reported that there was much more involved in the recovery process than medication.

The results regarding medication were consistent with the literature on recovery where effectiveness of medication in the recovery process was reported to be linked with a combination of medication and other supports chosen by people in order to live a meaningful life. The biopsychosocial or holistic model of treatment, which focuses on the whole person, both mind and body is based on the lived experiences of people with a mental illness (Brown et al. 2008). This model understands the goal of recovery as living a full and meaningful life. Based on the holistic view, clients have expertise by virtue of the lived experience of their disorder and their own intimate knowledge of what gives meaning, purpose and quality to their lives (Deegan, 2007).

Deegan (2001) strongly supports the combined approach to wellness and notes that she learned to use medication in conjunction with self-help and self-care strategies. She suggests that one must complement the other in order to give purpose and meaning to one’s life (Deegan, 2007). Mead and Copeland (2000) recommend using other strategies for recovery in combination with medication. Fisher (2008) also supports the goal of combined treatment to assist people regain control of their lives and be valued members in society, with or without medication, dependant on each person’s situation.

Participants openly shared their challenges and their desire to become stable. It was reported that once people accepted their illness, they developed a desire to change

and grow. On a personal note, the researcher was moved by the open sharing and bonding that took place. It took time as one person would share a little, another would share a little more and as people started to relate to each other, there was open and honest sharing which was good to obtain rich data collection.

Participants discussed “being normal” or returning to a “prior functioning state.” In this study, a more detailed definition of normal was not explored. However, in a study done by Borg and Davidson (2008), participants defined being normal in practical terms such as paying bills, shopping, cleaning, participating in social settings and performing other activities of daily life that most people take for granted, rather than meaning a pursuit of well being.

This statement is different from other meanings in the literature regarding “being normal.” For example, Deegan (1995) believes that the goal of recovery is not to become normal, but refers to recovery as gaining a new and valued sense of self and purpose through the lived experience. Walsh (1996) also states that it is necessary to find new meaning and purpose in one’s life without going back to the past. According to the participants in this study, recovery is about looking at the new possibilities that can lead to a more meaningful life, in spite of the “limitations” and “setbacks.”

Discussions took place regarding the major losses in people’s lives and participants discussed how they could regain what was lost. Families and friends were reported by participants to be important to regain a relationship with. Not everyone was interested in returning to work at this time but preferred, instead, for work to be a gradual process. Because people reported they had already lost most of their material possessions

such as cars, houses and money and were not in a position to accumulate them, this was not reported as being a priority at this time.

Participants in this study reported that they had lost a sense of self, and were working to regain this. Some statements used were “regain something that was lost,” “realizing you are a worthwhile person,” having a positive attitude and believing in your self.” In a study by Young and Ensing (1999) participants reported that upon acceptance of the illness, they gained new perspectives about themselves and the illness and also developed a sense of empowerment which gave their lives new meaning.

Rebuilding relationships with families and friends was reported to be important but difficult because of the emotional hurt that is caused when people are in manic or psychotic states of mind or are under the influence of substances and believe they don’t need anyone. In contrast to those times, participants discussed the importance of having a sense of belonging with family members and friends who care and understand. In this study, rebuilding relationships with families and friends was reported to be a high priority. Giving and receiving were emphasized as being important in these family roles, such as taking care of children or being supportive to a spouse or parent, rather than illness related roles where there is commonly a focus on receiving.

Reciprocal family roles are also supported in a study by Borg and Davidson (2008), where participants report that family roles such as parents, spouses, children or siblings are important and represent stability and continuity because of family responsibilities which provide a sense of self-satisfaction. This reason may have contributed to the high priority of family relationships in this study, as many of the participants either had children of their own, had spouses who were supportive or had

other family members who were understanding and supportive. Breier and Strauss (1984) and Hatfield and Hefley (1993) also indicate that supportive family relationships involving spouses and children are considered to be very important.

In this study, participants did see the value in peer relationships, but because building peer relationships was new for participants, it was reported that “it would take time to develop trust.” However, in a study done by Young and Ensing (1999), participants reported that although family relationships were important, relationships with peers were the most meaningful and supportive.

While there were different views on relationships, there appeared to be a consensus that relationships of some type are necessary in the recovery process. A report published by the World Health Organization (2003, p. 6) states that “people who are part of social networks feel cared for, loved, esteemed and valued. Being part of society – feeling included – has a protective effect on health.”

Health

In this study, participants reported that changing to a healthy lifestyle which would include “exercise” and nutritional eating was deemed to be an important factor in recovery. This was agreed upon by Plante and Rodin (1990) who found that data consistently suggest that increased physical fitness has a positive impact upon people with psychiatric disabilities and that exercise improves mood, psychological well being, self-concept and self-esteem. Mary Ellen Copeland (1997) states, from her experience, that exercise is the best natural anti-depressant and doesn’t have to cost any money.

Over the last decade, a growing body of research describes the high co-morbidity with physical illnesses and high mortality rates in people with psychiatric disabilities and

suggests that they can be at a higher risk for health-related issues which increase physical, emotional and social difficulties (Bartschy, Shern, Feinberg, Fuller & Willet, 1990; Berren et al., 1994; Koran et al., 1989 and Leff, 1996). People with psychiatric disabilities are experiencing serious physical diseases that are directly linked to lack of physical activity, including cardiovascular disease, diabetes, hypertension and obesity (Vieweg, 1995).

According to Williams (2008), another component of health is eating healthy food which is important to both physical and mental health. She states that eating fresh fruit and vegetables provides more energy and prevents life threatening illnesses and discusses how food choices affect your mood, ability to concentrate and energy level. While participants in this study also reported the importance of healthy eating they also discussed the difficulty of buying healthy food while on a disability pension.

The literature states that although healthy food may be more expensive, there are still ways to eat healthily. Ventrelle (2009), a clinical nutritionist and registered dietitian maintains that it is possible to eat healthy while shopping on a budget. She states that money can be saved by planning ahead and watching the weekly sales. She also recommends buying fresh fruit and vegetables in bulk when they are in season and less costly.

Recipes made from vegetables and other sale items can be frozen to create personal TV dinners rather than buying prepackaged and processed food with little nutrients. Eating foods high in fiber also keeps one feeling full longer and reduces the cravings for junk foods, she notes. Some examples of high fiber foods were sweet potatoes, brown rice, beans, lentils and green vegetables.

Paul, Segal, Segal and Smith (2009) also state that it is possible to eat healthily on a budget; however, it takes time and planning. Some suggestions include: cutting out junk food, eating out less, making a grocery list and sticking to it, shopping at markets to get better deals, cooking larger portions to freeze, and making soups, stews and casseroles that will last for multiple meals.

Participants in this study report that “changing to a healthy lifestyle” is important for them and that “good physical health is required to work on good mental health.” The results of other studies, as indicated above concur with this and also point out that healthy eating on a budget is possible with proper planning.

Canada’s Food Guide (2007) supports healthy eating and physical activity which provides people with more energy and better overall physical and mental health while reducing life threatening illnesses. This change in lifestyle may further motivate or initiate the process of self-actualization.

Recovery Includes a Process of Self-Actualization Supported by Both Natural and Professional Supports

Various processes leading to self-actualization were identified by participants, based on each person’s definition of living a meaningful life. Some processes discussed and further elaborated on include: awareness, forgiveness, belief in oneself and hope.

Awareness

Participants discussed how growth and change started to occur in their lives when they became aware of their illness and learned about symptoms and triggers and became motivated to change. Statements from participants regarding awareness included:

“recognizing limitations and being able to accept them,” “accept what you can’t change,”

“acknowledge illness and make a commitment to recovery,” and “realization that you can change your life.”

A study by Young and Ensing (1999) seemed to have similar findings where, although participants reported that acknowledging and accepting the illness is admitting the need for help which could mean a loss of control and independence in their lives, they reported having to make peace with their condition and accept the illness as a fact of life before moving forward. Considering the idea that the future can be different, one first has to develop the awareness that change is possible (Onken et al. 2002). Mead and Copeland (2000) state that once people become aware of their illness, they work at their own pace and consider the options available to them.

Forgiveness

Forgiveness of self and others was reported to be an important process for recovery because, according to participants in the study, shame and blame tend to reduce one's self-worth and affect the growth process. Because of low self-esteem, hurt can be experienced and the other person may not even be aware there is an issue. Some statements from the study relating to forgiveness and emotions include: “be less angry because of the illness,” “be more willing to let go of the past,” and “wanted revenge and justice” for what one has experienced (losses due to mental illness).

According to Worthington et al. (2001), it is believed that the comprehensive nature of forgiveness involves both health and mental health and has both direct and indirect effects. The direct effects deal with the ability to forgive and involve feelings and emotions of resentment, bitterness, hatred, residual anger and fear. The ability to forgive is thought to be associated with personal control in one's life (Benson, 1992).

The indirect effects involve mental health through such variables as social support, interpersonal functioning and health behaviour (Temoshok & Chandra, 2000 and Worthington et al. 2001). In further studies by Toussaint, Williams, Musick, and Everson (2001), forgiveness of self and others was shown to be associated with less distress and a greater sense of well being.

According to Richmond (2009), bitterness acts like a mental poison that only hurts oneself. He further states that if issues cannot be resolved, whether intentional or not, without forgiveness, it will drain one's strength and prevent or slow down growth and healing. The literature supports forgiveness as presented in this study as having a positive outcome if a person has the ability and willingness to forgive. According to the literature as cited above, the inability to forgive can hold resentment within the person and affect relationships with others which could prevent people from moving forward to have a meaningful life.

Belief in Oneself

"Belief in oneself" and in the ability to recover was considered to be an important part of recovery in this study. This is supported in the literature by Chamberlin (2008, p. 3) who states that "one of the elements that make recovery possible is the regaining of one's belief in oneself." This is also supported by Borg and Davidson (2008) who found that in addition to believing in oneself, having the belief and faith of other people is valuable and meaningful.

Hope

Hope is a process identified by participants as "the only thing left to hold on to" when people were at their lowest. In this study, there was no specific definition of hope.

Jacobson and Greenley (2001) indicate that hope is a frame of mind that colours every perception and that it is hope that leads to recovery. They state that the first step to recovery is when individuals believe that recovery is possible because hope creates its own possibilities and begins the healing process.

In a study done by Young and Ensing (1999), participants reported that seeking out a source of hope helped motivate them to change. Prayer and spirituality were reported to be sources of help for people to survive even in severe crises. Deegan (1996) states that hope is the alternative to despair and discusses the importance of creating environments that are filled with hope which will nurture growth and recovery. She further discusses (2001) how prayer and spirituality, as components of hope, offered her a way to find meaning in her suffering.

Although the various other studies indicated prayer and spirituality as components of hope, in this study some people acknowledged that prayer and spirituality are important in their lives but not all did and one participant reported that he had “regained his lost faith.”

Based on the data collected in this study, participants indicate that having a more meaningful life would not have been possible without “reaching out for help.” Participants in this study recognized the importance of seeking professional help when needed, referred to by participants as “good clinical support – psychiatrists, psychologists, social workers and other mental health workers.” Regarding professional help, participants made statements such as “trusting the doctor,” “taking meds as prescribed,” “networking into mental health agencies,” and “taking all available programs.”

As participants acknowledged the importance of medication in stabilizing their illness, they also acknowledged that being on medication was only a partial answer to wellness. They all were aware of and in the process of complementing the medical treatment with other non medical methods of recovery, such as using the services of community support workers, crisis workers, psychosocial rehabilitative services, all of which include numerous supports for participants to assist people live a meaningful life.

From this study, it appears that the holistic model of recovery is supported by some psychiatrists in this area, because participants reported being referred to many of the above mentioned services by their psychiatrist. This would also be supported by VanKruistum (2003) who concludes that with the transformation of the mental health system, it is now being recognized that persons with a mental illness can live a meaningful life with adequate resources. Leete (1987) also believes that while hospitals and medicine have a place in treatment and stabilization, community based programs are more successful in the long term because of the flexible environment in which people can rebuild their lives.

While support was reported to come from professional services, participants also reported using the natural support of family members, friends, peers and other sources. Seeking support from others was a process of recovery indicated in this study and agreed upon by many in the literature (Breier & Strauss 1983; Cohen & Berk, 1985; Deegan, 1988; Leete, 1989, Lovejoy, 1984; Walker, 1986).

In a study done by Young and Ensing (1999), one of the findings reported by the majority was that relationships with peers were more meaningful and supportive than relationships with family members. This also supports the belief of Davidson, Chinman,

Sells and Rows (2006a, p. 443) that people who “have faced, endured, and overcome adversity can offer useful support, encouragement, hope and perhaps mentorship to others facing similar situations.”

The findings in this study indicate that although value was seen in individual peer support, family relationships appeared to be a higher priority. However, this is not consistent with the findings in the literature which state that peer support is found to be more valuable, as stated above. Some reported statements from participants regarding family included: “acceptance by family and friends,” “having a relationship with family,” “good rapport with family,” and “having a family connection and understanding.”

A point of interest from this study is that although individual peer support is not considered to be a priority by participants, the Wellness Recovery Action Plan (WRAP), a peer led group is reported to be strongly recommended, as are other educational sessions. While participants reported being willing to learn from peers, especially in an educational setting, it appears they may not be ready to take on a supportive role at this time. This could be viewed as a positive effect, because although their own personal growth may be a current priority, with time participants may feel ready to be supportive to others and be prime candidates for peer support because of their personal growth.

While focusing on the original data, a supposition made by the researcher from this study is that this group of participants, although not new to the mental health system, was new to the notion of having a meaningful life and may want to learn as much as they can at this point about themselves and their illness. This supposition could be supported from such statements as: “recovery is an ongoing process,” “focus and take care of self,”

“no quick fix,” realizing you are a worthwhile person,” “learning who I am and what I stand for,” “getting to know yourself better,” “learn to be your own master and be a productive member of society,” “learning to accept what you can’t change.” The list could continue; however, these statements indicate that participants appear to be seriously focused on their own personal growth to help give meaning to their lives and although they may not be ready to provide to others at this time, the personal growth could make them potential candidates for peer support at a future time. This supposition on the part of the researcher may require further investigation.

While participants discussed strategies for stability, participants also discussed barriers that can make it challenging to move forward.

Barriers to Recovery

In this study, stigma was indicated as one of the main barriers to recovery. According to Webster’s Dictionary (1991), stigma is defined as a mark of disgrace. Stigma exists because of ignorance, prejudice and discrimination (Martin & Johnson, 2007). The effects of stigma limit opportunities for people with a mental illness such as income, housing, employment, education and medical care. These factors are considered to be social determinants of health for all people by the World Health Organization (2008) which refers to them as conditions in which people are born, live, work and grow old, including use of the health care system.

According to Raphael (2004), social determinants of health can influence people’s ability to cope with their environment, fulfill their needs, identify and achieve their goals. The inability to obtain the basic necessities of life, as reported in this study tends to lower “people’s self-esteem and worthiness.” This point is consistent with a view from Link

and Phelan (2001) who state that stigma attached to mental illness can have lasting effects and result in low self-esteem.

In a discussion paper (MOHLTC, 2009), the Ministry of Health and Long Term Care suggests that the same opportunities for income, employment, housing, education and lifestyles should be available to people with a mental illness. However, oftentimes stigma, poverty and other barriers in society over which people have no control create inequities for people with a mental illness. This may cause people to isolate themselves and lose hope, thereby depriving themselves of the opportunity to live a meaningful life. As quoted by Deegan (1995) “healing from mental illness is the easy part, it is healing from the effects of poverty and second class citizenship which is more difficult.”

Self-Stigma

While social stigma is indicated by participants as a barrier to recovery, self-stigma was reported to be another barrier. Self-stigma as presented by Martin and Johnson (2007) is described as internalizing negative attitudes regarding one’s own situation leading to the belief that one is only worthy of poor treatment and rejection which is coped with by secrecy and withdrawal.

Another study by Watson and Corrigan (2001) states that the primary effect of self-stigma among people with a mental illness is reduced self-esteem and self-efficacy. They further state that people with a mental illness who have internalized self-stigma are less likely to seek treatment for symptoms, than people without self-stigma. Therefore, according to Bromley and Cunningham (2004), they are less likely to receive support when needed.

Watson and Corrigan (2001) argue that education helps to reduce and prevent self-stigma. They further state that if people with a mental illness had better information about the structural causes of stigma and discrimination, they might be less likely to internalize stigma. As a means of combating self-stigma, enhancing empowerment is mentioned as being helpful and it is stated that cognitive reframing therapies may help build empowerment and reduce self-stigma (Watson & Corrigan, 2001).

Corrigan (2004) describes empowerment “as a measure of the control people with the experience of mental illness have over all areas of their lives” which includes internalizing the principles of recovery, using cognitive restructuring to challenge self-stigmatizing thoughts, supporting consumer operated health initiatives, supporting consumer conducted research, supported employment and education, clubhouses, lodges and increasing mental health service accountability to consumers. Shih (2004) also supports the view of Corrigan that empowerment helps people with mental illness to develop feelings of mastery and self-efficacy which may help to avoid internalizing stigma.

The literature is similar in some degree to the results in this study where participants report the importance of working with a counselor to process their internalized emotions. As the literature supports enhancing empowerment to reduce or avoid internalizing stigma through various methods, working with a counselor could be perceived as one of the means to enhance empowerment. It was reported in this study that when people internalize negative emotions either due to self-stigma or previous life situations, they believe the services of counselors are necessary to process such feelings; however, those services are considered to be either “short term” or “unaffordable.”

Participants in this study reported that it is difficult to process intense feelings and emotions from trauma or self-stigma when individual counseling services are not available or affordable and expressed feeling uncomfortable discussing such feelings and emotions in a group session. Psychological and counseling services, which are not covered by the Ontario Health Insurance Plan, are reported by participants to be a major gap in the services for people with a mental illness.

According to Peterson et al. (2008), self-stigma can have a greater negative impact on an individual's health and well-being than social stigma. As stigma is a barrier with multidimensional challenges, it is one of the barriers to be faced while working through recovery.

Facing Barriers Using Steps Toward Recovery

The goal of participants to have a meaningful life was reported not to come without difficulties. One participant stated that for her, wellness doesn't just happen, it has to be worked on. Coming to the "realization that you can change your life," and having reported that finding a "quick fix" to cure the illness wasn't found, it was clear that other steps to achieve the goal would be necessary.

Participants said that finding and using steps to create change would include a "commitment to the process" acknowledging that effort would have to be put into changing their lives. While taking medication to control symptoms provided stability, participants reported that in order to have a meaningful life, they would have to do the work and could not do it alone.

Participants reported that they would need to stop the over reliance on medication to feel good about themselves and use other strategies to help in this regard, such as

having a safe place to live, exercise, healthy eating, talk therapy and other available options. Participants reported that these steps would include support from both professional and natural sources and would be necessary if they wanted to have more control over their own lives, and feel like valued members of society.

This process is consistent with Brown (2009) who states that the recovery process is not easy and it took her many years and many crises to have this insight. She further states that if you really want something out of life, with the right mix of supports and resources, it can happen. In her case, this mix included family, work, self-care, therapy, medication and love. This combination is what she considers to be the impetus for recovery.

Fisher (2008) also agrees that recovery is possible through a combination of supports needed to help people reestablish their role in society and regain a sense of becoming a whole person again. He also views self-help and peer support as being fundamental elements to attaining this success.

As participants discussed the positive and negative effects of having a psychiatrist, most people believed that “having a caring psychiatrist who listens was important.” Participants also believed in the value of “community support workers - more caseworkers are needed,” “counseling – better access and affordability” “crisis workers - good back up support” and other forms of professional support. When participants discussed support from service providers, they discussed “helping to make decisions and learning patience.”

Stewart et al. (2003) discuss a shared decision making process which addresses the voice and values of the service user as well as the provider, when charting a course of

action with a desired outcome. Schauer et al. (2007) also state that people usually have better outcomes when they perceive they are involved in treatment decisions.

Participants described the value of psychosocial rehabilitation services, some of which include “doing physical fitness,” “learn about healthy eating,” “get involved in groups,” “learn about budgeting,” “participate in positive activities,” “safe place,” “socializing with positive people” “meet other peers.” Participating in daily activities was reported to give people a “purpose” and provide some “structure and routine,” as well as create an avenue for socialization and personal growth.

Participants strongly recommended the Wellness Recovery Action Plan (WRAP), one of the peer support programs offered through the psychosocial services. The program covers topics such as triggers, relapses, health, networking for resources, boundaries, self-esteem and developing a crisis plan. The plan would include their wishes for treatment, people to be involved in their plan of care, to take care of the children, pets or any other personal or financial responsibilities.

Copeland (1997), who developed this plan, describes how this plan can help people feel more prepared and may relieve additional stress during a particularly stressful time, such as a relapse, accident or any other unplanned event.

Young and Ensing (1999) also support the value of psychosocial supports by indicating that an effective way to prevent illness from controlling people’s time and energy is to participate in various adaptive activities which can result in positive outcomes and provide an enhanced sense of well-being. Anthony et al. (2002) also support the need for this type of service which could complement existing services.

Crosse (2003) refers to psychosocial rehabilitation as the key to integration back into the community.

While many different options for living a meaningful life are available, each person has to find and use the steps that work for them. As one participant pointed out, “do research to find out what services are available” and “take all available programs.”

As pointed out by Deegan (1995) each person’s journey is unique, people need to find what works for them and with the right combination of supports and services, people can recover and lead fulfilling lives.

Mead and Copeland (2000, p. 23) explain the person who experiences the symptoms has to do the work and “not even the most highly skilled health care professional can do the work for us. We need to do it for ourselves with your guidance, assistance and support.”

Summary

Recovery is a lifelong journey that needs to build on the strengths of each individual in order to help them have a meaningful life. As reported by participants, acknowledging and becoming aware of the symptoms of the illness and developing strategies to become stable are first steps to recovery. Once stable, with the support of others, people can start working to change their lifestyles.

Living a meaningful life for a person with a mental illness can be complex, especially if they are facing major barriers while lacking supports in their lives. It is difficult for people to focus on self-actualization when they have no money, no food and no place to sleep. According to Simons (1987), regarding Maslow’s Hierarchy of Needs, the basic needs of life must be in place before self-actualization can occur.

As indicated by the data, overcoming the challenges and barriers of having a mental illness takes a lot of courage and determination. In many cases, a change in lifestyles may be the result of facing a life threatening crisis. The social determinants of health such as income, affordable housing, education and employment are an integral part of living for everyone, making it difficult to lead a healthy lifestyle when they are not in place.

As reported in both the literature and the study, the barriers of social and self-stigma reduce people's ability to move forward with their lives. Participants noted that facing the barriers and working hard to overcome them was not easy but with the assistance and encouragement of both natural and professional supports, they may be able to break down some of the existing barriers in their lives. It is evident from the literature that people with a mental illness can have a meaningful life if they engage in, and take responsibility for, their own recovery process. Mead and Copeland (2000) state that each individual is unique and people recover at their own rate and time, based on personal choice.

Implications for Social Work

The researcher was interested in further exploring recovery from the experiential perspective of people living with a mental illness. The data collected in two focus groups, from participants who generously contributed their lived experiences, provide a wealth of knowledge regarding the experiential perspective of recovery from mental illness. It is hoped that the results of the study expand our understanding beyond the boundaries of the traditional views of recovery.

The overall goal of the participants as reported in this study is to have a meaningful life in spite of the challenges and barriers they have to confront. The data indicate that many people want to live interdependently with strong circles of support made up of professionals, family members, friends and peers and to have the opportunity to live in safe, affordable housing integrated into the community.

The type of recovery process where people want to live a meaningful life relates to the holistic approach to wellness as discussed by Anthony (1993) who states that people need more than relief of symptoms. Young and Ensing, (1999) discuss the fact that although much has been written about recovery from many different perspectives, there is not a lot of consensus about the nature of the phenomenon. According to Ralph and Corrigan (2005), although there is conflict between recovery as an outcome and recovery as a process, because of the lack of consensus around the definition of recovery, psychological well being and quality of life is still the intended goal.

The holistic model of care provides a more comprehensive method of recovery within a multi-disciplinary system based on the lived experiences of people with a mental illness and offers them a sense of hope and dignity. People need to feel empowered to take an active role in their own recovery and participate in their treatment and plan of care, making them more self-sufficient and less dependent on the system (Fisher, 1999, 2001; Jacobson, 2001; Jacobson & Greenley, 2001).

Participants reported not being able to achieve this accomplishment on their own, and required the assistance of professional and natural supports to help them through the recovery process. Participants also discussed the negative and positive effects of

medication and the many other factors that are helpful and necessary in the recovery process in addition to medication.

Many factors affect the recovery process. Services need to be person centred and build on the hopes, dreams, strengths and growth potential for people living with a mental illness.

In a study done by Meehan and Glover (2007), a distinction was made between the “lived experience” and the “learned experience.” The value of the lived experience was noted to be a resource instead of a vulnerability and there was a perception that mental health staff were not always able to fully appreciate the value of the lived experience. The value of the lived experience is also supported by Bassman (2000, p. 152) who states that people who have experienced a mental illness can bring “unique insights and personal accounts to the learning environment that are usually outside the capacity of academic staff.” Since the value of the lived experience and personal accounts of persons with a mental illness are indicated to be resources in the recovery process, social workers could benefit from the knowledge and experience of people with a lived experience. This training could be obtained in work-related training programs as well as academic training by bringing people in to share their stories and advice to offer efficient and effective services and supports based on the holistic approach which would provide the respect and dignity that each person deserves in order to live a meaningful life. As well, social workers should take every opportunity to listen to the personal accounts of stories about the lived experiences.

According to Nelson (1994), change in the system is occurring because of a strong social movement of consumer/survivors, families and a broad network of

professionals who are committed to change. Social workers committed to change must ensure that consumers and families are involved in provincial and federal consultations and have an opportunity to provide input into the planning and implementation of current and future services which will lead to recovery and a meaningful life for people living with a mental illness.

The attitudes, skills and beliefs of social workers are an integral part of providing services to meet the needs of persons living with a mental illness. The need for improved services in the mental health system continues to redefine the practice of social work as we work through the shift from the medical model to the holistic model of care. There are numerous ways one could determine the level of training dollars appropriate for quality in-service training; however, a way to ensure quality progressive learning would be for agencies to allocate a percentage of the budget for training regarding the holistic model of care. In some agencies, additional funding may need to be requested from the Ministry of Health and Long Term Care for this training to become a reality.

Ongoing training in the field of mental health is imperative to ensure that services are provided in a respectful, competent and person-centred manner, building on the strengths and goals of people, rather than focusing on their illness. Using a strengths-based approach to care shifts the focus from the illness to a more positive approach which means concentrating on a person's existing strengths (McCormack, 2007).

Deegan (2005, p. 5) states that "professionals must ask what we need and listen to what we say because help isn't help, if it is not helpful."

Regarding social work, Tutty (1990, p. 13) suggests, "it is important to provide the most effective treatment available. This entails professionals keeping current on the

research on treatment effectiveness for their particular client populations.” In the field of mental health, it is important for social workers to acquire the knowledge and skills to provide needed services as required in a timely manner. It is also necessary for social workers to use their knowledge and skills to ensure that people participate in their own care and provide them with a choice of services that will enable them to plan for their own recovery.

Practice and Policy

According to Statistics Canada (2006), one in five Canadians will be affected by mental health issues at some time in their lives but only 32 percent of those with mental health issues seek professional help. Between 1995 to 2003, the Ministry of Health and Long Term Care invested over \$212 million into community based services which are supposed to be comprehensive, integrated, available, accessible and accountable (Prowse & Carpenter, 2003). People with mental illness require comprehensive services that meet all their needs in the form of a holistic approach to care.

A range of services to meet the diverse needs of the whole body approach to wellness is crucial. For example, additional funding is required to cover the cost of psychological services for persons who have experienced traumatic situations in their lives. The services of psychologists need to be covered under the Ontario Hospital Insurance Plan similar to the services covered for psychiatrists. Participants in this study reported that counseling is not “accessible or affordable.”

Additional funding is also required to break down the social stigma which prevents people from getting the help they need and leaves them having to suffer in silence and isolation instead of having the resources to lead a meaningful life. According

to McCullough (2003), public education provides opportunities to change attitudes and dispel myths about mental illness in order to support the recovery of people who have experienced mental illness. Watson and Corringan (2001) also believe that education is helpful to reduce and prevent stigma and also argue that education should be provided to people living with mental illness to assist them to reject self-stigma and to constructively avoid public stigma.

The Kirby Commission raised stigma as a major issue in its report on mental health and recommended the creation of a Mental Health Commission to launch a nation wide anti stigma campaign (Canadian Institute of Health Research, 2006). The Mental Health Commission and the anti stigma campaign have since become a reality, but much work in the way of education still needs to be done regarding the impact of stigma to reduce or eliminate the negative attitudes that exist.

Nelson, Lord and Ochocka (2003) discuss an empowerment paradigm shift to transform services which require redefining the power relationships between providers and consumers, thereby building better relationships between providers and consumers and also among consumers themselves. "The shift from doing for, to doing with, needs to be supported through organizational changes and staff training" (Lord, Ochocka, Czarny & MacGillivray, 1998, p. 115). They further recommend that the narrow focus on mental health services needs to be broadened to include housing, employment and community support. These recommendations are necessary for empowerment and recovery. Such a recovery-oriented system would include partnerships in care, safe and affordable housing and access to income, education and employment which would better

meet the needs of people living with a mental illness by offering a more stable environment.

Not all consumers have full access to quality services and the kinds of relationships and basic supports that help make recovery a reality for people because not all services are recovery-oriented. Therefore, it is critical for social workers to work with people to provide timely information and access to all services that gives people equal opportunities to include housing, employment, education, income and access to health and community supports so they can have opportunities to live a fulfilled and meaningful life.

The Ministry of Health and Long Term Care is currently undertaking a 10 year strategy to further improve the mental health system. Through this strategy plan, input is being collected locally, regionally and provincially from service providers, people with a mental illness and family members. While people with a mental illness are now more aware of their needs and able to articulate them well, their participation is important at all levels of reporting so that the mental health system will continue to move forward in a way that allows more people to live a meaningful life.

It is therefore important for people with a mental illness and their families to be involved in designing an improved mental health system and developing policy. This is more likely to ensure that opportunities for recovery through service provision meet the needs of people using the system thus providing them with strategies for a meaningful life.

Research

Several areas of research that could be further explored as a result of this study are related to experiential perspectives of people with a lived experience, self-stigma, and medications. These have been indicated by participants in the study to be barriers to or supports for fully participating in the broadest spectrum of what it means to live a meaningful life.

Future research for the social work practice could include advanced research from the experiential perspective of people living with a mental illness. Our understanding of mental illness from the lived experience perspective has been a neglected aspect of provider education (Meehan & Glover, 2007). Therefore, research needs to be conducted with social work educators who bring consumer survivors into their classroom to share their recovery stories.

Another area for research is self-stigma. Facing barriers that emanate from the impact of social stigma presents a monumental challenge for people living with a mental illness. However, the most overwhelming barrier might be self-stigma, the stigma that is unseen, and can paralyze some individuals and prevent them from accessing the care and treatment they need to live a meaningful life they want and deserve. Research in this area to further understand the impact of self-stigma could prove to be a major key to unlocking one of the most challenging barriers to a person's journey to wellness.

Another area for future research is the use of medication. While from experience, some people believe that their lives would be better by taking fewer or no medications, most of the people in this study indicated that they were comfortable with their level of medication which was adjusted and over time appears to work for them. Because there

does not appear to be a consensus on the matter of medication, further research into this topic would gain more knowledge in this area.

Conclusion

From the results of this study, it is apparent that people want to recover and lead meaningful lives; however, the road to recovery is filled with many obstacles which have to be overcome in order to have a fulfilled and meaningful life. It is also clear from the results of this study that people want more than just stability. They want to rebuild their lives. While reaching stability may come with its struggles, the challenge of facing the barriers to self-actualization and putting steps in place toward continued growth are also difficult.

Stability and self-actualization require a strong commitment to the process of wellness. People with a mental illness have to be commended for their ability to be resilient in the face of what so often appear to be insurmountable difficulties. If effective and efficient supports and services are in place to meet this growing need, the challenges and struggles of people with a mental illness can be a little less daunting on their journey toward a more meaningful life. Instead of lives that are marginalized and merely maintaining an existence, people can look forward to the future with hope and enthusiasm.

As Karl (2008, p. 3) states “finally with courage in your heart and with God by your side, you take a stand, you take a deep breath, and you begin, as best as you can, to design the life you want to live.”

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APPENDIX A

Interview Questions

1) What is your definition of recovery?

2) What does recovery mean to you?

Prompt: What does being well look like?

What does satisfaction to your life look like?

What do you need to have in place to feel that you are doing well?

3) What has your journey been like for you?

Prompt: Positive Impacts - Accomplishments

Negative Impacts - Barriers

How did you feel when you received a diagnosis of mental illness?

Do you take medication and how do you feel about that?

Prompt: What has been important in your recovery process, i.e. housing,
employment, relationships, quality of life?

Are there any people who have been important in the process?

How did they help?

What type of supports did you have?

Do you feel that you have been listened to?

4) What would you recommend to others starting on a recovery process?

Prompt: If you were starting over, what would you like to do different?

What type of supports would you like to have in place?

APPENDIX B



CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: **Recovery from Mental Illness – The Experiential Perspective.**

You are asked to participate in a research study conducted by: Jean Laforge, Master of Social Work Student supervised by Dr. Jill Grant, a faculty member in the School of Social Work, University of Windsor. The results will be incorporated into a thesis, which is a partial requirement for a Master's Degree in Social Work.

If you have any questions or concerns about the research, please feel to contact either Jean Laforge, the student researcher at Tel. (519) 256-4854; Email: jlaforge@mhc-wec.on.ca or Dr. Jill Grant, Thesis Supervisor at Tel. (519) 253-3000, Ext. 3074; Email: jgrant@uwindsor.ca.

PURPOSE OF THE STUDY

The purpose of the study is to understand what recovery means to people who have experienced mental illness. There are many views of recovery in the literature, however, it appears that there is not a lot of information on experiential views. This study may contribute to the experiential perspective.

PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

Participate in a focus group for one and one half to two hours in length.

POTENTIAL RISKS AND DISCOMFORTS

The risks associated with focus groups are that focus groups are a group event. This means that while confidentiality of all the information given by the participants will be protected by the researchers themselves, this information will be heard by all the participants and will not be strictly confidential.

There are no other foreseeable risks, discomforts, or inconveniences. Since the meeting room will be on the second floor, there is an elevator available for anyone who has physical needs.

If anyone might experience any emotional impact, they will be referred to their community support worker or the crisis centre for support.

POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

The potential benefit to you is that by viewing the results, you may find hope from the experiences of others in terms of your own recovery.

The potential benefits to society are that service providers may glean a deeper understanding of recovery from the perspective of the person with mental illness and as a result, increased recovery outcomes based on the needs and wants of the client may occur.

PAYMENT FOR PARTICIPATION

Refreshments and light snacks will be served.

CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. There is no intention to share individual information with any person for any reason. Information collected will be stored in a locked file cabinet inside a locked office. The data collected will be analyzed in a collective manner rather than individually in order to protect the confidentiality of each participant. When the project has been completed, the data collected will be shredded.

Focus groups are a group event. This means that while confidentiality of all the information given by the participants will be protected by the researchers themselves, this information will be heard by all the participants and therefore will not be strictly confidential. Participants will be asked to keep the information confidential, however, there is no guarantee that this will happen.

PARTICIPATION AND WITHDRAWAL

You can choose whether to participate in this study or not. If you volunteer to participate in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

The only reason a participant may be terminated from the group would be if a person was disruptive to the group and interfered with the facilitator's ability to collect the data pertinent to the study. The participant could then have the option of whether or not they would like to include their data in the study. This situation is a possibility but not anticipated.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE SUBJECTS

The results of the research can be made available to you on the University of Windsor web site under study results

Web address: www.uwindsor.ca/reb

SUBSEQUENT USE OF DATA

This data will not be used in subsequent studies.

RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research subject, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario, N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: ethics@uwindsor.ca

SIGNATURE OF RESEARCH SUBJECT/LEGAL REPRESENTATIVE

I understand the information provided for the study **Recovery From Mental Illness – The Experiential Perspective** as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

Name of Subject

Signature of Subject

Date

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Signature of Investigator

Date

Revised February 2008

APPENDIX C

Today's Date: March 31, 2009
Principal Investigator: Ms. Jean Laforge
Department/School: Social Work
REB Number: 09-072
Research Project Title: Recovery from Mental Illness - The Experiential Perspective
Clearance Date: March 30, 2009
Project End Date: May 31, 2009

Progress Report Due:
Final Report Due: May 31, 2009

This is to inform you that the University of Windsor Research Ethics Board (REB), which is organized and operated according to the *Tri-Council Policy Statement* and the University of Windsor *Guidelines for Research Involving Human Subjects*, has granted approval to your research project on the date noted above. This approval is valid only until the Project End Date.

A Progress Report or Final Report is due by the date noted above. The REB may ask for monitoring information at some time during the project's approval period.

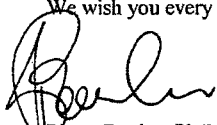
During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the REB. Minor change(s) in ongoing studies will be considered when submitted on the Request to Revise form.

Investigators must also report promptly to the REB:

- a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) all adverse and unexpected experiences or events that are both serious and unexpected;
- c) new information that may adversely affect the safety of the subjects or the conduct of the study.

Forms for submissions, notifications, or changes are available on the REB website: www.uwindsor.ca/reb. If your data is going to be used for another project, it is necessary to submit another application to the REB.

We wish you every success in your research.



Pierre Boulos, Ph.D.
Chair, Research Ethics Board

cc: Dr. Jill Grant, Social Work
Mark Curran, Research Ethics Coordinator

This is an official document. Please retain the original in your files.



VITA AUCTORIS

Jean Laforge was born in St. John's, Newfoundland in 1949. She graduated from Holy Heart of Mary High School, St. John's in 1966. She obtained a Bachelor of Arts Degree in Psychology in 1995 and a Bachelor of Social Work Degree in 1998 both from the University of Windsor. She is currently a candidate for the Master's degree in Social Work at the University of Windsor and will graduate in the fall of 2009.