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Exploring women's perspectives of living with mental illness, stigma, and receiving community services.

By Alexa Stovold

According to the Canadian Mental Health Association (CMHA) (2015), one in five individuals will experience mental illness personally, which means that all Canadians will be indirectly (or directly) influenced by mental illness at some point in their life. Unfortunately, due to historical trends and negative stereotypes mental illness has become heavily stigmatized (Camp, Finlay, and Lyons, 2002; Chernomas, Clarke, and Chisholm, 2000; Link, Struening, Neese-Todd, Asmussen, and Phelan, 2001; Sands, 2009; Szeto, Luong & Dobson, 2013). Although many studies have assessed the relationship between mental illness and stigma, little research has included a gender lens when exploring these topics. Therefore, the primary research objective of the current study is to explore women's perspectives of living with mental illness, stigma, and receiving community services. In total, five women from the Kitchener, Waterloo, and Cambridge area participated in the study. Similar to the literature, results found that the women experienced feelings of loneliness and sadness due to their mental illness diagnosis and the stigma they experienced from friends, family, and service staff. Some women talked about being relieved to have a label or diagnosis for their illness, however, the majority of their narratives suggested that living with a mental illness is difficult due to the internal and external stigma they experience. Findings from this study have implications for contributing to the field of social work, improving service delivery within various healthcare facilities, and future research.

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Introduction

I think that there's an incredible stigma attached to mental health issues, to mental illness because it's so invisible. So many people have come in, asked me for help with mental health issues, either for themselves personally, or for a family member, friend, a coworker, someone that they care about because they just don't know what to do...Because most people when they're struggling, they're confused, they don't know what's going on and so the judgment is there because I think of misunderstanding, lack of education, and plain ignorance, and we need to be better

- Clara Hughes, Bell Lets Talk Campaign.

According to the Canadian Mental Health Association (CMHA) (2015), one in five individuals will experience mental illness personally, which means that all Canadians will be indirectly (or directly) influenced by mental illness at some point in their life. To clarify, mental illness is often referred to as psychiatric disorders such as: schizophrenia, bipolar disorder, depression, anxiety, addiction, eating disorders, and more (CAMH, 2015). This statistic regarding mental illness is striking as it demonstrates the prevalence of mental health within our society, and further supports the notion that education and awareness around mental health is an important matter (Wahl, 1999). It might be prudent to consider if these statistics point to increased discussion due to the prevalence of mental health in today's society.

Due to depictions of individuals diagnosed with a mental illness as being dangerous, unstable, violent, and incompetent, this population has become heavily stigmatized (Camp, Finlay, and Lyons, 2002; Chernomas, Clarke, and Chisholm, 2000; Link, Struening, Neese-Todd, Asmussen, and Phelan, 2001; Szeto, Luong & Dobson, 2013). Studies have shown that the stigmatization of mental illness has led to social rejection, discrimination, and the marginalization of individuals living with mental illness (Link, Struening, Neese-Todd, Asmussen, and Phelan, 2001; Manuel, Hinterland, Conover and Herman, 2012; Wahl, 1999). Stigma towards individuals living with mental illness can take many forms. For example, stigma can be expressed through using language such as: “nuts”, “crazy person” or “psycho”, “nutters” or

lunatic” (Camp, Finlay, and Lyons, 2002; Szeto, Luong & Dobson, 2013). They may also express discriminatory, or prejudicial attitudes towards individuals with mental health issues, which can be detrimental to ones self-esteem, self-worth, and self-efficacy (Link, Struening, Neese-Todd, Asmussen, and Phelan, 2001; Rosenfield, 1997; Wahl, 1999).

According to the literature, individuals who have been diagnosed with a mental illness feel stigmatized by their family, friends, and the media (Camp, Finlay, and Lyons, 2002; Manuel, Hinterland, Conover, and Herman, 2012; Wahl, 1999). In his article, Otto Wahl (1999) found that 70 percent of individuals diagnosed with a mental illness encountered “hurtful or offensive media portrayals of mental illness at least sometimes; almost half (47%) indicated this occurred often or very often” (p. 470). Literature also suggests that some individuals may internalize stigma based on social constructions or norms that have in turn influenced their perception of themselves (Crocker, 1999; Camp, Finlay, and Lyons, 2002). For example, if a child was raised with a negative perception of mental illness, and that child is later diagnosed with a mental illness, they may apply the same negative stereotypes and attitudes toward themselves (Crocker, 1999; Camp, Finlay, and Lyons, 2002).

Although mental illness affects everyone, the literature indicates that there are differences related to mental health, stigma, and gender (Scheyett and McCarthy, 2006). Although there are commonalities between the genders, it seems as though women are subjected to forms of stigma that men are not (Scheyett and McCarthy, 2006). More specifically, the literature indicates that women are more likely to experience negative attitudes toward their mental health, as well as their ability to parent or care for their children (Chernomas, Clarke, and Chisholm, 2000). According to the literature, this act of questioning parental responsibility is more commonly attributed to women than to men (Scheyett and McCarthy, 2006). Another theme within the

literature is the lack of research focused on understanding the difference between gender and experiences of severe mental illness (Scheyett & McCarthy, 2006; Ritsher, Coursey, & Farrell, 1997). Additionally, Scheyett and McCarthy (2006) explicitly express that “fewer studies have looked at the different ways in which women and men may view and experience general services within the mental health system” (p. 408). Moreover, Wahl (1999) expressed that few studies have actually researched mental health consumers, and how they feel about their experiences of stigma.

Although stigma is still prevalent in our society, action is also being taken on an individual, communal, and societal level to challenge stigma connected to mental illness. For example, Bell Canada runs a Nation wide, annual “Let’s Talk” campaign, which helps to raise funds for mental health agencies and programs, it encourages individuals to talk about mental health, and it also works to end the stigma associated with mental illness (Bell Canada, 2015). Additionally, many communities and agencies are getting involved to promote anti-stigma campaigns related to mental health. For example, Niagara’s Mental Health Anti-Stigma Campaign promotes, “Shatter the Stigma Mend the Mind”, and the Mood Disorders Society of Canada also has a campaign called, “Elephant in the Room Anti-Stigma Campaign” (Niagara’s Mental Health Anti-Stigma Campaign, 2014; Mood Disorders Society of Canada, 2015). Thus, although stigma toward mental health exists, these campaigns along with education and awareness are working challenge societal attitudes, and stigma toward individuals with mental illness. Although great advances have been made to combat negative attitudes and behaviours toward individuals with mental illness, I would argue that as a society more change is needed.

As a young woman, I grew up in a rural community, and there was very little diversity or discussion about prevalent social topics like racism, mental illness, social class, etc. It was not

until my undergraduate and masters education that I began to discover a whole new world of social issues. This new exposure ignited my passion and interest for the social determinants of health, environmental injustice, indigenous issues, gender inequality and so on. As I moved from my Masters in Community Psychology, to my Masters in Social Work (MSW), I began to discover new passions for clinically related issues such as: mental illness, stigma, effective ways of working with individuals, addressing needs, and more.

Furthermore, as a woman living and working within the mental health discipline I felt compelled to learn more about how mental illness and stigma influence women's experiences. However, after scanning the literature I was disappointed to learn that there is limited research exploring this topic. My frustration regarding this misrepresentation of gender, my curiosity to learn more about women's experiences, and my goal of contributing to a growing body of literature inspired the topic for my MSW thesis.

Throughout the following sections, I will review literature focusing on: 1) Mental health and stigma, 2) labeling theory, and 3) the medical model, followed by discussion of the study methodology. Finally, findings from the data, including interpretations and observations will be discussed.

Literature Review

Mental Illness and Stigma

According to the Mental Health Commission of Canada (2012), "in any given year, one in five people in Canada experiences a mental health problem or illness, with a cost to the economy of well in excess of \$50 billion". Further, CAMH (2012) also explained that the leading cause of disability in Canada is mental illness. These numbers are quite significant and suggest that due to the prevalence of mental health in our current society, it is not surprising that

mental health is becoming a leading concern for our world leaders, and policy makers (CAMH, 2012).

According to Crocker (1999), “A person who is stigmatized is a person whose social identity, or membership in some social category, calls into question his or her full humanity—the person is devalued, spoiled, or flawed in the eyes of others” (p. 89). Additionally, Girma, Tesfaye, Froeschl, Möller-Leimkühler, Muller, & Dehning (2013) explain that, “stigma is generally a result of illogical generalization, lack of knowledge, and fear about people who are different from oneself.” (p. 1). Similar to other authors, Goffman (1963) discusses stigma in relation to “social identity” and the attributes that we observe or assign to others. He explains that the term ‘stigma’ directly relates to attributes that are negative and deeply discrediting in nature. This means that individuals who do not assume a “normal” social identity, and instead possess alternative attributes are viewed as tainted, handicap or failures (Goffman, 1963).

Furthermore, Goffman (1963) explained that there are three types of stigma

First there are abominations of the body - the various physical deformities. Next there are blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behaviour. Finally there are the tribal stigma of race, nation, and religion, these being stigma that can be transmitted through lineages and equally contaminate all members of a family (p. 4)

Identifying the various types of stigma is noteworthy and provides an understanding for the various areas in which stigma may be rooted. The current study will focus on Goffman’s (1963) second form of stigma, which relates to individual character.

When looking at historical trends dating back to the late 1700’s, people living with mental illness were isolated from society, they were treated very poorly, and there was little intervention or treatment (Sands, 2009). According to Sands (2009),

At the time of Australia's settlement by Europeans in 1788, people with mental illness in England were housed together with "idiots" (intellectually disabled), paupers, and criminals, and managed in a variety of institutions, such as poor-houses, private mad houses, work houses, and prisons (p. 364-365).

During these times, individuals with mental health issues / illness were socially isolated, viewed as incompetent "lunatics" or "idiots", and they were often seen as criminals requiring punishment (Sands, 2009). Toward the mid 1800's facilities dedicated to individuals with mental illness became more popular, and they were known as "asylums", since individuals who were admitted to these facilities were viewed as insane (Sands, 2009). In the early 1900's, the language around treating mental health began to shift, as "Hospitals for the Insane" were developed (Sands, 2009). The language around "hospital" suggested that mental illness was something that needed to be treated through therapy, and intervention rather than punishment (Sands, 2009). Throughout the 1900's more therapy and interventions were explored to help treat mental illness (Sands, 2009). The purpose of this brief overview is to demonstrate that as an early society, we have socially isolated individuals with mental health issues, viewing them as dangerous, criminal, or idiotic. As a result of our history, the stereotypes, and labels of individuals with mental illness have been carried throughout our social norms, and today stigma is still a prominent concern for individuals living with mental illness (Camp, Finlay, and Lyons, 2002; Szeto, Luong & Dobson, 2013; Wahl, 1999).

During his study, Wahl (1999) found that "80 percent of survey respondents said they had overheard people making hurtful or offensive comments" (p. 470). Moreover, the way that the media depicts mental illness in today's society is also a challenge. Wahl (1995) explained that the media often depicts mental illness in an unfavourable, and inaccurate way, which perpetuates or maintains stigma and negative stereotypes about those living with mental illness. Interestingly, Szeto, Luong & Dobson (2013) found that in today's society, words like "nuts",

“psycho” and “crazy” are still used when relating to an individual with a mental illness. In his study, Wahl (1999) found that participants reported feeling hurt, discouragement, anger, sadness, and lowered self-esteem due to stigma. Wahl’s (1999) findings suggest that mental health symptoms may worsen due to increased feelings of sadness, isolation, and loneliness, which is very problematic. Overall, these findings are concerning as this research was conducted quite recently, and researchers are finding that the stigma and negative stereotypes derived from historical times are still quite prevalent today. Given the evidence to support the prevalence of stigma toward those living with mental illness, we will now explore the negative implications of such stigma.

Among the many ways that stigma can negatively influence those living with mental illness, the literature suggests that marginalization, discrimination, and social isolation and rejection are among the most detrimental (Camp, Finlay, and Lyons, 2002; Manuel, Hinterland, Conover and Herman, 2012; Link, Struening, Neese-Todd, Asmussen, and Phelan, 2001; Wahl, 1999). Link, Struening, Neese-Todd, Asmussen, and Phelan (2001) found that, “Stigma can affect people through mechanisms of direct discrimination, such as a refusal to hire the person; structural discrimination, such as the availability of fewer resources for research and treatment; or social psychological processes that involve the stigmatized person’s perceptions” (p. 1621). Research has also found that individuals with mental illness are also viewed as less competent or intelligent, which further fuels the desire to conceal their illness (Link, Struening, Neese-Todd, Asmussen, and Phelan, 2001; Wahl, 1999). Additionally, Chernomas, Clarke, and Chisholm (2000) and Manuel, Hinterland, Conover and Herman (2012) also discuss the implications of stigma with regard to job loss, relationship instability, and lack of resources among women with living with mental illness. Manuel, et al. (2012) found that this marginalization is particularly

challenging for women versus men with regard to financial resources and opportunities for employment. Another challenge for women specifically, is judgment around being a good parent (Chernomas, Clarke, and Chisholm, 2000). Researchers found that, “a deep sense of loss, grief, and some anger haunted the women who had lost their children to child and family services” (Chernomas, Clarke, and Chisholm, 2002, p. 1519). Alternatively, Wahl (1999) found that individuals with mental illness were being ‘over parented’ by their friends and family as their competence, and ability to look after themselves was questioned.

Wahl (1999) and Link, Struening, Neese-Todd, Asmussen, and Phelan (2001) also found that individuals with mental issues or illness often conceal their illness from prospective employers due to fear of rejection, or loss of employment. Interestingly, literature found that individuals with mental illness were not only concerned about mistreatment from prospective employers, but also from medical practitioners (Scheyett and McCarthy, 2006). According to the researchers, “ The lack of caring shown by mental health providers, such as psychiatrists and psychiatric social workers, was particularly painful for some women” (p. 412).

Due to discrimination and marginalization faced by women with mental illness, many are socially isolated or rejected as a result (Camp, Finlay, and Lyons; 2002; Wahl, 1999). To clarify, marginalization involves pushing certain populations to the margins of society where they are unable to receive necessary resources, or advance economically, politically, or socially (Sociology Guide, 2016). Alternatively, discrimination refers to negative actions toward an individual or group for reasons such as: race, age, gender, ethnicity, or disability (Canadian Human Rights Commission, 2013). Chernomas, Clarke, and Chisholm (2000) argue that, “Adding to the prevailing sense of social stigma was the reality of the experiences of rejection, which made participants acutely sensitive to the messages they received from people around

them. They felt judged as inferior and felt that they did not belong, no matter where they went” (p. 1518). The literature suggests that women with mental illness were not only rejected or socially isolated from strangers, but also from their close friends and family (Manuel, Hinterland, Conover and Herman, 2012; Wahl, 1999). Throughout their study, Chernomas, Clarke, and Chisholm (2000) found that women experienced,

the loss of friendships and relationships with family members who didn’t understand their illness and with the difficulty they now have relating with and connecting to the world around them. Pervasive in this group of women, no matter what their age, was an overwhelming sense of loneliness and isolation (p. 1519).

The social rejection experienced by women living with mental illness is especially important as literature suggests that we are social beings, and social support is very important, especially for women (Manuel, Hinterland, Conover and Herman, 2012; Wahl, 1999).

In conclusion, understanding the historical trends of mental health and the way individuals were treated is important, as it helps to inform where our social norms and stereotypes derived from (Sands, 2009). Moreover, it is also important to acknowledge that mental health is still very prevalent in today’s society, and so is the stigma that surrounds mental health (Camp, Finlay, and Lyons, 2002; Manuel, Hinterland, Conover and Herman, 2012; Link, Struening, Neese-Todd, Asmussen, and Phelan, 2001; Wahl, 1999). Stigma is shown today through many avenues, primarily through marginalization, discrimination, and social rejection, which is not unlike the historical ways individuals with mental illness were treated (Szeto, Luong & Dobson, 2013). Although advances have been made toward treating mental health and understanding mental health (Sands, 2009), it could be argued that there is still a long way to go. Chernomas, Clarke, and Chisholm (2000) write, “In the face of multiple losses, social stigma, limited interpersonal contact, poverty, and feeling out of the information loop...women described leading marginalized, deprived lives in the pervasive shadow of their illness” (p.

1520). Moving forward, I will now discuss labeling theory, and how this is a large contributing factor in regards to the production and maintenance of stigma toward individuals with mental illness. Labeling theory was selected as a theoretical framework in an effort to learn more about how labels influence individuals and the general public. Szeto, Luong, and Dobson (2013) discuss how labels can negatively influence attitudes and perceptions. Moreover, Forsyth and Eifert (2007) express that “the label can even become a self-fulfilling prophecy – something you become. It’s hard to shake labels once they’re applied” (p. 32).

Labeling Theory

According to Rosenfield (1997) “labeling theorists examine mental illness as a form of deviance: The label rather than the behaviour per say shapes the fate of the mentally ill persons, by creating chronic mental illness or by compromising the life chances of those so labeled” (p. 660). Rosenfield (1997) goes on to mention that labeling mental illness can lead to cultural stereotypes or negative images of those associated with such psychiatric labels. Given that many individuals diagnosed with a mental illness are provided with a “psychiatric diagnosis” or “label” this suggests that labeling theory and its implications are worth exploring.

According to Martinez, Piff, Mendoza-Denton, Hinshaw (2011), the relationship between mental health and stigma has been widely studied, however the relationship between stigma and labels has not. Similarly, Szeto, Luong & Dobson (2013) found similar results with regard to the lack of research dedicated to understanding the connection between psychiatric labels, and stigma. According to the literature, labeling theory has roots in criminality, and delinquency (Martinez, Piff, Mendoza-Denton, Hinshaw, 2011; Revisto and Lanier, 2015; Rosenfield, 1997). Author Sara Rosenfield (1997) writes about the negative implications of labels, and the way it can further perpetuate stigma, especially in relation to mental illness. Similar to stereotypes

associated with criminal activity, individuals with mental illness were regarded as dangerous, unpredictable, and violent (Martinez, Piff, Mendoza-Denton, Hinshaw, 2011). Literature suggests that these labels reflect a form of deviance, and that the label only reflects behaviour rather than the actual individual and internal processes, which can have detrimental impacts on life outcomes (Rosenfield, 1997). Further, in her article, Rosenfield (1997) states,

Originally, labeling theory held that the expectations attached to the label perpetuate the mental illness. The theory was modified later to claim that the devaluation and discrimination created by the label interfere with a broad range of life areas, including access to social, and economic resources and general feelings of well-being (p. 660).

Throughout the remainder of this section, I will review the literature to highlight ways that labels have influenced individuals living with mental illness. One prominent theme throughout the literature is the association between a psychiatric label, and a loss of identity. Scheyett, and McCarthy (2006) researched the different service needs between men and women, and found that women felt invisible, as mental health practitioners focused solely on the mental health diagnosis, and less on the women themselves. Ritsher, Coursey, and Farrell (1997) suggest that even gynecological symptoms or other physical symptoms may be dismissed, as medical practitioners are too focused on the psychiatric diagnosis. Researchers Chernomas, Clarke, and Chisholm, (2000) also found that there was a connection between mental illness labels and loss of identity. They wrote,

The women felt that the health care system focused on their illness and that they had become invisible as women. In fact, they vacillated between seeing themselves as women and seeing themselves as “schizophrenics.” Over time these internal conflicts took a devastating toll on their self-image and well-being. With a tenuous sense of self, the women began to perceive themselves as powerless to control their lives and vulnerable to the demands of others (p. 1518).

Chernomas, Clarke, and Chisholm, (2000) findings are significant as they highlight to two detrimental elements of mental illness labels: 1) loss of identity, and 2) loss of self-worth,

self-esteem, and self-efficacy. This notion that labels create decreased self-worth, and self-esteem was another large theme throughout the literature (Camp, Finlay and Lyons, 2002; Ritsher, Coursey, and Farrell, 1997, Rosenfield, 1997).

In their article, Camp, Finlay and Lyons (2002) discuss the process of internal stigmatization as individuals learn and adopt attitudes from their social environment. Scambler (1998) describes internal stigmatization as “felt stigma”, which refers to the shame, and expected discrimination that individuals may face, which can then lead to withdraw and isolation. As a result, individuals with mental illness anticipate the mistreatment, and therefore withdraw from social ties, engage in secrecy, or attempt to educate others in an effort to deal with their mental health diagnosis (Camp, Finlay and Lyons, 2002). The authors argue that this process of internalized stigma is almost inevitable given that individuals with mental illness apply negative stereotypes and ‘unfavorable social conceptions’ to themselves (Camp, Finlay and Lyons, 2002, p. 824). Rosenfield (1997) contributes to this notion further through exploring the way that modified labeling theory effects one’s self-esteem and self-efficacy. Rosenfield (1997) explains that a sense of mastery and self-esteem are pivotal for setting and accomplishing goals. However, labels, and the stigma associated, greatly impede this sense of self-mastery and negative impacts result. Further, Rosenfield (1997) explains that stigma and the negative stereotypes associated with mental illness become the new ‘master status’, and as a result individuals’ evaluations of themselves decreases, and their self-esteem, and self-efficacy is compromised (p. 661).

Understanding label theory and the negative implications of labels with regard to mental health is critical for gaining a holistic perspective of mental illness, stigma, internalized stigma, and well-being. In the next section I will review the medical model, ways that practitioners have

approached working with individuals who have mental illness, as well as recommendations for change.

The Medical Model and Recommendations for Change

According to Beecher (2009) “the practice oriented medical model typically focuses on a process of seeking to identify the cause or root of a problem (usually through a diagnosis) and then prescribing treatment to eradicate or rehabilitate the problem” (p. 10). Therefore, the medical model views mental illness as a neurological problem that can be treated through the use of pharmaceuticals (Beecher, 2009). According to the literature, when a mental health diagnosis is made, treatment options are often explored in the form of medication as opposed to alternative interventions (Beecher, 2009).

Beecher (2009) writes that, “the medical model has a central importance of pharmaceutical medications, and most other treatments are supportive to psychiatric medical treatment” (p. 10-11). Some have argued that the medical model is too limited in scope, too simplistic, and too driven toward problem solving without accounting for environmental contexts (Beecher, 2009). The medical model can also be seen as problematic due to its close relationship with capitalism and a profit driven economy (Currie, 2005; Stickley, and Timmons, 2007). According to Currie (2005), “between 1981 and 2000, total prescriptions for all antidepressants increased by 353% from 3.2 to 14.5 million” (p. 1). Currie’s (2005) findings also state that global sales of pharmaceuticals topped \$400 billion, which is very noteworthy in our current profit driven economy. Currie’s (2005) findings are significant, and support the notion that the medical model is the prominent way of addressing treatment for mental illness. Throughout her book, “the marketization of depression: prescribing SSRI antidepressants to women” Currie (2005), explores the exponential growth of the pharmaceutical industry over the

past three decades, and the way our society has come to rely on medical intervention for mental illness. According to the literature the medical model has dominated in our society, but perhaps it is time to consider alternatives (Beecher, 2009; Currie, 2005).

Throughout the literature, a prominent alternative to the medical model is ‘relational theory’ (Manuel, Hinterland, Conover and Herman, 2012; Ritsher, Coursey, and Farrell, 1997; Scheyett, and McCarthy, 2006). Throughout the literature, researchers have found that relational theory is the preferable way to interact, and treat individuals living with mental illness (Manuel, Hinterland, Conover and Herman, 2012; Ritsher, Coursey, and Farrell, 1997; Scheyett, and McCarthy, 2006). Manuel, Hinterland, Conover and Herman (2012) suggest that the need for relationships and connectedness may be different among genders. More specifically, authors note that women have been socialized to be more connected, and therefore, relationships and social support may be more influential for women and their recovery (Manuel, Hinterland, Conover and Herman, 2012). Interestingly, Scheyett, and McCarthy (2006) also highlighted that other feminist researchers acknowledge the importance of connection and relationship in order for change to occur. Researchers also found that both men and women,

Emphasized the need for a relationship with mental health providers that is based on mutuality and respect. This finding is congruent with the large body of research that has suggested that nonspecific therapy factors, such as warmth, respect, genuineness, and the provision of hope, may be the most important component in effective therapy (p. 414).

Moreover, researchers Ritsher, Coursey, and Farrell (1997) found that participants felt respected by their physicians, and were given the option of being involved in their treatment planning. Researchers indicate that these findings were surprising, and not anticipated due to the extensive literature that claims otherwise (Ritsher, Coursey, and Farrell, 1997).

Similar to relation theory, another approach to working with individuals who experience mental illness is ‘recovery theory’. The literature indicates that individuals with mental illness

want a model that focuses on their abilities, their hopes, and their goals (Scheyett, and McCarthy, 2006). Manuel, Hinterland, Conover and Herman (2012) explain that, “Since the 1990s, we have seen a push for more recovery- oriented services that promote people’s health and well-being instead of focusing on their mental illness and symptom management (p. 307)”. Researchers also suggest that a recovery based model reinforces independence, and helps the transition process as individuals with mental illness move from hospital settings back into the community (Manuel, Hinterland, Conover and Herman, 2012).

These alternative approaches are noteworthy, as the literature indicates that the medical model may not be best suited for working with clients who have mental illness concerns. Additionally, the literature also suggests that individuals who have received services for their mental illness concerns prefer relational, or recovery base models due to the level of vulnerability and sensitivity involved. According to the literature, the medical model does not necessarily account for sensitivity, or genuine concern in the way that a recovery, or relational based model would.

Addressing the Gaps

After scanning the literature pertaining to mental illness, stigma, and women’s experiences a number of gaps have been identified. Firstly, it seems as though there is little research that focuses specifically on women’s experiences of living with a mental illness, and the relationship to stigma and discrimination (Scheyett and McCarthy, 2006; Wahl, 1999). Scheyett and McCarthy (2006) explicitly express that “fewer studies have looked at the different ways in which women and men may view and experience general services within the mental health system” (p. 408). Moreover, it appears as though there is literature pertaining to women and mental illness, but the element of stigma is lacking in the research. According to Wahl (1999)

few studies have actually researched mental health consumers, and how they feel about their experiences of stigma. Furthermore, after scanning the key articles used to inform the current research, seven included both male and female participants, whereas only three included only female participants. Interestingly, one article titled, “A Survey on Issues in the Live of Women with Severe Mental Illness” appears to be female focused, however, their participant sample included 107 women, and 59 men (Ritscher, Coursey and Farrel, 1997). This title is misleading, as the title suggests it is a female driven study, however, both genders are represented and studied.

Additionally, when initially scanning the literature for peer reviewed journals on the Wilfrid Laurier University Library database search results were disappointing. When searching the database using the keywords, “mental illness”, “stigma”, and “women” only 1,111 results appeared. Alternatively, keywords, “female”, “mental illness”, and “stigma” only yielded 685 results. The volume of articles that resulted could be perceived as quite low in comparison to other searches. Furthermore among the peer reviewed academic journals that did result, very few academic journals actually met the criteria for all three keywords. For example, some articles focused on “mental illness”, and “stigma”, but they lacked the female component.

Interestingly, it appears as though there is a problem of longevity given that research written in the late 1990’s and early 2000’s identified a gap in the literature relating between mental illness, stigma, and gender, and recent scans of the literature suggests the gap continues (Ritscher, Coursey, Farrell, 1997; Scheyett and McCarthy, 2006; Wahl, 1999).

Due to the identified gap in the research, the current study seeks to address this gap by contributing to a growing body of literature through exploring the relationship between mental illness, stigma, and the female experience. More specifically, this study will involve qualitative

interviews with women who have mental illness in an effort to explore their experiences of stigma on personal, or communal level as a result of their illness.

In conclusion, this extensive literature review provides an overview of historical trends that have greatly influenced our current society with regard to stigma and mental health. This literature review also included the definition of stigma, as well as an extensive examination of the ways that stigma can negatively influence individuals living with mental illness.

Additionally, the relationship between stigma and labeling theory was also explored, as well as the ramifications of such labels. Finally, the medical model of mental illness was also explored to provide insight into the way that mental illness is being treated, and the lack of focus on relationships, and recovery.

Methodology

The current study seeks to understand the lived experiences of women diagnosed with mental illness, and their experiences of stigma and oppression, using thematic analysis. This study also aims to provide suggestions and recommendations for ways to improve mental health services based on findings. Finally, another aim of this study is to produce meaningful results that will be useful for creating positive change through adjusting negative attitudes associated with mental health, and ultimately working to combat stigma.

Research Objective and Research Questions

The primary research objective of the current study is to explore women's perspectives of living with mental illness, stigma, and receiving community services. More specifically, my research objectives are: (1) To better understand the lived experience of women living with a mental illness, (2) To learn about how women define stigma, (3) How often women experience stigma, and discriminatory attitudes or behaviour from the public, family and friends, (4) To

explore, and better understand women's experiences of stigma and oppression, and how they cope, and finally (5) To explore avenues for changing attitudes and stereotypes toward mental illness.

Methods

Personal Standpoint and Social Location

Throughout this section, I will provide some background information regarding my personal standpoint, and I will also express my views around the topic of mental illness.

Some theorists believe that within qualitative research it is important to acknowledge the researcher's personal standpoint or how they view the world, since researchers are the primary instruments throughout the research process and their perspectives could influence data collection and interpretation (Denzin, 2009; Patton, 2002).

Throughout my childhood and adolescent years, I grew up in a middle class home in a rural area, and I was rarely exposed to topics such as: oppression, marginalization, diversity, or social justice. It was not until my undergraduate career that I became more aware of these prevalent social issues, and I was encouraged to think critically about them.

Throughout my undergraduate and masters level education, the prevalence and importance of mental health, possible interventions, and complex social systems were frequently discussed. Moreover, my professional work with individuals experiencing varying levels of mental health issues or illness, in conjunction with my values of justice, equality, and equity ignited my passion, and interest toward mental illness, and related topics. As an MSW student I have had the privilege of working as an MSW intern within local counselling agencies, which provided me with unique opportunities to meet individuals (primarily women) who shared their life stories and struggles with me. As a woman I could personally relate and understand some of

the challenges discussed, and some of the feelings they expressed. As a result of my personal and professional experience, it became important to me that women feel they have a voice within the larger social context to discuss their mental illness and the stigma they have experienced.

I personally feel that the stigma, and negative stereotypes aimed toward those experiencing a mental illness is unjust, and too frequent in today's society. Although efforts are being made to combat the stigma toward mental health or mental illness, I would argue that more needs to be done on a sociopolitical level. For instance, I feel that we need to move away from the 'neoliberal' model, the privatization of health care, and access to services. Instead of eliminating services and cutting budgets I would argue that we actually need to increase healthcare budgets, offer more subsidized housing, and create more social services to better serve the growing needs of our growing communities. I feel that the lack of political and media attention directed toward mental health will continue to disadvantage the continuously growing population of individuals living with mental illness(s). Although efforts are being made to reduce stigma toward mental health amongst the general population, I feel that more aggressive interventions are needed throughout all levels of society to create long-lasting change.

Theoretical Perspective

Using a critical feminist lens, guided by constructivist principles this study utilizes values and theoretical concepts from three contemporary paradigms, which compliment each other to create a holistic foundation that guides this research. The three frameworks guiding this study are: 1) Constructivism, 2) Critical theory, and 3) Feminist Standpoint Theory.

Constructivism. According to Ponterotto (2005) the constructivist approach suggests each and every individual constructs their own reality, and makes meaning of the world through their experiences. Similar to Ponterotto article, Wahl (1999) shares a similar philosophy with

regard to constructivism, and respecting the individual's reality, and lived experiences. Wahl (1999) writes, "to truly understand and appreciate what stigma is and how it affects people with mental illnesses, we have to hear from the ones who face that stigma on a daily basis" (p. 468). This is particularly important for the current research study, as it is believed that the participants' are the experts within their own lives, and therefore, understanding their realities, the way they view the world and their experiences are key.

Unlike a more positivistic approach, the constructivist approach also assumes that it is difficult for the researcher to remain neutral or removed from the research they are conducting (Ponterotto, 2005). Thus, given that the researcher will also have their own values, experiences, and meanings of life, the constructivist approach encourages the researcher to be aware of their own biases, but not dismiss them from the research process (Ponterotto, 2005). Therefore, the decision to use the constructivist paradigm as a foundation for this study was strong because the primary researcher has worked with many individuals experiencing mental illness, and has developed a strong passion, and interest in this topic.

Furthermore, according to Ponterotto (2005), the constructivist approach encourages a rich, 'researcher-participant dialogue' to co-construct findings, and bring forth underlying meanings, and interpretations of the world to the research surface (Ponterotto, 2005). Since the constructivist paradigm focuses more on individuals' realities, and personal experiences, qualitative research methods are commonly used. Qualitative methods refer to research instruments that seek to understand and interpret a person's reality within a context-specific situation (Ponterotto, 2005). In conclusion, since the current study sought to investigate participant's experience of mental illness, and their experiences of stigma, negative attitudes, and

oppression due to their conditions, the constructivist paradigm was the most appropriate foundation for this study.

Critical Theory. The second paradigm that will be used to guide the current research is the critical-ideological paradigm (Ponterotto, 2005). Similar to the constructivist paradigm, the critical-ideological also believes that: 1) a researcher's values, and perspectives should be considered, if not immersed within the research, 2) there are multiple realities, and 3) qualitative methods are preferred (Ponterotto, 2005). The primary difference between the two paradigms, is that the critical-ideological paradigm aims to 'disrupt and challenge' the status quo, to empower participants, and to use research to transform societal norms (Ponterotto, 2005). More specifically, "criticalists conceptualize reality and events within power-relations, and they use their research inquiry to help emancipate oppressed groups" (p. 130). Together, the constructivist paradigm, and the critical-ideological paradigm promote research that is meaningful to all parties involved, as well as challenge social norms, and power imbalances through knowledge mobilization and empowerment (Ponterotto, 2005).

Feminist Standpoint Theory (FST). The final paradigm that will help to guide and inform the current research study is FST. According to Swigonski (1993) FST "directs researchers to identify research problems within the daily reality of marginalized groups – groups whose life experience have been put into the margins of scholarly works – and to take these groups...out of the margins and place their day-to-day reality in the centre of the research" (p. 172). Furthermore, FST attempts to address social structures that have lead to marginalization, and understand how these social structures have created and perpetuated problems (Swigonski, 1993). FST was selected as a theoretical framework for this study due to its awareness of patriarchal norms, power dynamics, systems of oppression, imbalances of

equality among genders, and human rights (Arslanian-Engoren, 2002; Gedro & Mizzi, 2014; Swigonski, 1993). FST was also identified as a framework for this study, as it was important to understand women's experiences, and realities directly from their perspective to learn how social structures have influenced their daily lives (Swigonski, 1993). FST was also appropriate for the current study because understanding women's experiences relative to mental illness and stigma was the core objective of the research (Swigonski, 1993).

Choosing a feminist framework to guide and inform the research was important because the current study wanted to create a gendered understanding of living with mental illness and experiencing stigma. Furthermore, according to the research woman's productive rights, and ability to parent were called into question due to the presence of their mental illness, and this was something I wanted to explore further throughout my study in regards to gender (Chernomas, Clarke, & Chisholm, 2000; Ritsher, Coursey, & Farrell, 1997). For example, Chernomas, Clarke, and Chisholm (2000) found that "a deep sense of loss, grief, and some anger haunted the women who had lost their children to child and family services" (p. 1519). Also, the current research wanted to provide an opportunity to give voice to women and their experiences in a research area that was lacking. Although studies have been conducted using both male and female participants when studying mental illness and stigma, it seemed as though the research focusing solely on the female perspective was lacking. Therefore, this helped to inform my decision to focus on recruiting only females for my study.

In summary, the current study will utilize elements and concepts from the constructivist paradigm, the critical-ideological paradigm, and the feminist theory to create a comprehensive, holistic foundation for conducting this research. Collaboratively these paradigms compliment one another, and promote research that is focused on understanding the individual's reality,

while also dissecting complex social, economical, and political, norms. Furthermore, these paradigms encourage research that promotes change, knowledge dissemination, and challenges society's engrained attitudes, and behaviours. Finally these theories also encourage the researcher to engage in critical thought, and evaluate the findings using a socio-political, gender specific lens.

Research Design

In total, five women from the Kitchener, Waterloo, and Cambridge area participated in the study. Participant's ages ranged from 30 years to 50 years, they all had children of their own, and none of them were working at the time of the study. Additionally, four out of the five women were Caucasian and the other women's racial and ethnic information has been withheld for confidentiality reasons. Additional participants were expected, however, recruitment was difficult and possible limitations could have decreased participant interest. Participant recruitment and limitations will be explored in subsequent sections.

All participants were recruited using a community flyer developed for the study (see Appendix B). This flyer was posted within local social service agencies in the Kitchener-Waterloo, and Cambridge areas so that participants could respond on their own accord. Additionally, some individuals were offered to participate in the study by staff of a local agency that felt their clients might have an interest.

Using the information provided on the flyer, individuals could then contact my supervisor, Magnus Mfoafo-M'Carthy, faculty member at Wilfrid Laurier University, to express their interest in participating in the study. My supervisor would then notify me, the primary researcher that an individual was interested in participating in the study, and the primary researcher would contact the individual via phone or email to determine an appropriate date,

time, and meeting place to have the interview. All participants were given a \$20 gift card to Conestoga Mall, as compensation for their involvement in the study. This compensation was justified as participants may have dismissed themselves from other commitments in order to participate in the current study.

The purpose of involving my supervisor was to maintain my privacy and restrict my personal information from participants. Given that I would be meeting with participants to discuss personal information I felt that it was important to implement boundaries and maintaining my privacy was one way of accomplishing this.

Interview procedures

Semi-structured, qualitative interviews were conducted with participants. The interview guide was developed using identified research objectives and previous literature to inform the development of questions (see Appendix A). Special considerations were made when the interview guide was being developed in an effort to limit participants' possible feelings of discomfort, or distress when answering the interview questions. All participants completed a consent form prior to beginning the interview and they were reminded that they could decline answering a question, or withdraw from the study at any time (Appendix C). All interviews were conducted in public spaces such as coffee shops or Community Centres near participants' homes. Together, the primary researcher, and the participants determined an appropriate place that was public, and accessible. Recruiting started in May 2015 and ended in November 2015. All interviews were conducted within this time and most of the interviews lasted approximately 1 hour in length. Interviews were audio recorded, and then downloaded on to a password-protected laptop. Using a confidential USB, audio files were then transferred in person to the transcriptionist for this study who downloaded the files on to her password-protected laptop.

Ethics

It should be noted that the current study was approved by the Wilfrid Laurier University Research Ethics Board (REB) prior to research starting. The REB approval number for this study is: 4088.

Possible Benefits. The proposed study was beneficial because it explores a topic that is quite relevant and important in today's society. According to the CAMH, "20% of Canadians will personally experience a mental illness in their lifetime" (CAMH, 2015). Thus, approximately 1 in 5 people will experience a mental illness. Due to the high prevalence of mental illness among our population, it is important to explore attitudes and behaviours toward those living with a mental illness. As the literature has demonstrated our society has adopted negative stereotypes, and perspectives of mental health, and therefore, it is important to understand the way that stigmatizing, and oppressive views affect individuals living with mental health conditions. Furthermore, this research study will provide participants with a safe, welcoming opportunity to share their experiences of living with a mental illness, and the ways in which they have been treated.

In addition to exploring individuals lived experiences of stigmatization and discrimination, this study will also provide sociopolitical suggestions and possibilities for change. It is also anticipated that participant's narratives will provide recommendations for changes due to their lived experiences of being stigmatized, and marginalized due to their mental illness.

Possible Risks. Firstly, the psychological risks associated with this study were minimal. There was a risk that during qualitative interviews participants may have become uncomfortable, or upset as they recalled difficult memories or life experiences. For example, when thinking

about their experience of living with mental illness, and being stigmatized, some participants may have felt sad, lonely, helpless, angry, or frustrated when answering interview questions. As a precaution, the primary interviewer was intent on providing empathy, active listening, and compassion when interviewing participants. Moreover, the primary researcher also reminded participants that they could withdraw from the study, or take a necessary pause if needed. Further, if suicide or suicidal thoughts were discussed during the interview, the primary interviewer and the participant discussed a safety plan, and external supports were identified. If participants were distraught during or following the interview, participants were encouraged to seek the support of distress helplines, or the support of family and friends if needed. Additionally, potential psychological or emotional risks were minimized by carefully wording interview questions so as to avoid inspiring feelings of shame, isolation, or embarrassment. Further, my thesis advisor and I collaboratively developed the interview guide (see Appendix A) with an emphasis on limiting participants' distress during the interview process.

Secondly, the social risks associated with this study were minimal. The primary concern for this study was that all interviews were conducted in public places such as coffee shops, or community centers, and therefore people sitting nearby may have been able to hear the content of our conversations. This is a possible ethical risk as participants may have been uncomfortable, or concerned about others' perceptions of the participant narrative given the sensitive nature of the study. As a result, participants could have been uncomfortable, or less willing to share due to these concerns. In an effort to control this ethical risk, the primary researcher made an effort to observe the participant's comfort level during the interview. If participants appeared upset, the primary researcher may have checked in, paused the interview, or suggested another time to have the interview.

Confidentiality. Due to the sensitive nature of this study, confidentiality was very important for the proposed research. In order to ensure that participants remain anonymous, a number of precautions were taken. Firstly, participant's names were replaced with pseudonyms and all identifying information was removed prior to any publications. Secondly, all researchers involved in this study have taken the 'Tri-County Policy Statement: Ethical Conduct for Research Involving Humans' training, and are listed in the ethics application, thus they were aware of ethical responsibilities. Thirdly, all identifying information, interview audio files, and transcripts were kept on a password-protected laptop of which only identified researchers have access to. Additionally, all consent forms were stored in a secure location, of which I will be the only one with access. Lastly, all paper files were kept in a secure location with lock access and all electronic files were kept on password-protected laptops.

Feedback to participants. Participants were notified in the consent letter that the findings of this study would likely be published in professional journals and presented at conferences and forums in the community. If participants expressed interest in obtaining a copy of the findings they were asked to provide a phone number or email address when signing the consent form in order to receive a copy.

Analysis

Thematic analysis was used throughout the current study when analyzing and interpreting the qualitative data collected from interviews. According to Braun and Clarke (2006), "thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data"(p. 79). To demonstrate my use of thematic analysis I will provide a detailed account of my analysis processes.

To begin, a thorough analysis of the data began with reviewing each transcribed audio file, and coding the data to look for key words or emerging themes (Ponterotto, 2005; Patton, 2002). For example the quote, “I’m lonely, I’ve lost a lot of friends, I lost my boys, and I lost my freedom. I gained a lot of weight. I’ve lost who I am” was identified as a theme of ‘mental illness’, which was further categorized into ‘diagnosis’, which was then further categorized as ‘personal changes following a mental illness diagnosis’. From there, the quote was broken down further by what changed specifically in the participant’s personal life including: emotions, physical changes, worldview, social life, etc.

Transcripts were created verbatim through listening to the audio files of the qualitative interviews and transcribing all communication word for word. Among the interviews, I personally transcribed three of the five interviews, and a hired transcriptionist completed two. Further, myself and the external transcriptionist discussed a process for transcribing in an effort to keep the completed transcripts clear and consistent.

Once emerging themes were identified, I used Nvivo software to categorize my research by various codes. Nvivo 10 is a software program that allows you to easily organize and categorize qualitative data directly from participants’ transcribed interviews (QSR International, 2012). More specifically, Nvivo allows you to drag text directly from the transcript into the created categories (QSR International, 2012).

To begin the analysis process, I reviewed one interview at a time making note of different key words, and emerging themes by dragging text directly into the appropriate codes in Nvivo (QSR International, 2012). It is important to note that all possible themes or key words were identified when reviewing the first interview in an effort to capture all possible categories and codes. I then moved onto the next interview and repeated the same process. Additionally, I added

more codes if necessary, and went back to previous interviews if something had been missed, or something new was discovered. Once I finished coding all interviews, I organized primary themes and key words in relation to the research questions asked. That way, I could break up the data according to my identified research objectives.

In addition to thoroughly coding transcripts, I also kept detailed notes of emerging themes or interesting insights. Keeping notes about methodological decisions while reviewing the data may help to add validity and credibility to the study if similar patterns are discovered throughout memos and the final analysis outcome.

Rigor. Throughout this research project rigor was present in numerous ways. Firstly, as a researcher I have completed two additional theses and worked as a Research Assistant for my professors completing multiple research projects. Therefore, having worked under qualified researchers and been mentored by established professionals, this adds integrity to my skills and work ethic as a researcher.

Secondly, throughout this study I had multiple points of engagement with the participants. More specifically I communicated with participants prior to the interviews, I conducted all of the interviews myself, and I had contact with participants following interviews as well. Due to my close engagement with the participants, especially during the interview process I am most informed and familiar with the data. Furthermore, I also transcribed three out of the five interviews, which is yet another point of contact with the data. Therefore, having been involved at multiple points throughout the research process adds to the credibility of my analysis and findings of the data.

Thirdly, I completed member checks with my Supervisor throughout different stages of the research process and I also kept researcher memos to document interesting thoughts and findings along the way.

Finally, there is value in being a woman-identified researcher working within the field of mental health and doing research with woman-identified participants. Unlike a male researcher, one could argue that I am able to connect with and understand the women on a deeper level, as well as their presented issues and concerns. Additionally, there is credibility in being deeply connected and passionate about the research topic, as the breadth and depth of my understanding may exceed others. Moreover, my personal investment in completing rich, meaningful research in this area adds to rigor as well.

Results

The results section of this study will be broken into three categories: a) mental health, b) stigma, and c) services, which was informed by the interview guide. Through the use of thematic coding a number of emerging themes were identified within each category based on the questions that were asked. As a reminder, all participants' names have been replaced with pseudonyms in an effort to maintain confidentiality.

Mental Health

Questions regarding clients' mental health were designed to learn more about participants' experiences, feelings, and concerns regarding what it is like to live with a mental illness. Findings are reported using some the questions used throughout the interview guide. These particular questions were selected as they highlight some of the major themes, and subthemes throughout the data. These questions provide a context for the way that participants feel about their diagnosis, and how things may have changed in their life due to their illness.

Could you tell me how it feels to be diagnosed with mental illness? Participants provided a number of responses with regard to how it feels to be diagnosed with a mental illness. Among some of the answers at least two or three participants said that living with a mental illness is: hard, frustrating, lonely, they wondered ‘why me’, they feel they can’t do anything, and they had feelings of sadness. They also mentioned feelings of being: numb, embarrassed, lost, trapped, shameful, stupid, and relieved. Below are a few narrative examples demonstrating some of the more prevalent themes.

When discussing her experience Amy stated, “It’s hard. Because you know the name of your illness, it all comes with a sadness that an illness that is now with you for the rest of your life, and knowing that there may not be hope that it ever goes away”.

Linda expressed her feelings of loneliness,

It made me feel very lonely. Because I was always surrounded by people, and then all of a sudden in dealing with all of this bull shit and nobody’s there. If I wanted to call up my friends and say “Hey, lets go out and get some coffee and have some fun” it was there, but then after three months in the hospital, “Oh were busy, we can’t come”.

Additionally, Mary said, “Like, just what is wrong with me? Why do I have this? You know, why do I have bi-polar. I didn’t understand”. Interestingly, four of out the five women also reported feeling relieved after learning about their diagnosis. Participants talked about feeling relieved that they could put a name to how they were feeling and they could move forward with a course of action after learning what was going on. For example, when I asked Sandy how it felt to be diagnosed with a mental illness, she said she was relieved, and why I asked why, she replied, “Because they couldn’t figure out what was wrong. I knew there was something wrong, but I didn’t know what”.

Based on participant responses, it appears as though the participants felt a wave of emotions once diagnosed with a mental illness.

Are you the only person who feels this way? When participants were asked if others living with a mental illness may feel the same way they do, all five participants expressed that they believe they are not the only ones. Originally, Barbra stated that she felt like she was the only one, however, later she changed her response to say she was not. When I asked Sandra if other people feel the same way as her, she responded by saying, “No I think other people do. I do not think that I am the only one, I think other people feel that way too. Yeah.”

What were some of your concerns once diagnosed with a mental illness, if any?

Participants expressed a variety of concerns once they learned about their mental illness. For example, participants said that they were concerned about the lack of understanding around mental illness; they feared being limited by their illness, they worried about their future, and how others might respond to them. Participants also talked about their concern around not being trusted, and financial stability. Among these responses at least two, or three participants explained that their primary concerns were lack of understanding, being limited by their illness, and considerations for their future. Here are a few examples:

Amy stated, “He doesn’t understand. I don’t think he has enough life experience to understand. I don’t think he really understands what it’s like”. Interestingly, Mary shared similar feelings when she said, “Yeah, nobody seemed to understand”.

Alternatively, Linda shared her concern around being limited by her diagnosis, and worry for her future when she said, “Yeah, I wanted to go to school, and I wanted to learn, and I wanted to work, and I wanted to paint, and I wanted to have friends and go to bars, and I couldn’t.... I was worried about how I was going to live.”.

Barbra had similar thoughts as she told me her difficulty in keeping a job, and her concern around keeping a job in the future “I wanted to go to a job, and keep up with the job, cause sometimes I can’t keep the job”.

How have things changed for you since you were diagnosed with a mental health condition? Participants explained that following their mental health diagnosis some things in

their life changed. These changes have been categorized into ‘personal changes’, and ‘social changes’. Data reveals that all women experienced a personal change once they were diagnosed with a mental illness. There were some similarities, and some differences in their experiences. Following their diagnosis some women talked about feeling constricted in their personality, and sense of self. Others talked about how their physical identity changed due to taking medication and gaining weight.

When discussing how her mental illness has affected her life, Amy said, “I’m lonely, I’ve lost a lot of friends, I lost my boys, and I lost my freedom. I gained a lot of weight. I’ve lost who I am”.

Similarly, Mary said that she also gained weight due to her medications, and that was one of the primary reasons she wanted to stop taking it. Mary also expressed that before her diagnosis she felt more confident, and useful in the community,

I had more – what is the word I am looking for – more confidence. Like I would do things more and now I kind of second guess myself, I think well I don’t think I can do that, you know, but before the condition I would do stuff... Today I don’t think I would have the confidence, the self-esteem, or you know, the trust in myself to do it. So that changed that one, my daughter said that to me one day. She said mom, you used to do a lot of stuff before you were bi-polar. She was right, I did, now I don’t know if I could. Maybe if someone came with me and pushed me – but on my own I don’t think I would.

Sandy talked about how her mental illness led her to feel down some times, "With depression, sometimes I just want to walk through it and other times I put myself down about it. That is why I need the medication... I think really bad thoughts about myself"

Interestingly, when I asked the participants if their perception of themselves changed due to their mental illness, two women said that it didn’t. Barbra clearly stated that “No” her mental illness didn’t change her perception of herself. Similarly, throughout her narrative Linda suggested that she always knew who she was, and after being diagnosis with a mental illness, her personality and identity only began to evolve and grow.

In addition to personal changes in their life due to mental illness, participants also talked about the way that their social lives were influenced. The most common response among participants was the way their relationships with their friends changed. Participants expressed that their friends began to distance themselves, or act differently around them. Mary explained,

I think they behaved different, I think they didn't know how to behave. I don't know, like they behaved like something was wrong with me. Like I was retarded...not retarded but just...I don't know, it was just different. I know they acted different because I could feel it, like...I don't know it is hard to answer. I don't know it was just different. Not now, but at the beginning they were. Even people I knew were different when they found out I was bi-polar.

Linda shared a similar story about her friends learning of her illness, and what it felt like to be isolated, and not accepted.

It kind of made me think about what was wrong with me. It kind of made me think about-it made me feel damaged, it made me feel-I don't know? It just-damaged, and not accepted. It made me feel very lonely. Because I was always surrounded by people, and then all of a sudden in dealing with all of this bullshit and nobody's there. If I wanted to call up my friends and say "Hey, lets go out and get some coffee and have some fun" it was there, but then after three months in the hospital, "Oh were busy, we can't come".

Two participants also spoke about how their relationships, and willingness to date was affected by their mental illness. When I asked Amy if her diagnosis affected her personally, she responded by saying: I wont date. [I: And I why is that?' Because who wants to deal with this? Who would want somebody who has this? You know?

Linda expressed similar concerns as Amy when she said,

Like a dating type situation I was always wondering, do I tell someone when I first get to know them that I have-cause my illness is, it's a little bit sort of severe compared with some other people's mental illnesses, you know? So ...that's what I always wondered always...at one point, do you tell someone that you've just met, if you wanted to continue having them in your life? [I: So did you fear that by being honest and telling them, that they wouldn't want to be in your life?] Yeah.

Both women suggested that the presence of their mental illness made them feel undesirable, and that their mental illness made seeking a prospective partner challenging, as they feared that no one would want to commit to them.

How open are you with speaking to others about your mental health? When I asked participants if they are comfortable speaking with others about their mental health, the responses were mixed. Throughout their responses some participants said that they were: open about their mental health, but it also depended on whom they were talking to, and how they felt that day. Participants talked about feeling vulnerable, and ‘feeling’ people out to see if they felt comfortable enough to share. Sandy shared,

It depends. I just depends on who it is...And I just get to know like if they will understand or not. Like sometimes I know when people are going to be judgemental so I don't tell them nothing. Well I can feel if they are going to be like, what's wrong with you, or whatever, why are you like that. I tell certain people I don't tell everybody.

Alternatively, participants mentioned that when talking about their mental illness they feel vulnerable, and fear possible judgment or rejection. Interestingly, participants talked about feeling a range of emotions when it came to talking to others about their illness. Amy expressed that at times she feels embarrassed to share that she lives with a mental illness because people can be very judgmental and mean at times. Despite this, Amy also shared that the topic of mental health is something that needs to be talked about.

It's embarrassing, it was embarrassing, and it can be embarrassing when people judge you on it. But people need to know that it's ok...I talk to my workers, I talk to my friends, my daughter knows, my kids know, I talk to-and I had to let my kids know because they're very dependable, you know it's genetic, and anybody that needs to know. So that's why I called you, as soon as I saw that-cause I think I need to talk about this.

Overall, participants' narratives suggest that they are open about talking with others about their mental health providing it is a safe, comfortable, understanding environment. Further,

if participants felt that the recipient would be judgmental, or take the news poorly, they would refrain from opening up.

Stigma

Another large section of the interview guide was developed around stigma, and understanding how participants define stigma, and how they are affected by stigma in their lives. Findings in this category help to inform some of the challenges faced by those with a mental illness, and the negative implications that result.

What is stigma? After asking participants a number of questions related to mental health, we then began to discuss stigma, and what it means to them. Among the five women, each of them provided a different answer however, there was a distinct theme. Three of the women talked about stigma in reference to something “bad” or “negative”. Alternatively, Linda referred to stigma in terms of judgment, and placing judgment on others based on social norms. She said,

I think it's like someone judging based on that they shouldn't judge you about. And stigma is like-I think it's a preconceived notion if what somebody else has mental illness from TV, movies, pop culture, they think if they see something as “Oh well, you're crazy” that's stigma.

Although she does not say it explicitly, throughout her response Linda addressed many things such as: social norms, stereotyping, media influences, and the use of negative language such as “crazy”. Finally, Barbra expressed that stigma is ‘sadness’. When I asked her what she meant by sadness, she said “Because people don't want to be with you, or they afraid”. Similar to Linda's understanding of stigma, Barbra suggests that stigma is informed by predetermined ideas, or societal attitudes that have been created around mental health.

Signs of stigma. As just mentioned by participants, stigma can be expressed and communicated in many different ways. Throughout the interviews participants shared stories of

experiencing stigma, and the various ways that they could sense that they were being judged, mistreated, or stigmatized. The women suggested that stigma was identified by: tone of voice, use of language, and eye contact, facial expressions, and body language.

Tone of Voice: Firstly, four women talked about tone of voice as sign of stigma. Linda explained that people speak to her in a ‘special voice’. For example, when getting her medication from the pharmacist she said, ““So these medications might make you a bit sleepy (in special voice)” and it’s like “Come on lady! I’ve been taking these medications for longer than you’ve been alive!” Amy shared a similar experience when working with a mental health worker,

He talks down to me, and I hate that. I absolutely hate being talked down to. I’m intelligent, and I really hate that...being constantly talked down to. And whether he realizes it or not, it’s happening... Yeah. I’m an adult, I’m older than he is, and he needs to talk to me like I’m an adult

Three of the four women who felt like they were being talked down to felt as though they were being treated like they were stupid or unintelligent. Linda and Amy particularly refer to the fact they were older than the individual speaking to them, and they appear to be quite frustrated.

Use of Language: Similar to tone of voice, four women also made reference to use of language when sharing their experiences of stigma. Throughout their stories, I commonly noticed participants using words or phrases like: ‘crazy’, ‘freak’, ‘snap out of it’, ‘get over it’, and ‘normal’. Throughout my interview with Linda she used the word ‘crazy’ six times to describe herself, the way that people may see her, and stereotypical ideas of what mental illness looks like. For example, when describing what mental illness might look like she said, “crazy lady who lives in the attic bedroom that has 87 cats and loves Star Wars”. Mary also used the term freak when considering how people may see her. She explained, “But other people, it is like, taboo. Like oh she is bi-polar, she is a freak, ... lets not let my kids be with her. That is what I think. They have never said that, but I think they think that.”

Additionally, Amy and Sandy talked about how their friends or family members would tell them to ‘snap out of it’ or just ‘get over it’ when it came to dealing with their mental illness. When talking about her friends, Amy said, “They would say to me, “I’m depressed-I was depressed, but I snapped out of it”, “I’m depressed, but I take a pill every day and I’m fine”. Amy was suggesting that her friends felt that she could also snap out of her mental illness and move on, when she that wasn’t necessarily the case. Sandy shared a similar experience and said, “People will think, just get over it type of thing. It just doesn’t work that way”.

Finally, I also noticed that participants used the term “normal” quite a lot when discussing their experiences. Three out of the five women used it throughout their interviews. For instance, Mary said, “Well because when you are normal, you don’t have a mental illness you don’t have a stigma behind you. Mental illness means stigma, and have to pay that price for your whole life”. I asked Mary if she thought that normal was the absence of mental illness and she said “Kind of... Because it is about labeling”. Amy also expressed a similar thought about being ‘normal’ when talking about her friends, “And life revolves around mental health, whereas theirs revolves around a normal life, and mine used to be a normal life, and it isn’t anymore.” These women suggest that you are not ‘normal’ if you have a mental illness, which is interesting given that the term ‘normal’ is so ambiguous, and complex. Nonetheless, these women suggest that they feel different, or have been identified as ‘different’ once they are diagnosed with a mental illness.

Eye contact and Keeping a Distance: Three of the five women referred to instances where others’ eye contact clearly conveyed their thoughts and feelings. For example, Linda said that once a neighbour learned that she is schizophrenic, she avoided all eye contact with her, and would no longer socialize her. Linda also mentioned that prior to telling this neighbour about her

mental illness they would talk at the bus stop, and socialize when Linda would take out the garbage, however, this changed once her neighbour learned of her mental illness. Linda shared that this particular neighbour also avoided eye contact with her, and her body language changed upon learning of Laura's mental illness. Laura shared,

I was speaking with a woman, I was waiting for the bus, and I was speaking with a woman who lives in my complex, it's like a 50 unit townhouse, so she was talking to me about where do I work, and other things like that, and "well I don't work", and "oh you injured?" you know, because you can't see-so I'm like "No I have a mental illness and its called bipolar disorder" and she's like "Oh". And I'm like "Ok?"

Barbra also said that people have rolled their eyes at her on different occasions. Finally, Sandy expressed that "people look at you kind of funny. It is not something that you can control". Although it wasn't explicitly said, these women suggest that they felt stigmatized or uncomfortable due to the fact that others were avoiding eye contact, or making unnecessary facial expressions.

Facial expressions: Both Sandy and Barbra discussed occasions when people were making facial expressions that lead them to feel judged or uncomfortable. Sandy said that during an interview she was asked a lot of odd, and unnecessary questions. Sandy said that they were questions not commonly asked, they were leading, and the man was smirking at times. Sandy suggested that the man was asking questions about her mental health, and he found some of her responses humorous. Additionally, when Barbra and I were discussing certain facial features, she proceeded to make funny faces, and said that people sometimes look at her that way. Barbra was suggesting that she can recognize when people are making fun of her.

Seeking support, and challenges in finding connection. All of the participants expressed that when seeking support from friends, community members or family, they had both positive and negative outcomes. More specifically, three out of the five women explained that

they received support from some friends. The women expressed that these particular friends have been good supports, because they are trustworthy, reliable, and compassionate. Sandy shared a personal experience about the way her friends have supported her, “I would say they have supported me a lot, I get a lot of support from them... They take me to doctor office appointments, everything I want to do.” Although some friends have been supportive despite the presence of mental illness, not all social connections lasted. This topic will be explored in subsequent sections.

In addition to receiving support from friends, four out of five participants expressed that they received support from their immediate community members, and local services. For instance, Linda was telling me about a time when she was speaking with someone from the community and telling them about her mental illness, and they responded by saying, ““Oh my sister’s boyfriends, friend’s husband’s nanny had that problem” and you’re like “Really! That’s interesting”. Instead of feeling judged by her mental illness, Linda was able to create a connection with this community member. Amy also shared a story about when she was experiencing a panic attack at her daughter’s school, “And I as I panicked, I bumped into the Vice Principlal and he’s like “Ok, wait a minute, I will get you a seat, here’s the door you can see (name removed) and you can get out if you need to””.

Participants also shared stories about receiving support from their family members. More specifically, three women said that they received support from family members whether it was a parent, spouse, or child. For example, when describing her relationship with her Mom, Mary said “We had a good relationship, and she died eight years ago. It will be eight years this December and yeah I miss her a lot. She helped me a lot, you know, she supported me a lot over the time.” Similarly, Linda shared a similar relationship with her Mom,

My mom really supported me throughout the whole thing. The first time I was in hospital, I was in for 6 months, and she came every single day at lunch, cause she worked at *name* so she just walked over, and then she would come in the evening as well.

Interestingly, throughout the women's' narratives I noticed support may have been present, but stigma was also evident as well. For instance, Linda highlighted that her Mother may have been there for her physically, but she was not very supportive emotionally. Linda stated that her Mother was never very emotionally supportive, and she still is not to this day. Linda shared that while driving to an appointment with her Mother she said to Laura, ""You should make friends with other people like you". I was like, "Why would I do that?", she's like "Well you know, just other people like you"". This interaction suggests that Laura's Mother views her differently once she was diagnosed with a mental illness, and she should associate with others who live with a mental health condition. Additionally, Barbra had a similar response from her family with regard to medical vs. mental health concerns. She expressed that her family were much more understanding of her physical illness because it is something they can see, and it may be more accepted, whereas mental health was completely avoided.

Further, all five women reported that their family would not acknowledge or converse about their mental illness, and things were to be kept private. Amy shared, "I was very depressed as a teenager, but...weren't to talk about it, because that's the way it was, the family doesn't talk about it.". Linda and Sandy mentioned very similar experiences. Linda mentioned that her family is very "veiled", and "everything is inside the family", and Sandy said, "We didn't talk about it much in our family".

Participants also talked about friends distancing themselves once their mental illness became known. Amy said that she once had a close friend that she would hang out with often, but after she disclosed that she had a mental illness, this particular friend did not want to

associate with her as much. Linda shared a similar story when she told me about how things changed for her once she was diagnosed with a mental illness,

It felt kind of crummy because I thought that I had all these friends, like I had thought that-like I was going to (Name of school removed) then and I thought that I all these friends awesome friends, because I was popular and bubbly, and I knew everybody, and then I got sick and it just snowballed and then people like they cared, and then they moved on, just like anything else. And it felt shitty; it felt shitty to have people just give up on you, or for you to just become passé. It's like "OH well we did that, and now we're moving on" so...

On a more communal or societal level, three out of five participants expressed that the media portrays and depicts mental health in a very negative light, and consequentially stereotypes and preconceived notions are established. Amy said, "I feel like it's-people look negatively toward mental health because it's so reported so negatively in the news, and in public, and in everything, so of course everyone looks at it negatively". She went on to say that because the media suggests that because murder, suicide, crime, or bombings are associated with mental illness people develop the wrong understanding and perspective. Linda also made a similar statement expressing that media and pop-culture have created negative attitudes toward mental health. However, she also commented on the ways that mental health is changing within our society. She said, "I think that now that everyone's talking about it, the support system that was in place and dealt with everybody and now that it's better or it's more acceptable to say you need help".

Participants' feelings due to stigma: Despite campaign efforts and changing social norms, there is still a lot of stigma associated with mental illness. Participants shared instances of receiving support from family, friends, and community members, but they also talked about being exposed to negative attitudes and stereotypes, judgement, and rejection. When I asked what it felt like to be stigmatized, the women shared that they felt: sad, left out, hurt, lonely, like

a monkey at the zoo, and at times the stigma made things worse. Throughout their responses, four out of the five participants said that being stigmatized made them feel sad. For example, Amy said, “It’s sad. It makes me question, whether I’m worthy of being here? Whether I’m wanted? Whether there’s any point in being here?”. Participants talked about feeling very isolated and lonely”. Amy also talked about feeling as though her intelligence, and her ability to parent was being questioned by her family, “Maybe we can take care of (name of daughter removed) better than you can?” Or “maybe you should start asking for -and just relax” and it just hurts because I’ve been coping for 14 years, and that-that hurts”.

Alternatively, Linda told me that she felt like a “monkey at the zoo”, and what it was like when she was first admitted to the hospital, “big groups would come on visiting times, like “Oh hey!” and then it dwindled, and it became, like it was fashionable, it was a fad to go see the ‘girl in the psych ward’”.

Due to the increased feelings of loneliness, and judgment, I noticed that participants stigmatized themselves without necessarily acknowledging it. When talking about her relationship with her husband, Linda said, “And he has to deal with the weird, right? Poor guy- when my brain is-it’s chaos inside so it needs to not be chaos outside. ...and I’m not OCD weird like that”. Linda suggested that her husband and is ‘poor-guy’, because he has to ‘put up with her’, and the ‘weird’. Linda also made another interesting comment when she said, “I think it did. I think I turned more inwards, and I wasn’t quite as-if the people around you are uncomfortable around you then you eventually become uncomfortable with yourself”. Her comment suggests that because of the cues she picked up from her social environment, she began to internalize those feelings as well. Also, as discussed earlier, Amy and Sandy talked about this

notion of being ‘normal’, and they suggested that they were no longer ‘normal’ now that they are living with a mental illness.

Additionally, four of the five participants talked about the way in which their self-esteem was affected by the stigma they experienced. When I asked Amy how stigma affects her self-esteem she replied, “Oh, it nips, totally low. Really low. Not wanna be here low.”. Sandy also shared a similar experience to Amy’s. She said, “It does affect you, I think it definitely does affect you. You get more sad and more depressed, so it is a vicious cycle”.

Due to the decreased self-esteem, and feelings of isolation, four out of five participants talked about purposely avoiding certain social situations with friends and family. When I asked Sandy how she copes with stigma, she said “Yeah, I withdrew every once in awhile...yeah, basically vegetated”. Barbra shared a similar experience, and said that she will lie, and say that she has another commitment in an effort to avoid a social gathering. Alternatively, Linda said that she has to assure her husband that she is comfortable staying at home when he goes out, “Sometimes you have to say to your husband, “Go! Don’t worry about me, I will watch a movie!””.

Participants also talked about coping with stigma in other ways. Linda shared that she and her husband have a very close bond, and they reserve an hour each day to discuss their feelings and concerns. She also said that she and her husband use humour to lighten the mood,

It’s great. It’s really kind of been one of those things that held us together through all the shitty times, and our ability- we have an amazing ability to joke about it, you just can’t take mental illness so seriously all the time you know?

Additionally, Sandy also said that she likes to walk, and Barbra shared that she engages in mindfulness and deep breathing.

Services

There were no interview questions that strictly focused on participants' experiences when accessing or receiving support from local service agencies. However, throughout the interviews participants regularly commented on whether they had positive or negative experiences with services. One question that was asked is, "What would you consider to be some of the challenges you face as a person diagnosed with mental illness receiving support in the community?". During this time, participants highlighted some of the existing challenges within the mental health service system. To clarify, the term 'services' refers to things such as hospital care, social service agencies, and professional health care staff.

Positive and Negative Experiences of Receiving Service: All five participants expressed a positive experience or benefit of being connected with a service worker, attending programs, seeing a counsellor, or speaking with their doctor. Participants specifically talked about having very good experiences with 'their worker' provided by a local service agency. The women talked about being supported emotionally, as well as having their everyday needs met. Amy explained that having a worker has been very beneficial for her,

They help me get out, whether I'm feeling good or bad, they make sure I get out. They call me when I'm really low. They help me get my laundry to the laundry mat because I don't like to do it in my building....They've really helped me.

Three of the five participants talked about turning to their service worker for support whether in emotional distress, or receiving assistance with basic needs. Additionally, all five participants reported that during their consultations with doctors and health care providers all have had a positive experience at some point throughout their history of mental illness.

Participants used terms like, "nice", "responsive", "helpful" or "supportive" when reflecting on some of the doctors they have worked with in the past.

Alternatively, four out of the five participants also had negative experiences with doctors and other healthcare providers at one time or another. After seeking support from the hospital Amy said, “Well, when they know that you are a mental health sufferer, they look at it like a psychiatric issue, rather than a medical issue. And if it’s a psychiatric issue, I won’t go unless it’s a medical issue.” Throughout her narrative, Amy shared that she has had both medical and mental health issues, and the lines between the two are often blurred when it comes to treatment, and that shouldn’t be the case. Additionally, Amy shared a time when one of her doctors wasn’t very supportive,

Because of the way she was speaking to me, she was speaking to me in a very abrupt tone, and she wasn’t very comfortable with me... this one was just made me feel like I was faking, and...I’m looking for help. Additionally, Sandy shares a very similar experience,

I had doctor (name removed) before. It was a woman, and I didn’t like her. She was very cold, and some people like her. I didn’t like her. I was there maybe five minutes, she just didn’t have very good bedside manner. I just didn’t like her.

It seems as though participants have experienced both positive and negative interactions with healthcare staff when accessing different services and agencies. Interestingly, one participant talked about receiving peer support while utilizing services, and the importance of her connections. Mary explained, “I got support, not so much from the staff but the people who lived there. Like myself as a patient, we would rally together and kind of help each other, support each other. I found that was really good.”

Identified Challenges When Receiving Support in the Community: When I asked the women if they faced any challenges when seeking support, they provided a variety of responses. One identified challenge is finding suitable housing. Three of the five participants talked about seeking support from a worker, or local service to secure housing. Linda had a unique experience when she was placed in a retirement home due to lack of housing availability within the local

area. She expressed that it was a “weird” and “eye-opening” experience, but eventually she had to be relocated when she attempted suicide and the facility was not designed to support her efficiently.

Another identified challenge is a lack of information and advertising regarding available services. When I asked Barbra why she didn’t access services, she said, “I didn’t know if support was available”. This is quite problematic if people feel that help and support is not available. Participants also expressed that staff do not listen to clients and their needs, and instead participants felt that doctors and psychiatrists are “pushing pills” rather than dealing with the real problem. Linda expressed that the services in this area are good, but “it just seems like not everybody can be taken in and helped when they really need to be, and not everybody can get the help long term. A lot of it’s a quick fix. Like here take these pills, call me in a year”. Later in her narrative, Linda shared a personal experience of when she went to her psychiatrist and felt that he wasn’t really listening to her,

“Well ok, so I’m going to raise your meds” and I was like “Why? I just told you everything’s great, I’ve got a boyfriend, I’ve got an apartment, things are going well” “Well I just want to raise them” ...So that was a negative experience because he was not there for me when I needed to be helped, and then when he wanted to get more prescriptions going on... So I haven’t seen a psychiatrist since, and I asked my doctor if he would handle my psych meds and he said yes so...

Luckily, Linda had another support in the community that she would turn to. Linda also shared that throughout her history of mental health she has worked with four or five different psychiatrists as she feels the quality of service is lacking.

Another identified challenge revolves around long wait times and limited support. Two participants expressed that the amount of time it takes to receive service is a concern. Linda said, “And if you’re in need of help and you have to wait two and a half weeks to see a doctor, those two and half weeks are the longest two and a half weeks of your entire life.” In some instances

the wait times may be much longer to seek services, and this can be very difficult for people in crisis or those living with severe mental illness. Additionally, Amy pointed out that once services are available the amount of time actually spent with the service could be quite limited. She explained, “I went to a supportive counsellor at (name of agency removed), but they only provide like six sessions now, and you’re supposed to be cured, and that’s ridiculous”. In many instances individuals may only have coverage for three to eight sessions, which may not be sufficient, especially when working with trauma or complex situations.

In addition to the other challenges mentioned, Barbra raised an interesting point when she expressed that services are only accessible during limited times. She expressed that if she were working, or raising children on her own the ability to access services during the evening would be very difficult, since many services are only available during daytime hours. Barbra explained that she feels torn between looking for a job, while also receiving support. She said, “when you have a job you can’t ask two times a week to go to the doctors”.

Finally, another challenge for many living with mental illness is seeking services without the help of reliable transportation, or good physical health to walk from service to service. Sandy explained that there are programs that she would like to access, but due to their location she is unable to attend, and therefore she refrains from getting involved.

Discussion

Throughout this section I will discuss a number of interpretations and observations that were identified during the analysis process. Similar to the result section, I will discuss key findings in relation to the three categories: 1) Mental Health, 2) Stigma, and 3) Services. Additionally, I will draw connections between findings from current study to existing literature in an effort to validate, and increase the credibility of the results. Finally, I will address some of

the limitations of this research, discuss implications of findings, and make recommendations for future research.

The Relationship between Mental Illness and Stigma

A major objective of this study was to understand how stigma affects women living with mental illness, and therefore this will be explored thoroughly.

Before interpreting the relationship between mental illness and stigma, it is important to review what participants defined as stigma. Throughout participants' responses all of them suggested that stigma is perceived as something bad, or negative. More specifically, Linda expressed that stigma refers to judging others based on preconceived notions from the media, and social norms. Additionally, Barbra said that to her, stigma represents sadness, as people may be afraid or fearful of her. Interestingly, participants' understanding of stigma is similar to definitions discussed in previous literature. Researchers explain that stigma involves viewing others as flawed, or devalued, and people often fear others who are different due to lack of knowledge, understanding, and "illogical generalizations" (Crocker, 1999; Girma et al., 2013).

This 'illogical generalization' toward those living with mental illness may have been formed by historical influences (Sands, 2009), however, negative attitudes toward those with mental illness are also being perpetuated and maintained by social norms, and mainstream media (Camp, Finlay, and Lyons, 2002; Manuel, Manuel et al., 2012; Szeto, Luong & Dobson, 2013, Wahl, 1999). This notion that the media continues to perpetuate negative stereotypes of mental illness was echoed in the participants' narratives. For example, Amy talked about how the news and the public in general create connections between crime, and mental illness when this may not be the case. Additionally, Linda repetitively used the word "crazy" throughout her stories, and at one point she said, "the crazy lady who lives in the attic bedroom that has 87 cats and loves Star

Wars”. It could be argued that Linda’s description of “crazy” was likely informed by the numerous depictions of mental illness throughout media and pop-culture.

In addition to experiencing stigma from the media and social norms, individuals living with mental illness are also negatively impacted by their friends, family, and service providers. For example, Linda and Amy talked about how others speak to them like they are less competent or less intelligent because they have a mental illness. Linda shared that sometimes people speak to her in the “special voice”. Linda said that when people talk in a “special voice” they can appear condescending, and it seems as though they are talking down to her. She shared this example,

When you go into the pharmacy, and it’s a brand new pharmacist, and get your bag, you know your big ol’ bag of tricks, and they’re like “So these medications might make you a bit sleepy (in special voice)” and it’s like “Come on lady! I’ve been taking these medications for longer than you’ve been alive!”

Alternatively, Amy shared a time when her family questioned her ability to be an effective parent, and raise her child despite being diagnosed with a mental illness. When discussing the event, Amy shared that her parents said, ““Maybe we can take care of (name of daughter removed) better than you can?” Or “maybe you should start asking for -and just relax” and it just hurts”. Interestingly, Chernomas, Clarke, and Chisholm (2000) found that women from their study experienced a “deep sense of loss, grief and some anger” as their children were taken by Child and Family Services. Furthermore, according to the literature this notion to question one’s parenting skills is more common among women than men (Scheyett, and McCarthy, 2006). Using a gendered lens, one might consider the failure to address physical issues as being related to the participant’s gender. Based on other literatures it appears women's experiences of physical symptoms may be downplayed compared to other genders.

In addition to being treated as lesser than, the participants also recounted times when others would use stigmatizing or negative language. Camp, Finlay, and Lyons (2002) and Szeto, Luong & Dobson (2013) discuss that stigmatizing language such as “crazy”, “lunatic”, “nuts” or “psycho” is often used today to describe those living with a mental illness. As already discussed, Linda used the term “crazy” quite often, and other participants expressed that they had been called a “freak”, or they were told to “snap out of it” or “get over it”. Interestingly, the phrases “snap out of it” or “get over it”, could be used to suggest that the individual needs to overcome their illness in an effort to become more normalized.

Interestingly, Amy, Sandy, and Mary used the term “normal”, which suggested that “normal” is the absence of mental illness. More specifically, Amy said, “And life revolves around mental health, whereas theirs revolves around a normal life, and mine used to be a normal life, and it isn’t anymore”. Further, I distinctly asked Mary if she feels that “normal” is the absence of mental illness, and she said “kind of”. This notion that if you have a mental illness then you are by default considered “not normal” was evident throughout the narratives. Moreover, as discussed in the results, stigma was also communicated through tone of voice, eye contact, body language and facial expression, however, use of language seemed to be the most prominent form of stigma found in this study, and indicated in the literature.

Although stigma is present, participants turned to their family, friends, and community members for support. In some instances, participants felt that they received support, and at other times they felt they had not. One interesting observation from the findings is that there appeared to be a distinct difference between physically being there for someone, versus emotionally being there for someone. For example, Linda expressed that her Mother was very supportive while she was in the hospital by attending appointments, and visiting regularly. However, Linda went on to

say that her Mother said to her, ““You should make friends with other people like you””.

Alternatively, Barbra shared an example when her family was supportive of her physical illness, but not her mental illness. Therefore, on the surface support may be available, but the genuine connection and relationship may be lacking. Previous literature indicates that a lack of support from family or friends is common, and many struggle with this reality (Chernomas, Clark, Chrisholm 2000; Manuel et al. 2012; Walh, 1999). In their study, Chernomas, et al. (2000) found that, “

Participants talked about the loss of friendships and relationships with family members who didn't understand their illness and with the difficulty they now have relating with and connecting to the world around them. (pg. 1519)

In addition to seeking support, participants also expressed that they had concerns that others would lack understanding. For example, Sandy, Mary and Amy all shared that they were concerned that family, friends, and service staff would not understand what they were going through. For example, Sandy said “Well, because I don't think people understand this illness, so instead of trying to understand it they are just negative about it”. This is problematic as the literature indicates that support is very important, and can aid in the recovery process (Manuel, Hinterland, Conover and Herman, 2012). According to Ritsher, Coursey, and Farrell (1997) “social support is a major buffer against stress”, therefore, those lacking social, or familial support may experience more difficulties. Thus, the lack of support could make things worse for individuals (Scheyett, and McCarthy, 2006).

Given that participants may not have received adequate support during times of need, it is not surprising that the women from this study reported feeling: lonely, sad, hurt, and at times things got worse due to the stigma they faced. Throughout the women's narratives there was a large theme of loneliness. As evidenced by the data all of the women did not receive genuine

support at one time or another, and in turn this caused great feelings of loneliness. Four out of five women specifically talked about feeling alone socially, and some expressed that their friendships changed and dwindled once their mental illness was disclosed. Linda shared,

I thought that I all these friends awesome friends, because I was popular and bubbly, and I knew everybody, and then I got sick and it just snowballed and then people like they cared, and then they moved on, just like anything else. And it felt shitty; it felt shitty to have people just give up on you, or for you to just become passé.

This notion that individuals living with a mental illness feel loneliness and social isolation was reinforced in the literature. In their research, Manuel et al. (2012) found that, “Participants expressed concern about feeling lonely and isolated because of difficulty making or maintaining friends (pg 303). Additionally, Chernomas, Clarke, Chrisholm (2000) found similar results.

Due to the social rejection, and loneliness felt by the women of this study, four out the five participants talked about purposely avoiding social situations or isolating themselves. More specifically, Barbra talked about a time when she was invited to a party, and she said that she had another commitment so she could not go in an effort to avoid being judged or feeling uncomfortable. This is very similar to what Link et al. (2001) described when explaining that people with a mental illness may act less confident, become more defensive, or they may avoid social interactions all together in an effort to avoid potential for stigma from others. Walh (1999) also found that individuals with mental illness were more likely to avoid social situations, refrain from applying to jobs and less likely to disclose their illness.

Further, Linda and Amy talked about avoiding dating, and intimate relationships in fear of stigma or negative reactions. Researchers Link et al. (2001) also found that men and women believed that they would be discriminated against or negatively viewed by prospective partners.

Interestingly, there was very little discussion about the relationship between living with mental illness and concerns around dating or looking for a prospective partner throughout the literature.

In addition to avoidance and social isolation, it seemed as though stigma and stereotypes negatively impacted women's self-esteem and confidence. Out of the five participants, four women talked about ways that their mental illness has impacted them. Throughout her story, Mary talked about the way her mental illness greatly affected her self-esteem and confidence when she explained that she does not get involved with community events, or workout. Mary explained that additionally she finds it hard to motivate herself, and she second-guesses herself more than ever. Similarly, when I asked Sandy if her mental illness affects her self-esteem she said, "It does affect you, I think it definitely does affect you. You get more sad and more depressed, so it is a vicious cycle". This notion that mental illness affects self-esteem was very evident in the literature (Camp, Finlay and Lyons, 2002; Link et al. 2001; Wahl 1999). In his study Wahl (1999) found that over half of the participants reported that they had lower self-esteem and loss in confidence, which is similar to Mary's experiences. Additionally, researchers Link et al. (2001) stated, "although the existence of a connection between stigma and self-esteem may not be surprising to some readers, the magnitude of the association that we uncovered is startling and disturbing (pg.1625). Given the evidence in the literature to suggest that there is a large relationship between stigma and self-esteem, it was not surprising that the current study found similar results.

Furthermore, as a result of living with a mental illness, and developing a lower self-esteem, some participants also began to stigmatize themselves as well. For example, when I asked Linda if her mental illness affect her self-esteem this was her response, "I think it did. I think I turned more inwards, and I wasn't quite as-if the people around you are uncomfortable

around you then you eventually become uncomfortable with yourself.” This notion of turning the stigma inward, and adopting the view of those around was mentioned by Camp, Finlay and Lyons (2002). Authors write, “Symbolic interactionism proposes that either by taking the perspective of particular others, or by viewing ourselves from the standpoint of the community and its values (the generalized other), we come to see ourselves as others do”.

One last interesting observation was that not one participant expressed that being labeled with a mental illness affected their sense of identity. Throughout the works of Rosenfield (1997) and Chernomas, Clarke, and Chrisholm (2000) it was discussed that being assigned a label or diagnosis led to a loss of identity or self-worth. Contrary to the literature, Linda and Amy talked about how their diagnosis only led to personal growth and development.

Alternatively, it could be argued that although the women do not speak directly about being “labelled” and how that affected them, the data suggests that participant’s lives did change once they were diagnosed with a mental illness and obtained a “label” or “diagnosis” for their conditions. Based on the women’s narratives it appears as though there were negative implications once they were diagnosed with a mental illness, specifically with regard to relationships with family and friends, withdrawal, and self-esteem. This finding is consistent with the literature (Rosenfield, 1997)

Stigma, Healthcare Staff, and Service Delivery

Another objective of this research was to discover whether individuals living with a mental illness experience stigma from local service workers, or healthcare staff. Moreover, this was an important topic to study, as Scheyett, and McCarthy (2006) indicated that there was little research addressing this topic.

As indicated throughout the data all women had at least one negative experience when

receiving support, and services from doctors, psychiatrists, or hospital staff. When talking about her time at a mental health hospital Sandy expressed that the staff were not very helpful, and they did not have time to listen to the clients. Interestingly, these findings were consistent with the literature (Chernomas, Clarke, and Chrisholm, 2000; McLean, 1990).

In addition to lack of time, participants also felt that at times healthcare staff is not caring or compassionate, and they see the mental illness rather than the individual. For instance, Amy talked about how her experience with hospital staff was cold, informal rather than compassionate and empathetic. Amy describes that the hospital staff sounded as though they were reading from a piece of paper, rather than truly engaging with her. Moreover, Amy shared that she no longer goes to the hospital for psychiatric or mental health concerns, as she feels that her physical concerns are overshadowed by her mental illness. More specifically she said, “Well, when they know that you are a mental health sufferer they look at it like a psychiatric issue, rather than a medical issue. And if it’s a psychiatric issue, I won’t go unless it’s a medical issue”. This notion of focusing on the illness rather than the individual and their physical needs was also evident in the literature (McLean, 1990; Scheyett & McCarthy, 2006).

Another key finding was the way in which participants felt mistreated by their doctor or psychiatrist. Amy shared a time when she was seeking medical attention for her ankle, and she felt that the doctor was very rude, arrogant, and she spoke in an abrupt tone. Additionally, Amy said that the doctor made her feel like she was faking it, and that she was looking for attention rather than seeking help. This is problematic as some women’s physical concerns are being completely disregarded in the face of their mental illness. Ritsher, Coursey, and Farrell (1997) also found that women’s gynecological symptoms were not being taken seriously due to the fact that they also lived with a mental illness. Interestingly, Amy shared a very similar experience

with her doctor, “Like my family doctor, he knows I have depression and anxiety, and he’ll say to me, “Is it the depression pain? Or it is the everything pain?” And that’s not fair”.

Furthermore, Linda and Mary felt that doctors and psychologists tend to “push pills” too much, rather than seeking alternative interventions. More specifically, Linda talked about a time when she met with her psychiatrist and explained that things were going very well in her life, but despite this her psychiatrist wanted to increase her medication without any logical reasoning. Linda expressed that she was very frustrated and angered by this situation. Further, Linda’s needs were not being heard, or addressed. This is an interesting example of power, and privilege and the ways in which healthcare staff and mental health service providers can profoundly influence their clients, for better or worse.

Additionally, four out of the five women reported that they did not want to be on their medication due to feeling dopy and unlike themselves, or due to weight gain. Participants’ concerns relate to Beecher (2009), and his discussion of prescription medication as the primary intervention and treatment of mental illness. Furthermore, in her article Currie (2005) also explains how the pharmaceutical industry has grown exponentially over the last 30 years, and the ways of our profit driven society. It leads one to question whether doctors and psychiatrists have the client’s best interest at heart, or whether there is a stronger connection between doctors and pharmaceutical companies than meets the eye?

Finally, it seems as though participants from this study are unhappy with the current medical model, and instead they would prefer a more relational, or recovery based approach (Manuel, Hinterland, Conover and Herman, 2012; Ritsher, Coursey, and Farrell, 1997; Scheyett, and McCarthy, 2006). Based on the data, it seems as though participants are seeking more support, compassion, and empathy from their doctors, psychiatrists, and healthcare staff.

According to Scheyett, and McCarthy (2006) participants wanted services that were more focused on respect, warmth, genuineness, mutuality, and the promotion of hope. Moreover, literature indicates that in addition to promoting more a “relational model”, individuals living with a mental illness hope for a more “recovery based approach”, which focuses on their abilities, strengths, and goals for the future (Scheyett, and McCarthy, 2006).

In conclusion, it seems as though findings from the current study are consistent with the literature. Similar to others living with mental illness, the women who participated in this study also want to work with doctors who operate from a relational/recovery based model, as opposed to those who work from a medical model (Chernomas, Clarke, and Chrisholm, 2000; McLean, 1990; Scheyett & McCarthy, 2006; Wahl, 1999).

Reflexivity

Throughout the entire research process, I felt that I had many up’s and down’s as the primary researcher. Firstly, I wanted to comment on my Supervisor’s role in the recruitment process. The purpose of involving my supervisor was to maintain my privacy and restrict my personal information from participants. I chose to have participants make first contact with my Supervisor for two reasons: 1) I would be conducting the interviews myself and I would have a chance meet and build a rapport with participants in person, and 2) I wanted to maintain a sense of privacy. On the one hand, I sought to build a genuine connection with the women during the interview process, however, I also wanted to implement some boundaries by leaving my contact information anonymous. Since the women had my Supervisor’s contact information if they needed to reach me, or they had additional concerns a point of contact was still available.

Another unanticipated challenge that caused some anxiety and frustration was participant recruitment. Despite my best efforts, we had only five participants, and I was hoping for at least

10 in total. Although this was a frustrating phase of the research, I could respect that mental health is sensitive subject for many, and I had to be patient, and understand that recruitment may be slow.

One process that I found quite rewarding and enjoyable was the analysis phase. For me, this is when the research comes to life! Having read the literature extensively, I find it rewarding to read through the data, and recognize similar trends, and emerging themes from existing research studies. Although my data is unique, I find that identifying similar emerging themes helps to validate the work I have done, and shows that there is credibility in these findings and this research topic in general.

Additionally, I also enjoyed writing the analysis and results sections because I was able to observe emerging themes of mental illness and experiences of stigma outside of the research context. For example, I have heard from numerous female guest speakers in my classes share similar stories of living with a mental illness and experiencing stigma from family and friends, while trying to balance their social worlds, and sense of self.

Interestingly, as I reflect on the prevalence of mental illness according to CAMH (2015) and the Mental Health Commission of Canada (2012), I am unable to identify the presence of mental illness within my own family or circle of friends. I am aware that my friends and family may experience episodes of anxiety, stress, or sadness at times, but I am unaware of any individuals close to me that are diagnosed with a mental illness. Given that one in five individuals will experience mental illness personally, this means that someone close to me must experience a mental illness or mental health concern. This leads me to wonder why I am not more aware of the prevalence of mental illness within my own environment? Are my own friends and family just as concerned about being open about their mental health as the literature

suggests? This is something to consider as I move forward and create connections between my research and my reality.

Overall, I thoroughly enjoyed conducting this research because mental illness is a personal passion and strong interest of mine, and I believe that the research I produced will have meaningful implications.

Limitations

Although efforts were made to account for challenges, there were some limitations to this research. One primary limitation was the sample size used in the current study. This is a major limitation as the sample size was quite small with only five participants. Originally, it was anticipated that at least nine or ten women would express interest in the study. Unfortunately this was not the case, and there are many possible explanations. Firstly, some women may have felt uncomfortable sharing sensitive material or vulnerable stories with someone they've never met. Secondly, some women may have been concerned about disclosing that they live with a mental illness and they also care for children. For example, disclosures of substance abuse with children in the home often lead to the involvement of Family and Children Services (F&CS). Therefore, some women may have been deterred to participate in fear that I may involve F&CS. Alternatively, if a woman is living with depression, and she cares for young children she may fear that I will judge her, or view her as an unfit parent and disclose to F&CS.

This leads to the third reason why women may have refrained from participation: confidentiality. The topic of mental health can be quite sensitive, and private, and therefore, some women may have felt that their identity and personal stories could not remain anonymous.

A fourth challenge that may have limited the sample size for this study is the presence of mental health itself, and the barriers it can create. For example, if a woman is experiencing social

anxiety the chance of her willing to meet a stranger in a public place to discuss her social anxiety is very unlikely. Further, if a woman has dissociative identity disorder, she may fear that she will not be able to stay present or grounded throughout the entire interview.

Another challenge to increasing the sample size could be that recruiting flyers were taken down, or removed. Flyers were placed in local service agencies and there is a chance that they were not posted or they were taken down at some point.

The final challenge for recruiting participants is that it may have been difficult for participants to express an interest in the study if they did not have access to a phone or internet. The flyers requested that all interested individuals contact us by phone or email. Thus, if individuals did not have access to these resources, it could be quite challenging to sign up.

Despite the numerous challenges presented attempts were made to recruit more participants. After completing four interviews, there had not been a lot of interest in the study. I then attempted to recruit using the snowball technique by contacting participants to see if they knew of anyone who may also want to participate in our study. Unfortunately, this was not successful, as none of the women could think of a friend or family member to suggest the study to. I then contacted one of our community partners to see if they could send out our flyer to their staff and possibly recommend any of their clients for our study. This effort was slightly successful as a fifth participant signed up for the study, however, there were no more participants following this. Although efforts were made to increase participant interest, more could have been done. For example, touching base with the service agencies monthly or bi-monthly could have ensured that the flyer was displayed and available for people to take. Additionally, more social services could have been contacted directly to promote the study and encourage participation.

Also, the flyer could have been more accessible by being placed in local business such as the library, grocery stores, or the mall, rather than just social service agencies.

Also, due to the small sample size the results from the current research cannot be generalizable. It is also important to consider that given the small sample size, diversity was not well represented given that the majority of participants came from a Western, North-American background. It was hoped that more diversity would appear in the sample size to explore how other cultures or ethnicities approach and deal with mental illness. Despite this, the qualitative interviews that were conducted provided rich and insightful information into the lives of five women and their experiences of living with mental illness, experiencing stigma, and receiving local services.

In addition to the small sample size, the interview guide also had some limitations. Given that the study sought to learn more about the female experience of living with a mental illness and experiencing stigma, one could argue that there was a lack of gender specific results. This could be due to the interview guide and the lack of gender specific questions. For example, specific questions related to being female and experiencing mental illness could have been explored. Also, more questions pertaining to parenting, physical needs being met, or gender specific challenges could have been addressed. For instance, “As a mother, has your parenting ever been questioned due to your mental illness”.

Additionally, one could argue that conducting a study with only female participants may not reveal gender specific challenges without a comparison. Therefore, conducting a study with both male and female participants could be useful for exploring gender specific challenges related to mental health, and exploring those themes further with only male or only female samples.

Another limitation of this study was the amount of attention directed toward participants' ways of coping. One of the primary objectives for this study was, "to explore, and better understand women's experiences of stigma and oppression, and how they cope". Although, some data was collected regarding this objective, the amount of focus and results were minimal compared to the other research objectives. Perhaps this could be strengthened in the future by asking more coping related questions and probes during the interview process.

Also, throughout this research project there was only one primary researcher, which some may find problematic. Firstly, some could argue that there is a large potential for bias, and personal expectations shaping the findings of this study. This could occur due to the fact that no additional researchers were involved, and therefore, inter-rater reliability, or consensus coding could not be utilized to confirm findings (Patton, 2002). Secondly, it could also be argued that things were missed, or overlooked during the analysis phases. Alternatively, as with qualitative research, a different researcher could have analyzed the data and found different results or made other interpretations (Patton, 2002).

As the primary researcher, I made an effort to account for this by speaking with my advisor about any thoughts, concerns, or emerging themes throughout the entire research process. Additionally, I consulted my advisor to share interesting findings once interviews were completed, and I also checked-in to ensure that research processes were being completed correctly. Further, as the only researcher I made the effort to be reflexive and self-aware of my social location, biases, and expectations of the research. Again, I spoke with my advisor about any of my concerns regarding my position as the primary researcher, and addressed any concerns or apprehensions during the various research phases.

Implications of the Research

Despite the small sample size, the current research study yielded interesting, and informative results. Many of the findings from this study reinforced findings from existing literature, which helps to add to a growing body of literature. Moreover, according to Ritsher, Coursey and Farreell (1997) “literature on gender and severe mental illness is sparse” (p.1273). Moreover, Scheyett, and McCarthy (2006) express that there is very limited research assessing the ways in which men and women experience mental health services. Therefore, this study has contributed to an under-researched area with regard to understanding the relationship between gender, mental illness, and service delivery.

Additionally, Walh (1999) argues that, “The relatively few studies that have sought information directly from mental health consumers provide evidence that they experience themselves as stigmatized” (468). Therefore, this study helps to address a gap in the literature through obtaining qualitative, information rich experiences from those living with a mental illness.

It could be argued that these concerns are no longer valid given that the above mentioned articles were written in 1997, however, when completing a literature review it was challenging to find peer-reviewed research pertaining to women, mental illness, and stigma.

In addition to contributing to existing literature the results found from this research could have important implications for service delivery, customer service, and social work as a discipline. Findings from the current study and previous research reflect that there are existing challenges when it comes to receiving genuine, supportive service, customer care, or bedside manner for individuals experiencing mental illness. This is important for the field of Social Work as social workers are taught to be invested in providing support to clients in way that is respectful, empathetic, client-centered, needs driven, empowering, and strengths based. Also,

more often than not, many social workers work within the field and discipline of mental health, which suggests that they should know or be aware of such concerns and how to account for them. For example, using relational theory or recovery-based models for treatment as discussed in the current research and previous literature (Manuel, Hinterland, Conover and Herman, 2012; Ritsher, Coursey, and Farrell, 1997; Scheyett, and McCarthy, 2006). Interestingly, one could argue that there are similar values and principles shared between the field of Social Work and recovery-based/relational models, however, research has shown that our practice and application of such values need to be enhanced in our local community. Therefore, this study has micro and macro implications for the field of Social Work and the way that social workers work and interact with individuals living with mental illness(s).

In addition to the field of social work, there are also important implications for service delivery and customer care within local social service agencies and businesses. More specifically, the findings from the current study could help to inform and educate psychiatrists, psychologists, family doctors, and other healthcare staff about customer care when working with individuals who have a mental illness. For example, this study reminds all professionals who work within the field of mental health to operate from an open, non-judgmental, respect oriented, person first, genuine framework. Moreover, results from the current study could be disseminated in the form of a “How to” or a “Tips” sheet that could be beneficial for hospitals or agencies that may be more focused on the medical model approach to treatment, rather than recovery-based/relational models.

Finally, results from the current research could help to inform future research and provide recommendations or ideas for how to develop on this area of research further.

Future Research

As indicated in the limitations, the sample size was one of the biggest challenges for the current research study. Therefore, a large recommendation for future research is to ensure that large sample size is established. One way to accomplish this could be having more than one researcher promoting the study, and recruiting participants. In addition to increasing sample size, it is also encouraged that future research also strive to increase the diversity of the sample if possible. Doing so will provide unique results and insight into the way that mental illness is viewed and experienced within different cultures. Also, dependent on time conducting a study involving both genders prior to exploring gender specific challenges with mental illness could be useful. For example, exploring both male and female experiences of living with mental illness and experiencing stigma may provide some unique similarities or differences that could help to inform future research exploring gender specific challenges.

Another recommendation would be to revisit sites where the recruiting tool is posted in an effort to ensure that it is still available and accessible to prospective participants. Moreover, it is encouraged to create community partnerships, and utilize connections to increase interest in the study. Also, checking in with services to ensure that they are continuously promoting the study could be beneficial.

Additionally, if conducting qualitative research it is recommended that researchers spend ample time developing their interview guide in order to be sure that their research objectives are reflected in the questions and they are obtaining the information they want.

Finally, organization and time management is something to consider. As discussed, participation recruitment was slow for the current study, since only five individuals signed up to participate over nine months. Although efforts were made to increase the sample size, they were not successful.

Therefore, in an effort to avoid low sample sizes it is recommended that future studies increase researcher teams, and allow for more time in an effort to maximize participant turn out.

Conclusion

In conclusion, the current research study helps to build upon an existing body of literature regarding women who are living with mental illness, and experiencing stigma due to their illness. Findings from this qualitative study were consistent with the literature in a variety of areas including: feelings associated with being diagnosed with a mental illness, lack of support, social isolation, stigma from friends and family, and challenges with healthcare professionals, and so on.

In addition to contributing to a growing area of research the current study had a number of limitations, which are important for future researchers to consider. Additionally, there are important implications for the field of Social Work, as well as recommendations for service delivery among healthcare agencies. Finally, the current study also identified possible barriers and challenges that are noteworthy for future projects in this research area.

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Appendix A: Semi-Structured Interview Guide

Stigma and Serious Mental Illness: The Case of Individuals Receiving Treatment from
Community-Based Mental Health Teams

REB # 4088

Primary Investigator: Magnus Mfoafo-M'Carthy

mmfoafomcarthy@wlu.ca

Questionnaire

Introduction: I am conducting interviews with individuals who have been diagnosed with serious mental illness to explore their experience with stigma. The interviews are being conducted as part of a pilot project at the Laurier faculty of Social work. The focus of the study is to examine your understanding of stigma, how you cope with it and the challenges you are faced with on a regular basis. Please remember that you can decide not answer any questions you are not comfortable with and you can decide to withdraw from the study up until the report will be published. The interview will be audio recorded with your permission. This project has received research ethics approval from the REB at Wilfrid Laurier University.

Do you have any questions for me?

Background questions:

1. Can you tell me a bit about yourself?

Probes:

- How did you get to this facility or where you are now?
- Can you tell more about the experience?

2. Can you tell me a bit about your family, caregivers, did you encounter any challenges or difficulties growing up.

Probes:

- How did they make you feel?

Mental Health Experiences

3. What was is like when you were first diagnosed with a mental health condition?

Probes:

- How did you feel about your diagnosis?
- How did it feel to be labeled with an illness?
- Did you process your diagnosis in any particular way? If so, how?

4. How have things changed for you since you were diagnosed with a mental health condition?

Probes

- Did your perception of yourself change?
- Did your diagnosis affect you personally?
- Was it refreshing to have answers?

5. What were some of your concerns once diagnosed with a mental illness, if any?

Probes

- Resource support?
- Social support?
- How others would react?
- Social isolation?
- New identity?

6. Could you tell me how it feels to be diagnosed with mental illness?

Probes:

- Do you feel supported by your family?
- How about the community?
- Why?

7. Are you the only person who feels this way?

Probes:

- Do you share your feelings with them?
- Are they supportive of you?
- Tell me more

8. How long have you been diagnosed with mental illness?

Probes:

- Any difference in the way you were treated then?
- How about now?
- How?

9. How open are you with speaking to others about your mental health?

Probes

- Who did you speak with about your mental health?
- Why did you choose to speak with those particular people?

10. If you did not speak with others about your mental health, why did you choose to keep things to yourself?

Probes

- What were some of your concerns or reservations?

11. Once others were aware of your mental health, how did they behave around you?

Probes

- Did they act differently or did their behaviour stay the same?
- If their behaviour changed, how did it change specifically?
- Were they receptive and supportive?

12. Do you talk to others openly about your mental health?

Probes

- If yes, what is the conversation like?

- It not, why do you

Questions Related to Stigma

13. Could you describe to me your perception or understanding of stigma? Or when we talk about stigma, how do you understand it?

Probes:

- What is your experience with stigma?
- Could you tell me more about the experience? A story or an incident?
- How does it feel?

14. Can you describe a time when others mistreated you because of your mental health condition?

Probes

- Who mistreated you?
- How did others treat you?
- How did they speak to you?
What did they do specifically?

15. What was that experience like for you?

Probes

- What are some of the emotions that you felt?

16. Would you say that you experience stigma on a regular basis due to your mental health? If so, where does this mistreatment take place?

Probes

- Social services
- The public
- Family home
- From friends
- What form is the mistreatment?
- Verbal
- Physical
- Facial
- Attitudinal?

17. How has this mistreatment and stigma affected you?

Probes

- Decreased self-esteem?
- Decreased overall health?
- Social isolation?

18. How do you cope with the mistreatment and stigma from others?

Probes

- What forms of support do you utilize or have access to?
- What resources can you use?

- Substance abuse?
- Withdrawal?
- Self-harm?

19. Do public attitudes and stigma affect the way you view yourself?

Probes

- Do you apply these views to yourself?

20. What would you consider to be some of the challenges you face as a person diagnosed with mental illness receiving support in the community?

Probes:

- Tell me more about that?
- Can you give me an example?
- How would you describe the feelings when you think about the challenges?
- Anything else you want to share?

21. Do you feel that you are treated like any other person in the community?

Probes:

- Why is that so
- How does that make you feel

22. Is there anything you would want to share or feel is important for me to know?

Probes

- Is there anything else you would like to share?

Appendix B: Participant Recruitment Flyer



Lyle S. Hallman
Faculty of Social Work
Kitchener | Waterloo | Brantford |
Toronto

RESEARCH STUDY: (REB # 4088)

Stigma and Serious Mental Illness: The Case of Individuals Receiving Treatment from
Community-Based Mental Health Teams

Have you been diagnosed with a mental illness?

Are you receiving treatment from a community based support team?

Have you encountered any challenges based on your diagnosis?

Are you comfortable sharing your experience?

**IF YOU ANSWERED 'YES' TO ALL THESE QUESTIONS, WE
WOULD LIKE TO HEAR FROM YOU!!**

**A STUDY IS BEING CONDUCTED ON HOW
INDIVIDUALS DIAGNOSED WITH MENTAL
ILLNESS EXPERIENCE AND COPE WITH
STIGMA.**

**YOUR PARTICIPATION IN THIS
RESEARCH WILL BE KEPT CONFIDENTIAL!**

**Contact Magnus Mfoafo-M'Carthy, Assistant Professor at
the Faculty of Social Work for participation in this study**

**Compensation
provided for
participation!**

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Appendix C: Participant Consent Form

Stigma and Serious Mental Illness: The Case of Individuals Receiving Treatment from
Community-Based Mental Health Teams - (REB # 4088)

Principal Investigator: Magnus Mfoafo-M'Carthy
Assistant Professor
Lyle S. Hallman Faculty of Social Work
120 Duke Street West
Kitchener, Ontario, N2H 3W8

CONSENT TO PARTICIPATE IN RESEARCH

Purpose of Study

The purpose of the study is to explore stigma as experienced by individuals diagnosed with serious mental illness and receiving support in the health care system. The focus of the research will be to understand how stigma is perceived and how they cope with it. The study will explore how participants' perspectives affect how they deal with the challenges they are faced with. The researcher intends to interview 10 -15 people for this study. Your participation is voluntary.

Procedure

You are invited to meet with a researcher for a period of about 60 to 120 minutes to answer questions on your experiences or challenges with stigma. The interview will be held at a secure location and your privacy will be assured. For the purposes of accurate data collection, the interview will be audio taped and eventually transcribed. Any information, for instance, names or quotation that links you to this interview will be deleted. Some of the questions or issues to cover during the interview will be: How do you understand stigma?; and what has been your experience with it since your diagnosis?

Potential Benefits and Risks

The outcome of the study may enhance the professional understanding of the challenges faced by individuals diagnosed with mental illness. At present, there are not a lot of studies that provide that perspective and your participation will add that point of view to the research literature. There will be no significant risks or negative consequences as a result of your participation. However, there is the possibility that describing your experience may generate unsettled feeling or stress. In the event of feeling unwell or exhibiting signs of stress the interviewer may pause or stop the interview and may seek professional attention on your behalf.

Compensation

There will be no costs to your participation in the interview. To thank you for your time and effort, a \$20.00 gift card will be given to each participant.

Confidentiality

Every effort will be made to maintain your confidentiality during the interview. All information identifying you that is provided during the course of the interview will be deleted. The information you provide in this study is confidential with the following exceptions: 1). If you disclose a plan or desire to harm yourself or someone else; 2) if you disclose a situation in which a child is being abused or neglected. As a participant, you have the right to make a request to review, erase or edit any part of the transcript of the interview. All the tapes will be erased after the interviews have been transcribed. You will get the opportunity to vet your personal data and quotes before they are used and a copy of the transcript will be sent to you. The document will be sent to you through mail unless you advise otherwise. Quotations from the interview may be used, but you will not be identified in any of the quotations. Participants in the study will be assigned codes or pseudonyms so they cannot be identified. All information gathered will be stored in a secure, locked cabinet and the researchers will be the only individuals with access to the information. All electronic information will be stored in password-protected files on a secure computer and all the information will be destroyed after five years. The documents will be deleted from the computer and all files shredded. On the publication of the information, no information identifying you or other participants will be included.

Participation and withdrawal

You have the right to agree or disagree to participate in this interview. On agreeing to be a part of this study, you have the right to withdraw at any time without consequences and information provided prior to withdrawing will be destroyed. Also, you have the right to either answer or decline to answer any questions.

Dissemination of Findings

The research findings of this study will be published in professional journals and presented at conferences and forums in the community. None of the information presented will identify you. The researcher will ensure that a summary of the findings will be made available to you via mail or email should you request it.

Agreement to participate

I, _____, have read the information sheet for the study named “Stigma and Serious Mental Illness: The Case of Individuals Receiving Treatment from Community-Based Mental Health Teams”. My role in this study is to help the researcher to gather information by sharing my experiences. I am aware that the interview will require audio taping. All questions / concerns I have regarding this study have been answered to my satisfaction. By signing this consent form, I do not waive any of my rights.

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant’s signature: _____ Date: _____

Investigator Signature: _____ Date: _____

I have read and understand the information as presented. I give permission to be quoted in this study.

Participant's signature: _____ Date:

Investigator's signature: _____ Date:

Dr. Bob Basso, Chair, Research Ethics Board, Wilfrid Laurier University may be contacted by research subjects to discuss your rights. Dr. Basso may be reached by telephone at (519) 884-1970 x 4994 or rbasso@wlu.ca