

SUFFERING IN SILENCE? THE EFFECTS OF THE STIGMATIZATION OF MENTAL
ILLNESS ON LIFE SATISFACTION

SUFFERING IN SILENCE? THE EFFECTS OF THE STIGMATIZATION OF MENTAL
ILLNESS ON LIFE SATISFACTION

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Abstract

The term ‘stigma’ is formally defined as the assignment of negative perceptions to an individual because of perceived difference from the population at large (The Free Online Dictionary by Farlex). Stigma, pervasive on a micro, mezzo and macro level serves to devalue individuals who have been diagnosed with mental illness and the support systems that are designed to assist them. Although efforts have been made in public awareness campaigns to reduce the stigma associated with mental illness, stigma continues to limit opportunities and restrain individuals from living full and enriching lives. Many individuals “suffer in silence” often resorting to maladaptive coping mechanisms to manage symptoms.

The purpose of this study was to uncover the short term and long term impact of stigma from the perspective of those who are labelled with mental illness in order to gain a deeper and more accurate understanding of the effects of such on life satisfaction. Existing literature suggests that the result of anticipated and experienced stigma can affect individuals in multiple ways: diminished self-esteem, self-efficacy, and self-worth; social withdrawal; identity ambivalence; secrecy and reduced opportunities (employment, housing, income).

This research utilized qualitative semi-structured interviews and photo elicitation to gain an understanding of experienced and anticipated stigma as perceived by those with mental illness. Theoretically, the study was influenced by the modified labelling theory which posits that social and internalized stigma associated with mental illness is a societal creation in that its’ development exists as a result of disapproving social attitudes about mental illness. Eight individuals with various diagnosed mental disorders participated in the study. The findings suggest that for each of the participants in this study, initial dealings with the mental health care system and its’ components are likely to impact individuals negatively but once effective

treatment, medication stabilization and a good practitioner are found, the experience becomes positive and empowering to individuals. Regardless of the level to which internalized stigma exists, all participants engaged in acts of secrecy, withdrawal, passing and selective disclosure adversely affecting life satisfaction. The implications for practice include recognizing the structural factors that influence clients' internalization of stigma which likely contributes to feelings of empowerment and control over ones' life. Revealing mental health status to others may be beneficial in contributing to an improved quality of life satisfaction.

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I would first like to sincerely thank the eight participants of this study who were so kind to share their stories and their experiences of the stigma imposed on their lives as the result of their diagnosis. You are all brave, resilient and have my deepest respect. I hope that I have adequately captured your thoughts and experiences and given you a voice that would otherwise likely be silenced.

My sincere gratitude to those special people in my life who, even at the darkest of times, cheered me on and rallied for me to continue on this new path in life. Even when I didn't think I would make it, you did, and your confidence and support mean everything.

Finally, to all those who are "suffering in silence": remember you are not alone and there will be positive outcomes in your journey to recovery.

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Introduction

The universal prevalence of the stigma associated with mental illness is undeniable. People with mental illness continue to endure a great deal of prejudice, discrimination and stigma from mainstream society (Hinshaw, 2005). In Canada, the estimated prevalence of mental illness has been reported as affecting 20% of the population (Mood Disorders Society of Canada, 2009). However, these statistics fail to factor in populations living on Aboriginal Reserves and Crown lands, residents of institutions, and full-time members of the Canadian Armed Forces (Covin, 2011). They also neglect the thousands of Canadians who are deterred from pursuing treatment due to the stigma inherent in accessing mental health services. Regardless of the actual prevalence of mental illness amongst Canadians, these statistics caution that mental disorders have become one of the leading causes of disability in Canada (Lim, 2008).

Relevant literature claims that having a mental illness is one of the most overly stigmatized attributes an individual can have, rivalled only by substance abuse or homelessness (Hinshaw, 2005). Stigma associated with mental illness diagnosis remains a significant social issue that is multifaceted and prevalent in today's society. Severe mental illness has been likened to drug addiction, prostitution and criminality (Albrecht, Walker & Levy, 1982; Skinner, Berry, Griffith & Byers, 1995, as cited in Corrigan & Watson, 2002). For example, in his second presidential debate speech in 2012, U.S. President Barack Obama associated criminals with those living with mental illness stating: "So my belief is that we have to enforce the laws we've already got, make sure that we're keeping guns out of the hands of criminals, those who are mentally ill" (ABC News, 2012). Meanwhile, subsequent devaluation and rejection of people with mental illness by society reveals the lasting effects and often permanent impact of stigma, over and above existing psychopathology (Link, Struening, Rahav, Phelan & Nuttbrock, 1997). However,

society fails to understand that often times ‘disruptive’ behaviour exhibited by those diagnosed is instigated through reactions of fear, loss and rejection associated with societal interactions.

My interest in researching how the stigma associated with mental illness impacts the life satisfaction of people diagnosed with such is both a personal and professional one. The onset of my major depression became evident when I was just a young girl. For many years, I thought that my suicidal ideations were a normal part of everyone’s thought process. It was not until I developed more intimate relationships with my friends that I learned that I was facing some mental challenges that many of my peers were not experiencing. Although I knew that I was dealing with some very intense emotional reactions, I did not share my feelings with anyone else for fear of being marginalized by my peers. Instead, I “suffered in silence” for many years with confusion about what was ‘wrong’ with me, fear that my true feelings would be revealed and I would be marginalized by my family and peers, anger that there was no safe space to confide my thoughts and worries, and despair that no one else seemed to be aware of the suffering that I was enduring. My sense of belonging was severely limited and I carry these feelings with me even today. As someone who has personally experienced the oppression associated with mental illness on various levels, I have a vested interest in dispelling the myths associated with mental illness and advocating for this vulnerable population. I believe that my story is not unlike many others today, even over twenty years later, as the stigmatization associated with mental illness is still so prevalent. Professionally, my hope is to work with youth who are dealing with mental health issues in an effort to help alleviate their feelings of isolation and loneliness.

I premise my research question with the phrase: “*Suffering in silence?*” I have incorporated this phrase into most of my academic research papers to define my personal experience in the journey towards mental health and well-being. In my personal and

professional experience, individuals with mental illness continue to be oppressed, under-served and inadequately treated for their conditions. Stigma is evident on a micro, mezzo and macro level; that is, individually, community based and systematically embedded.

My hope in conducting this research is to educate others with the hopes of alleviating some of the suffering that individuals encounter as they face the various barriers associated with the stigma of mental illness. My research attests to the negative impact that stigma holds over individuals with mental illness but also highlights the positive influences of seeking treatment and the value inherent in the recovery process. Participants were invited to ‘share their story’ and bravely reflected on their own journey.

Literature Review

My literature review begins with a historical overview of how stigma has been implicated in the lives of those living with mental illness. Next, I provide an overview of various terms and discourse surrounding the topic of stigma in existing literature. I then focus specifically on the two key foci of my thesis: stigma and life satisfaction as they relate to mental illness. I provide a summary of the influence of mental illness stigma on those diagnosed as articulated in relevant research studies. Following that, I conclude with the effect of stigma on life satisfaction as stipulated in current literature.

Historical Account of the Stigma Associated with Mental Illness

Throughout history, mental illness has frequently been associated with stigma, negative stereotypical assumptions and deviance. Early accounts of the societal reaction to mental illness were associated with acts of deviant behaviour that were attributed to one's possession by evil spirits or the devil (Hinshaw, 2005). This notion was usually met with harsh and punitive social responses like torture and death (Zilboorg as cited in Hinshaw, 2005). In the 17th century, individuals suffering from mental illness or 'hysteria' were confined to special institutions and deemed public threats (Rabkin, 1972). The biological emphasis on mental illness also added to the perception that the condition was permanent, hopeless and predetermined (Hinshaw, 2005). Into the 18th century, emphasis rested on moral (psychiatric) treatment which was based on the assumption that the 'disturbed' behaviour was caused by individualized ignorance that could be modified by manipulation of social, environmental and psychological variables (Rabkin, 1972). In the mid-19th century, the social construction of mental illness fabricated 'disturbed' behaviour as a physical disease of unknown etiology which could only be treated with chemical or physical

means, and, as a result, the trend towards custodial care resulted in increased institutionalization of people with mental illness within chronic mental hospitals (Rabkin, 1972).

After the turn of the century, many professionals in the mental health field argued that mental illness could be understood as an exaggeration of particular behaviours common to everyone brought on by stressful life conditions (Rabkin, 1972). Therefore, symptomatology was contextualized as a product of transactions between an individual and their social and physical environment but remained pathologized as individual weakness (Rabkin, 1972). Towards the 1950's and 1960's, secular views of mental illness began to emerge with the expansion of psychology and psychiatry which quelled the demonic connotation that had prevailed (Hinshaw, 2005). Rabkin (1974) concluded that individuals who were formerly institutionalized were not perceived with the same trust, good will, and restoration of the former 'normal' status that is reassigned to ex-medical patients.

Over the period between the 1950's and 1980's, most studies concluded that mental illness was defined in such narrow and extreme terms that the public feared, rejected, and devalued people with mental illnesses (Phelan, Link, Stueve & Pescosolido, 2000). Unfortunately, more recent studies have found that there has been a significant increase in the perception that violence is commonly associated with psychosis (based on a research study in 1996) (Phelan et al., 2000). Phelan and associates, (2000) attribute this increase in violence discourses associated with psychosis to the effects of the media and the de-institutionalization movement which resulted in the closing of several mental institutions displacing former inpatients into the community.

Today, individuals with mental illness are more likely to face inadequate social supports, issues related to employability, poverty and discrimination (Williams & Collins, 2002). There is growing evidence to suggest that society's perceptions of individuals with mental illness as being extremely dangerous serves to compound the stigma surrounding mental illness (Penn, Kommana, Mansfield & Link as cited in Scheyett, 2005). President Obama equating mental illness with criminality highlights the universal perception that violence is commonplace amongst such populations. Fear breeds stigma and often times, fear is ubiquitous with the unknown or that it may happen to oneself or someone close (Reidy as cited in Scheyett, 2005).

Stigma Discourse

Existing literature constructs the phenomenon of stigma in association with mental illness as internalized (or self) stigma and social (or public) stigma.

Social Stigma

Social stigma is conceptualized as: “the way in which the general public conceives of and reacts to people with mental illness” (Corrigan, Larson & Rüsch, 2009, p. 75). Corrigan and associates, (2009) discuss the social psychological model of social stigma in terms of stereotypes, prejudice and discrimination. Stereotypes are defined as “knowledge structures” that are acquired by most individuals of a particular social group about people in other groups (Corrigan and associates, 2009, p. 75). In most cases, these stereotypes form and reflect negative beliefs about a group, for example, as incompetent or dangerous. Many people often readily accept stereotypical ideas and negative social constructions associated with mental illness without hesitation. However, the fact that individuals are aware of these various stereotypes does not mean that they agree with them or have internalized them into their belief system

(Corrigan and associates, 2009). Those whose belief system does accept derogatory social constructions about a particular group are said to be prejudiced towards them and consider all individuals of that group to be exactly the same (Corrigan and associates, 2009). This results in damaging emotional reactions towards various groups that have acquired stereotypical status. An example of a prejudiced statement about those labelled with mental illness would be: “All people with mental illness are dangerous! I am afraid of them” (Corrigan and associates, 2009). Prejudice leads to the behavioural response of discrimination. Discrimination manifests as lost opportunities (e.g., being denied an apartment rental), coercion (e.g., a psychiatrist placing a person in involuntary admission to a hospital because the person was deemed incompetent) and segregation (e.g., establishing group homes for those with serious mental illness away from urban populations) (Corrigan and associates, 2009).

Social stigma can also be identified in the form of language and media which often associates mental illness with negative and derogatory stereotypes and highlights the prevalence of social stigma towards people labelled mentally ill. For example, in terms of discourse and language, responses to unconventional statements as: “What an insane statement!” or “Are you crazy?”, and song lyrics like “Psycho killer” by The Talking Heads point to the prevalence of stigma where such statements are not challenged as discriminatory (Holmes & River, 1998). Media, in the form of movies, television and newspaper often portrays those labelled with mental illness as violent, disturbed and erratic (Coverdale, Nairn & Claasen & Diefenbach, as cited in Hinshaw, 2005).

Internalized Stigma

Corrigan and Rao (2012) describe three stages that determine the presence of internalized stigma: knowledge of the existing and prevailing derogatory stereotypes that describe those with mental illness, agreement with those stereotypes, and application to one's self upon diagnosis. Therefore, they conceptualize stigma as a series of steps starting with awareness, agreement, and application (the “three A's” of internalized stigma) which ultimately leads to harm (Corrigan & associates, 2009; Corrigan & Rao, 2012). The last stage - harm - involves internalizing negative and distorted self-talk that is reflective of the prevailing stereotypical discourse and negative attributes ascribed to people identified as having mental illness.

Based on this stage model, the negative impact of internalized stigma becomes a behavioural response resulting in the “why try” effect for many individuals who become dissuaded from finding meaningful employment or pursuing life goals as a result of the label of being ‘mentally ill’ (Corrigan and associates, 2009). The “why try” effect, which has been developed to augment the modified labelling theory (Corrigan & associates, 2009), and the stage model of internalized stigma (Corrigan & Rao, 2012), are also highlighted in the discussion section of this thesis.

Regardless of whether stigma is actually experienced or perceived (see section entitled “Perceived/Anticipated and Experienced Stigma” below for definitions of these terms), if an individual has internalized the prevailing social discourse surrounding mental illness and applied it to themselves upon diagnosis, internalized stigma emerges. Stuart (2004) claims that when negative stereotypes are internalized, a diagnosis of mental illness results in feelings associated with personal failure. Everett (2006) states that internalized stigma can cause individuals to

“adopt attitudes of self-loathing and self-blame leading to a sense of helplessness and hopelessness” (p. 4). Other common reactions to internalized stigma include: lower self-esteem, diminished self-efficacy and lack of social confidence (Holmes & River, 1998). Holmes and River (1998) conclude that the negative impact of perceived social stigma on those labelled manifests in isolation and social incompetency. These all contribute to negative influences on life satisfaction and quality of life (Corrigan & associates, 2009).

Corrigan and Rao (2012) and Corrigan and associates (2009) discuss the “paradox” of internalized stigma. They surmise that internalized stigma, leading to lower self-esteem and self-efficacy, can be plotted on one end of a continuum, neutral or no response to stigma in the middle, and personal empowerment (which includes healthy self-esteem and self-efficacy) on the other end (Corrigan & associates, 2009). Corrigan and associates (2009) claim that “personal empowerment is a parallel positive phenomenon conceived as a mediator between internalized stigma and behaviours related to goal attainment” (p. 77). Individuals who can be plotted on the empowerment end of the spectrum express “righteous indignation” at the injustice that envelops stigma (Corrigan & Rao, 2012, p. 466). Empowerment involves feelings of power, control, activism and optimism and as such, has been associated with better quality of life (Corrigan & Rao, 2012). This group is also more likely to play an active role in treatment identifying strengths, weaknesses and needs (Corrigan & associates, 2009). Factors associated with reaction to stigma in an empowering way include: rejection of derogatory, prevailing negative social constructions attributed to people labelled mentally ill and development of a positive group identity through the interaction with other individuals who have been diagnosed (Corrigan & associates, 2009). The authors suggest disclosure of mental health status as the first step in decreasing internalized stigma (Corrigan & Rao, 2012).

However, they also caution that the risks of disclosing could lead to further marginalization due to rejection and discriminatory attitudes of others (Corrigan & Rao, 2012). Disapproval by others could also lead to further withdrawal and acts of avoidance from greater society (Corrigan & associates, 2009). Meanwhile, relapse may be more heavily scrutinized, judged and gossiped about by members in the individual's social circle leading to increased stress and acts of secrecy to hide symptoms on the part of the individual (Corrigan & Rao, 2012; Hyman, 2008). The idea of disclosure is analyzed in the discussion section of this thesis. These definitions and models of stigma have informed my thinking in several sections of this thesis.

Perceived/Anticipated and Experienced Stigma

Another approach to understanding stigma is framed in terms of perceived stigma and experienced stigma. Perceived (or anticipated) stigma is considered to be fears about what might happen if mental health status is discovered (Everett, 2006). Meanwhile, experienced stigma is considered to be overt forms of discrimination, violations of human rights, exclusion and/or loss of employment (Everett, 2006).

Effect of Mental Illness Stigma

Many researchers have studied the impact that stigma has on individuals diagnosed with mental illness. The compiled research to date suggests that anticipated and experienced stigma most often have detrimental effects on an individual's: self-efficacy (Corrigan et al., 2009; Holmes & River, 1998), self-esteem (Corrigan et al., 2009; Link & Phelan, 2001; Link, Struening, Cullen, Shrout & Dohrenwend, 1989; Rosenfield, 1997; Wright, Gronfein, & Owens, 2000), quality of life (Depla, de Graaf, van Weeghel, & Heeren, 2005; Rosenfield, 1997; Yanos, Rosenfield & Horwitz, 2001), satisfaction with life (Markowitz, 1998; 2001; Rosenfield, 1997),

affective state (Markowitz, 1989), and social participation (Depla, de Graaf, van Weeghel & Heeren, 2005; Holmes & River, 1998; Wright et al., 2000). As a result, many encounter additional negative consequences such as diminished self-worth, engage in acts of secrecy, disengagement or withdrawal from others which, ultimately, further marginalizes and isolates them (Wright et al., 2000). Perlick, Rosenheck, Clarkin, Sirey, Salahi and Struening (2001) found that individuals with severe mental illness often withdraw from social situations, experience decreased social networks and exhibit poorer social adjustment in order to avoid stigma. Furthermore, “the degree to which the stigma of mental illness is incorporated into individuals’ self-concept increases” with the likelihood that the illness is chronic in nature; a common occurrence with mental illness (Rosenfield, 1997, p. 661).

Vogel, Wade and Hackler (2007) contextualize internalized and social stigma in terms of willingness to seek treatment, finding internalized stigma to be the most important predictor of help-seeking attitudes. Internalized stigma can result in depression, sense of hopelessness, increased passivity, and compliance with authority (learning to act like a “mental patient”) (Reidy as cited in Scheyett, 2005).

Effect of Mental Illness Stigma on Life Satisfaction

Existing studies reporting the relationship between the stigma of mental illness and the impact on life satisfaction argue that stigma is a detriment to the level of general life satisfaction reported by participants. For example, Yanos and colleagues (2001) found that general life satisfaction, a component of subjective quality of life, is adversely impacted by negative social interactions where the individual was treated as if “something is wrong” with them (p. 414). Markowitz (1989) concludes that stigma directly influences perceived interpersonal and

economic dimensions of life satisfaction because of its' adverse impact on self-esteem and self-concept. In a subsequent study, Markowitz's (2001) findings indicate that life satisfaction improves as symptoms abate and social relationships and/or economic situations improve (the social stress-social support perspective). The social support-stress approach suggests that "a person's economic and interpersonal well-being may affect the severity of their illness" (Markowitz, 2001, p. 65). He advocates for social and vocational skills training in order to encourage positive social activity for individuals living with mental illness (Markowitz, 2001). Meanwhile, Rosenfield (1997) indicates that perceived stigma negatively impacts on happiness with life by compromising participants' level of self-worth and self-efficacy. She concludes that stigma represents a barrier to satisfactory quality of life (Rosenfield, 1997). Leavey's (2005) findings suggest that individuals experience a great sense of loss in being labelled mentally ill which becomes detrimental to life satisfaction. This includes loss of: identity, independence, academic functioning, family status and friends.

Conceptual and Theoretical Framework

This section begins with an exploration of my ontological approach to this research - constructionism - by addressing how mental illness and stigma have been socially constructed. Following this, the conceptualizations of quality of life and life satisfaction found in relevant literature that served to develop my definition of life satisfaction for the study are discussed. Next, I discuss the predominant theoretical framework associated with stigma and mental illness in research which also informed my approach to this study: modified labelling theory (MLT). Finally, I conclude this section with the definition of stigma I derived from my reading of the literature that was presented to the participants of my study during the qualitative interviews.

The Social Construction of Mental Illness and Stigma

My position entering into this research study was that the notion of mental illness itself is based on the social construction of what society regards as inappropriate behaviour based on societal norms and expectations of proper conduct (Lamb, 2002). Scheff (1984) proposed in his labelling theory that people engaging in social behaviours considered deviant (those that cannot be understood, explained or categorized) are designated as “residual rule breaking” and subject to a mental illness diagnosis and treatment by the medical community (Gove, 2004, p. 365).

Moreover, according to Brown:

Diagnosis locates the parameters of normality and abnormality, demarcates the professional and institutional boundaries of the social control and treatment system, and authorizes medicine to label and deal with people on behalf of the society at large. This labeling is often enough the legal basis for provision of health services, welfare benefits, unemployment certification, worker's compensation claims, and legal testimony (Zola 1972; Brown 1990 as cited in Brown, 1995, p. 39).

Diagnosis dictates the route of treatment and determines medication regimes. Psychiatric labels have been found to lead to more unfavourable evaluation by society, expectation of a poorer outcome and discomfort based on the assumption that such behaviour does not fit normal patterns of social reaction (Scambler as cited in Hayward & Bright, 1997). Unfortunately, different psychiatrists will place more importance on one symptom versus another based on their education and experience (Davis, 2006). A psychiatrist who specializes in mood disorders, for example, may not attend to the existence of other symptoms related to impulse control, dissociative or personality disorders. This phenomenon highlights the social construction of mental illness and the relatively subjective and arbitrary nature of diagnosis in the mental health care system (Gove, 2004). Contemporary Western society places high value on wealth, health, beauty, competence, independence and productivity, and with the recognition of a diagnostic label, people are viewed as lacking these values and therefore, as irrelevant and worthless (Scheyett, 2005). Unfortunately, diagnoses, whether accurate or not, follow the mental health ‘career’ of individuals as they are historically preserved in patient charts and records. Diagnosis may result in a derogatory stereotypical categorization that discriminates against labelled individuals and often excludes them from greater society due to the stigma associated with mental illness (Gove, 2004).

Moreover, my approach to understanding the prevailing stigma associated with mental illness is similarly entrenched in the theory of social constructionism where social phenomena and categorization become social entities that are continually being created and reinterpreted through daily interactions amongst social identities (Bryman as cited in Grix, 2002). This idea of social categorization of individuals based on an “undesired differentness” was first developed by Erving Goffman (1963, p. 5) and expanded upon by Bruce G. Link and Jo C. Phelan (2001).

Goffman (1963) defined stigma as an “attribute that is deeply discrediting” in social contexts describing individuals with mental illness as being characterized of having “blemishes of individual character” (pp. 1-2). Goffman (1963) contends that individuals with stigmatized attributes are deemed not “quite human” and therefore, become subject to discrimination (p. 5). As such, this “undesired differentness” is constructed into a belief that explains “his inferiority” and which rationalizes rejection and loss of power in social situations (Goffman, 1963, p. 5).

Goffman’s (1963) conceptualization describes stigma in terms of social relationships that have been subjected to social rejection, devaluation or discrimination. He identifies individuals with mental illness as having concealable stigmatized attributes that are at risk of becoming discreditable to ones’ social identity should they be exposed (Goffman, 1963). Goffman (1963) alludes to the likely emergence of shame and the notion of internalized stigma as he theorizes that individuals with mental illness perceive their attributes as a “defiling thing to possess” and subsequently seek the need for acceptance from others (p. 7). Derived from this basic need for belonging, individuals are said to resort to impression management tactics, acts of secrecy and engaging in “passing” with respect to one’s social identity (Goffman, 1963, p. 41). (A thorough examination of secrecy and “passing” as it pertains to the experiences of the participants in this study is outlined in the discussion section of this thesis).

A sociological conceptualization of stigma in association with severe mental illness was most comprehensively developed by Link and Phelan in “Conceptualizing Stigma” (2001) (Scheyett, 2005). They associate stigma with the marginalization and “socially defined differentiation” of particular individuals from those of the dominant society (Link & Phelan, 2001). They proposed that the phenomenon of stigma exists when: a) an oversimplified, affixed label, such as ‘disabled’, that is deemed socially salient essentializes individuals with that

particular characterization (Link & Phelan, 2001). This distinction is reflective of the dominant cultural values and power structures of that society and contextualized in time and place (Link & Phelan, 2001); b) labelled characteristics are devalued and linked to negative, preconscious and automatic stereotypes deciphering these individuals as fundamentally different from the rest of society (Link & Phelan, 2001). For example, individuals who have been institutionalized are often stereotyped as dangerous or violent (Phelan et al., 2000); c) differentiation occurs between ‘us’ and ‘them’ where ‘they’ are viewed solely on their putative negative characteristics and as such are seen to ‘be’ and referred to by their label (Link & Phelan, 2001). For example, instead of a person having schizophrenia, a person is described as being ‘schizophrenic’ (Phelan et al., 2006); d) these individuals experience loss and discrimination as a result of this label placing them as a subordinate group of people (Link & Phelan, 2001). This hierarchy is then instrumental in predicting their social performance within groups and defines inequitable social interactions that are tolerated as acceptable (Link & Phelan, 2001); and, e) the stigma process is dependant on the “social, economic, and political power” necessary to impose discriminatory experiences on the labelled individual or group (Link & Phelan, 2001, p. 367). For example, mental illness has been associated with such things as reduced income, lower levels of education and precarious housing status (Druss et al 2000, Link 1987 as cited in Link & Phelan, 2001). Link and Phelan (2001) state that the impact of stigma which functions on multi-dimensional contexts operates to severely restrict the distribution of life chances including satisfaction with life itself. Therefore, stigma abets the social construction of mental illness based on pathologized difference.

Furthermore, stigma is a social creation that perpetrates prejudice and discrimination (Corrigan & Rao, 2012). Stigma works to affect individuals’ identity, self-esteem, feelings of

self-efficacy, and political and social position within greater society, and most importantly, their quality of life. Stigma, in effect, serves to marginalize, isolate and attribute weakness and blame to those diagnosed and prevents many from seeking the necessary care and treatment they are required to live a full and happy life. As such, the social construction and stigmatization of mental illness represents a serious barrier to accessing medical and psychological treatment (Wisdom, Clarke & Green, 2006). Rates of mental health service use are predicted to be far below rates of mental health disorders (Dew, Dunn, Bromet & Schulberg; Hirschfeld et al.; Logan & King; Offer, Howard, Schonert & Ostrov; Wu et al., as cited in Wisdom et al., 2006). For those who do receive a diagnosis and accept therapy, many become further marginalized from society (Link & Phelan, 2006). As a form of interpretive social science utilizing a constructionist orientation, the experience of stigma as conceptualized by both Goffman (1963) and Link and Phelan (2001), explored at various micro and macro level social interactions, informs the basis of this study.

Quality of Life and Life Satisfaction Conceptualizations

Often times, researchers report life satisfaction in terms of quality of life measures with respect to people living with mental illness. Quality of life studies are often comprised of objective measures (which are essentially observable facets of social functioning) and subjective measures (which are self-reported). Subjective measures, which include satisfaction with social life, relationships, health and well-being tend to ascertain participant life satisfaction.

Meanwhile, some studies incorporate the level of life satisfaction into quality of life domains (Yanos, et al., 2001). A formal definition of quality of life was provided by Becker, Diamond and Sainfort (1993) who state that quality of life is: “a person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her”

(p. 240). In this definition, quality of life is dependent upon life satisfaction but not necessarily the same as life satisfaction. Moreover, Markowitz (1998; 2001) equates life satisfaction with subjective interpersonal and economic quality of life. He considers the various components of life satisfaction to be: amount of time spent with friends and amount of time spent with family (identified as interpersonal quality of life); and job status, income, and where they were living (called economic quality of life) (Markowitz, 1998; 2001). Rosenfield (1997) uses the term subjective quality of life and life satisfaction interchangeably throughout her study, contending that both are a critical component of well-being.

The focus of the few studies that specifically concentrate on life satisfaction (as distinct from quality of life) and the measures that comprise it have been researched in terms of the context of stigma (Markowitz, 1998; Rosenfield, 1997) or the process of recovery (Markowitz, 1998; 2001). Rosenfield (1997) identifies the following measures in her study entitled “The Effects of Received Services and Perceived Stigma on Life Satisfaction”: use of economic services, (including vocational rehabilitation and financial support), and access to services providing greater status through empowerment (like living arrangements, family relations, social relations, leisure activities, financial situations, employment status, safety and health), as well as the perception of devaluation and discrimination (Rosenfield, 1997).

Meanwhile, a study conducted by Test, Greenberg, Long, Brekke and Burke (2005) tested the validity of a quantitative tool: “Satisfaction with Life scale” (consisting of 18 questions) which categorizes four measures of life satisfaction into: living situation, social relationships, work, and self/present life. Test and associates, (2005) concluded that the Satisfaction with Life scale was a unique addition to measuring life satisfaction of those living with mental illness because it incorporated measures to explore participants’ satisfaction with:

current psychological condition, self as a whole, and amount of freedom and enjoyment experienced. However, the questions concerning the measures of life satisfaction neglected to specifically ascertain actual or perceived stigmatizing influences on life satisfaction.

Mental Illness and Modified Labelling Theory

The majority of studies relating to stigma and mental illness that were consulted offer evidence to support the use of modified labelling theory (MLT) as a theoretical framework for understanding the relationship between stigma and life satisfaction. Modified labelling theory (originated by Link, Cullen, Struening, Shrout & Dohrenwend, 1989), was initially developed from Scheff's (1966) labelling approach to understanding how the self-identity and behaviour of individuals may be determined or influenced by being labelled as mentally ill. MLT postulates that individuals with mental illness are stereotyped, regarded as inferior and discriminated against by society (Moses, 2009; Wright et. al, 2000). This process evolves once an ascribed label or diagnosis is applied which serves to differentiate and marginalize persons with mental illness from greater society (Link & Phelan, 2001). This would seem to resonate with Goffman's (1963) notion of an acquired "spoiled identity" which serves to limit opportunities like employment and social functioning.

Link and associates, (1989) identify five stages to MLT which, although much the same as Corrigan and Rao's stage model of self-stigma (2012), endeavours to incorporate the behavioural response to perceived and experienced social stigma. MLT suggests:

1. *Beliefs about devaluation and discrimination:* Individuals refer to negative social constructions and prevailing social discourse about what it is to be deemed mentally ill and internalize them as genuine. These social constructions (derived from socialization and

cultural contexts) carry with them the notion that those with mental illness will likely be devalued and discriminated against by members of their community (Link et al., 1989).

These predominant beliefs of devaluation and discrimination responses to mental illness are socially derived and shared amongst all members of society (Link, et al., 1989).

2. *Official labelling through treatment:* Once individuals are formally diagnosed, the internalized prevailing social constructions and negative stereotypes become personally relevant (Link et al., 1989). As such, those labelled with mental illness apply fears of devaluation and discrimination to themselves should their diagnosis become knowledge for public consumption (Link, et al., 1989).
3. *“Patients’” responses to their stigmatizing status:* Once individuals perceive that they will likely be subject to negative responses from their community, they react in three possible ways: secrecy, social withdrawal or educating others (Goffman, 1963; Link, et al., 1989). (These common coping reactions are relevant to this study and are discussed in detail in the discussion section of this thesis.)
4. *Consequences of the stigma process on “patients’” lives:* As the result of perceived devaluation and discrimination (or in response to a stigmatizing status) individuals are at an increased likelihood of experiencing negative outcomes (such as a sense of shame, experiences of social rejection, impacts on self-esteem and limited life chances as the result of social withdrawal and discriminatory practices) (Link, et al., 1989).
5. *Vulnerability to future disorder:* This all culminates in fewer opportunities, limited resources and support and can result in risk for the development of psychopathology (Dohrenwend & Dohrenwend, 1981; Turner, 1981; as cited in Link et al., 1989) while intensifying social isolation (Moses, 2009).

MLT presumes a social construction of mental illness where society views the status of those diagnosed with mental illness negatively, and that such labelling and social stigma can result in recurrence or exacerbation of symptoms (Link et al., 1989). Several of the studies researching stigma and its' effects on individuals diagnosed with mental illness referred to modified labelling theory (MLT) as a guiding theory (Camp, Finlay & Lyons, 2002; Moses, 2009; Vogel et al., 2007; Wright et al., 2000). Most concluded that the theory was supported by their evidence (Moses, 2009; Vogel et al., 2007; Wright et al., 2000).

MLT and the stigma associated with mental illness directly relate to one another, especially with respect to the negative impact of such on individuals' self-esteem and self-efficacy (Link et al., 1989). For example, Rosenfield (1997), who examined the mediating effects of stigma in association with attitudes towards counselling, concluded that her study supported MLT and added that internalized stigma operates to dissuade individuals from seeking appropriate treatment. In addition, Rosenfield (1997) concluded that “the greater the perception of devaluation and discrimination among individuals with mental illness, the lower their satisfaction with life in general” (p. 665). As mentioned, the stigma associated with formal diagnosis of mental illness is often closely associated with isolation and the negative effects on self-esteem. This not only intensifies the debilitating effects of the symptoms related to mental illness but contributes to the societal conception that individuals labelled as such are deviant in some way (Camp et al., 2002; Vogel et al., 2007).

My Construction of Stigma

Likely, a more comprehensive literature review (which is beyond the scope of this thesis) would reveal innumerable conceptualizations of stigma across multiple disciplines. In formulating, for this research, a definition of stigma as it relates to mental illness, I focused

specifically on the work of three well known sociologists who endeavoured to conceptualize and frame stigma within the field of mental health: Erving Goffman (1963) and Bruce G. Link and Jo Phelan (2001). I also drew from modified labelling theory to construct this definition of stigma and communicated it to my participants during the qualitative interviews. Given the multiple and complex understandings of stigma, my goal was to present a short, simple and comprehensive explanation of what stigma is, one that was easy to understand and convey to the participants. Stigmatization (stigma) of mental illness was conceptualized as:

- experiences of discrimination or discriminatory attitudes - both overt and subtle;
- a feeling of being treated in an inferior or devalued way – sense of being isolated, rejected or avoided, loss of identity, loss of power, loss of opportunity, impact on self-efficacy; and/or
- a feeling of differentiation or marginalization from others.

The basis of this definition is grounded in Goffman's (1963) description of stigma as manifesting in experiences of discrimination, as well as Link and Phelan's (2001) multi-level definition of stigma. Specifically, the first 2 points of my conception are derived from MLT – threat of discrimination and devaluation by predominant society. A sense of being devalued is then expanded upon based on common reactions, feelings and the findings in existing research related to impact of perceived or experienced stigmatizing experiences. The final point refers to Link and Phelan's (2001) theory that differentiation occurs where individuals with a mental illness label are ostracized and alienated from greater society.

Methodology

Purpose of the Study

I embarked upon this research to explore, from the perspective of individuals labelled with mental illness, the impact (if any) that stigma might have on their perceived life satisfaction. My central research question was: “What has the experience of the stigmatization of mental illness been for individuals diagnosed/labelled with a mental illness and how has it affected their life satisfaction?”

Research Approach

My approach to the research consisted of a self-developed life satisfaction exercise, an in-depth semi structured interview for data collection, as well as photo elicitation (see Appendices D & E). Taking an interpretative approach to my research, I focused on the social life and experiences of the participants with the understanding that social interactions, socially constructed knowledge systems and prevailing stereotypes related to the stigma of mental illness can influence personal life satisfaction (Neuman, 1997). Interpretive social science (ISS) assumes that “multiple interpretations of human experience, or realities, are possible” (Neuman, 1997, p. 35). In this study, the perspective of individuals who had either experienced and/or perceived stigma in a social context formed the basis of data analysis. By soliciting information related to the impact of stigma at the time it occurred and present day, I sought to determine what various experiences of stigma (both experienced and perceived) resonated for my participants and how they came to understand the influence of stigma on their previous and current level of life satisfaction (Neuman, 1997).

Reflexivity, the practice of recognizing how my social location, previous experiences, who I am, who I have been and my feelings about the subject was central in recognizing how I could possibly influence data collection and analysis (Pillow, 2003). Reflexivity can be conceptualized as the “ongoing practice of self-awareness during the research process which aids in making visible the practice and construction of knowledge within research in order to produce more accurate analyses of our research” (Pillow, 2003, p. 178).

Prior to conducting the qualitative interviews, it became important to recognize my motivations for doing this research, as well as my challenging my assumptions about how I felt participants would respond to the various questions I asked during data collection (Finlay, 2002). One of my assumptions rested in the high likelihood that everyone’s story (with respect to seeking treatment for their mental illness) would be a negative and detrimental experience. In an effort to offset this preconceived notion, I developed questions in the interview guide that probed participants about any positive incidences associated with their experiences especially in the context of navigating the mental health care system. This was in an effort to avoid skewing the research in particular directions (Finlay, 2002). If I were to only focus on the negative impacts of stigma on life satisfaction with the participants, my position of privilege and power would seek to minimize the participant’s voice (Finlay, 2002). Instead, I was certain to maintain my primary focus on the participant’s personal stories which often highlighted positive outcomes.

During the data collection phase, when interviewing the participants, issues related to an inherent power imbalance can easily materialize (Finlay, 2002). For example, while interviewing one participant in particular, I found that s/he did not elaborate much on the answers to my questions. As a result, I was more directive in asking questions and probing for more information. This often took the form of posing numerous closed ended questions to gain

clarification. As a result, the data gathered may have been limited in scope and any agenda that I may not have been conscious of could have materialized based on the questions I posed to him/her throughout the data collection stage.

Finlay (2002) cautions that the practice of reflexivity is difficult and uncomfortable at times. One strategy I imposed was adopting a mindset known as the natural attitude in ISS research. This involves approaching the research with no preconceived ideas, hypotheses or conceptualizations about the subject matter in question (Wertz, 2005). The process involves setting aside prejudgements and approaching interviews with an unbiased, open and receptive mindset (Moustakas, 1994). Therefore, in being cognisant of my preconceived presumptions about the effect that stigma may have on one's satisfaction with their life based on my own personal experience, I emotionally prepared and centred myself prior to data gathering and analysis. As such, I was mindful that I should take no position and attempt to remain value neutral adopting a "pure state of mind" (Moustakas, 1994, p. 88). A discussion of how my experiences of stigma may have influenced data collection and analysis is further elaborated on later in this section under the heading "Locating the Researcher".

Life Satisfaction Exercise

Based on the existing research compiled to date related to the various measures of life satisfaction and quality of life, I integrated the following into the Life Satisfaction Exercise (Appendix G): number of supportive and caring relationships, frequency of contact with these individuals, occupation, income, volunteering, residence, time spent doing leisure activities and other (please specify). As a result of my literature review, I was mindful of the common and key identifiers that the majority of quality of life and life satisfactions entailed and opted to select measures that were not too intrusive in nature (e.g., I chose not to ask about satisfaction with sex

life). The purpose of asking participants to fill out this exercise was to help me with facilitating the initial stages of the interview. Each interview began with questions asking for clarification on any score of 5 and below in terms of participants' present life satisfaction. The measures I chose incorporated existing measures while also integrating the choice of 'other' which gave the participants a space to articulate any other important facilitators that were personal to their life satisfaction. However, the Life Satisfaction Exercise was not a tested tool and does not purport to be as such. Moreover, other than exploring the lower scoring items, the quantitative and qualitative data were not connected in the data collection process.

Interviews

The qualitative interviews incorporated an interpretive approach to the study which maintains that: "social life is based on social interactions and socially constructed meaning systems" (Neuman, 1997, p. 69). Based on the notion that mental illness and stigma are socially constructed, integrating a qualitative measure that taps into each participant's lived social reality of the effect of stigma was fundamental to discerning their individual, and often unique experiences. Questions were asked surrounding their initial experiences with the mental health care system, effect of diagnosis on life goals, stigmatizing experiences with various individuals, the effects of stigmatizing forces on life satisfaction, as well as sense of empowerment and resiliency. Please refer to Appendix E for a complete version of the interview guide.

Photo Elicitation

To augment the qualitative component of the study, I also integrated photography into the process by requesting that participants bring two photos of themselves – one from a happy time and one from a difficult period in their lives. Photo elicitation strives to evoke information,

feelings and memories associated with the particular time period and serves to gather additional information from participants (Erdner & Magnusson, 2011; Harper, 2002). It can also prompt participants to begin reflecting on the study ahead of time and mentally prepare for a discussion surrounding a sensitive topic while encouraging their engagement in the process (Van Auken, Frisvoll & Stewart, 2010). Participants presented photographs capturing significant moments from their past. Photo elicitation has the potential to activate a new level of awareness associated with the experience of stigma, life satisfaction and mental illness. Photo elicitation has also been documented to potentially improve validity and reliability over methods that incorporate word-alone interviews (Harper, 2002). Requesting participants to bring photographs to discuss during the interview process aspired to offset the power differential inherent between the researcher and participant. By fostering a dialogue where the researcher refers to the participant to offer a definition of meaning to the images, the role of the researcher becomes that of a student of the topic (Harper, 1998). Harper (1998) contends that incorporating photo elicitation can result in data collection that is more deeply grounded in the experiences of the subject.

The primary objective of this research was to explore an individual's lived reality of stigma as it relates to their mental illness and how this then affects life satisfaction. The use of photographs to elicit memories of good and difficult times in participants' lives acted as the mechanism to elicit these internalizations. Questions posed during the interview process aspired to move the conversation from the stigma that was experienced and described in concrete terms (or, essentially, the 'what' of the experience) "towards its' reflexive reference in the 'how' of the experience" (Ihde as cited in Moustakas, 1994, p. 79). This was accomplished by discerning the

impact that perceived stigma and experiences of stigma had and presently holds on the participants' perception of their level of satisfaction in life.

Recruitment

Upon ethical clearance of this research study, recruitment of participants occurred via several channels, including emails to current undergraduate, graduate students, and alumni of McMaster University through the administrative staff of various departments (e.g.,: the School of Social Work, Faculty of Social Sciences, Department Of Psychology); emails to academic and professional contacts; and the posting of the recruitment poster at two community agencies (Sexual Assault & Violence Intervention Services of Halton in Oakville, Ontario and the Mental Health Rights Coalition in Hamilton, Ontario). The emails provided potential participants with information about the study and my contact information (Appendix B).

Emails sent to members of the McMaster University community were distributed by the administrative staff and, as such, I was not privy to them. Therefore, I had no knowledge of which students had been approached by the department administrators. Given that my name was on the recruitment email and, because this is a self-selection method of recruitment, there was the chance that students known to me might choose to participate. This was the case for two students with whom I was previously acquainted. Since the emails were made inclusive to all individuals irrespective of mental health status, only those that contacted me became known to me as individuals with a mental health disability thereby ensuring the confidentiality of those students with mental health issues who chose not to participate.

Since the parameters of the study required individuals to be formally diagnosed with a mental illness by a medical practitioner and over the age of 18, each individual that contacted me

was advised of these requirements before their suitability for the study was determined. I responded to participants in the order that they contacted me and through the medium in which they chose to do so (e.g., telephone, email). Once a participant agreed to participate, an interview time and place was determined. Following this, they were asked to select and bring two photographs (original or digital) representing a good and bad time in their lives to the scheduled interview and were emailed a copy of the Life Satisfaction Exercise (Appendix G) for review.

Of the eleven individuals who expressed an interest in participating, a total of 8 were interviewed (the maximum number of participants allowed for my study). One individual had not been formally diagnosed with a mental illness and therefore was not eligible to participate. A second did not return my calls after having left me a telephone message expressing interest. The third potential participant contacted me several weeks after the qualitative and quantitative data had been collected and analyzed.

Participants

Limited demographic information was gathered as a means of facilitating participants' confidentiality. Personal details are limited to what was shared in the interview. The majority of the participants proved to be current or past students of McMaster University. Of the eight participants, 6 were recruited through the McMaster University student body. Of these six, 3 were current students (one undergraduate and two graduate level students), 2 were recent graduates (one undergraduate and one graduate), and the final participant had been in the work force for approximately 5 years. The remaining 2 participants heard of the study through my

professional contact at a community-based agency in Burlington, Ontario who had forwarded my information to several mental health agencies in the Halton region.

Six of the participants were female and two were male. Formal diagnoses included: paranoid schizophrenia, major depression, anxiety, borderline personality disorder (BPD), post-traumatic stress disorder (PTSD), and anorexia. The time elapsed since formal diagnosis ranged from one year to over 25 years. Four of the 8 participants also struggled with issues of physical pain and/or illness. The participants ranged in age between 25 and 53 years old.

Data Collection

To ensure confidentiality, participants were asked to choose an appropriate location to conduct the interview. For three participants the interviews took place on the McMaster University, two others were held in the participants' homes, one in a private area in the community, and two conducted over the phone. Interviews were conducted between May 22, 2012 and June 1, 2012, and were 2 hours each on average. Each potential participant was provided with a Letter of Information and Consent (herein referred to as "The Letter", Appendix A) that was discussed in detail prior to the beginning of each interview. The Letter was reviewed to ensure comprehension and provide an opportunity for participants to ask any additional questions or voice concerns related to their participation in the research process. Upon agreement, participants were asked to sign the Letter to demonstrate accordance with its' contents.

The survey was used at the beginning of interviews to gain a sense of where participants rated their current life satisfaction and the importance of the various measures of life satisfaction. Any measures valued at 5 out of 10 and below served as prompts to begin the interview process.

The choice to only discuss items scored 5 and below was based on considerations of time. The concept of life satisfaction was also introduced in the questions that were posed during the interview. Identifying the various components in the survey helped to inform the participants of the components that I, the researcher, considered salient to life satisfaction.

Following the discussions regarding clarification of low scores (5 out of 10), the interviews began by referring to the interview guide (Appendix E) that had also been previously emailed to the participants for review. Finally, participants were asked to discuss their photographs. (At the close of the interview, these photographs were retained by each participant.)

Participants were asked to provide a pseudonym for reasons of confidentiality and, because only two individuals provided one, I assigned to each participant the first initial of each person's name or pseudonym. Two individuals had the same first initial so, in one case, the person's first letter of their last name was designated as a pseudonym. Qualitative interviews were audio-recorded with each participant's permission. The audio data was stored on the voice recorder and on my personal laptop which is password protected. Upon the completion of the transcriptions of the interviews the audio data was deleted from both the voice recorder and my laptop.

Given the sensitive nature of the material discussed, participants were also offered a listing of community resources related to mental health that they could access should they feel they required additional supports after the interview process. Only one participant requested this information and it was promptly emailed to him/her.

Data Analysis

Strategies I utilized for analyzing data involved immersion in the collected data through reading transcripts of the qualitative interviews several times in order to develop an overall sense of each participant's experience of the phenomena (in this case, stigma and the effect on life satisfaction) with a focus on relevant statements. Each statement was then thematized to capture its' meaning and used to develop a thorough understanding of each participants' experience of stigma (Hein & Austin, 2001). Thematic analysis of the qualitative interviews was achieved utilizing a constant comparative method to code the transcripts (Strauss & Corbin, 1998). I identified the themes emerging based on the two foci of the study: stigma and life satisfaction. I then grouped the data based on the following emergent themes: sources of stigma, impacts of stigma, forms of stigma, and positive and negative influences on life satisfaction.

For the photo elicitation piece, I reviewed the information provided by each participant to contextualize the images in terms of mental health status, age and time period. The photographs were thematized based on the participants' expressed feelings, experiences and whether any prevailing symptoms existed at the time the photograph was taken. Whether any exceptions to the common themes inherent in either of the qualitative components existed was also explored but none were found.

Locating the Researcher

As an individual with a formal mental health diagnosis, my approach to the research is likely biased by my personal experiences of stigma. Being ever-mindful of my own preconceptions, perspectives and social location as a researcher with a mental health diagnosis was integral to the processes involved in data collection, analysis and discussion. However, my inherent biases may not be fully known to myself as the researcher or fully uncovered during the

research process (Hein & Austin, 2001). I admit that some of the positive influences that came out during the interviews served to challenge my assumptions that all experiences with the mental health care system are difficult and marginalizing. Moreover, inadequately exploring participants' perceptions based on my possible 'taken for granted' assumptions that all experiences with the mental health care system are common to one another could have influenced my approach in data collection (LaSala, 2003). This is of concern to me as a researcher as it may have impeded on my ability to objectively and accurately interpret the data.

The emotional labour I experienced during this process did not go unnoticed. Hubbard, Backett-Milburn and Kemmer (2001) state: "...emotional labour may influence our interpretations of respondent's lives, may influence the data collected and may affect our professional and personal identity" (p. 131). All of the interviews were conducted within approximately a two week period where sometimes more than one interview would occur on the same day. Many of the participants spoke of experiences and feelings very similar to my own and there was a desire on my part to relate to the participants on a personal level many times during the course of several interviews. Pillow (2003) notes the common practice of the researcher using his/her own life experiences to find similarities with participants. Meanwhile, the 'emotionality' of one interview likely influenced my reactions in subsequent interviews (Hubbard et al., 2001). Due to the aggressive scheduling of interviews, one could deduce that as a researcher, I was more or less effective in establishing rapport and based on the diagnosis of the participants, able to relate at a different level to some participants more than others. I am quite certain that some of my personal reactions to their stories and my facial expressions conveyed 'an insider' position.

My decision to not disclose my diagnosis with the participants and thereby purposely withhold information from them likely influenced the entire process of data collection, analysis and findings. Although it cannot be said for certain that participants were not completely open and honest about their feelings and experiences, disclosing my mental health status could have added a higher level of intimacy, decreased the power differential in the researcher-participant relationship and contributed to a better level of understanding and connection with each participant thereby compelling them to be more engaged, at ease and possibly, reflexive in sharing even more personal stories during the interviews.

As an individual who is navigating the journey to wellness and mental well-being, the idea of disclosure is still a daunting and risky task for me – as I assume it is for everyone. I recognize that there was an expectation of the participants in my study to trust me in telling their story and how daunting an undertaking this likely was for them. Although most of the participants were actually grateful for the opportunity to reflect on their experiences, a power differential was still ubiquitous with the expectation that their personal and often difficult experiences would be explored during our conversations. Meanwhile, the perception of myself, the researcher, as an outsider to the participants inevitably placed me in a position of power. Some participants spoke of the hesitation they encountered in initially contacting me to state that they would like to participate in the study. Since, they explained, in doing so, it compelled them to wrestle with formally acknowledging that they had a mental illness. Some were worried about a possible breach of confidentiality.

I can understand their hesitation given that I, myself, rarely divulge my mental health status to others unless I trust them. In fact, it was not until I returned to school in 2009 to pursue my degrees in social work that I started to slowly disclose my experiences of stigma and mental

illness in my various academic papers. I felt that conveying my experiences in writing was a safe harbour to express the impact that mental illness and stigma has played in my own life.

With the eventual publication of this thesis, I know that I am vulnerable to stigma and scrutiny by those who read my thesis. I now recognize that I could not have been this open about my mental health status even 5 or 6 years ago and that the journey involved in the process of recovery is unique to everyone. Some may never have the desire or impetus to disclose their mental illness to others as each person's journey is specific to them. For those who keep their mental health status private, there should be no shame in doing so. Individuals living with mental illness have enough to manage in their lives without feeling pressured to become an advocate against the stigma associated with mental illness. The main issue lies with those who discriminate and not with those who are discriminated against. I am grateful that I am now more able to discuss my struggles with others in an effort to educate them on the myths associated with mental illness. However, that being said, it is still a difficult process for me. Moreover, I would likely never openly disclose my diagnosis to an employer as I believe that discrimination by employers is still quite common.

LaSala (2003) discusses the idea of countertransference reactions during data collection, from the participants to the researcher where common experiences between the researcher and participant end up being distorted in data analysis. This is due to the idea that the researcher assumes that each participant's emotional reaction to occurrences of stigma and the subsequent impact of such is perceived and experienced in the same way (LaSala, 2003). As an individual with a mental illness who has experienced social stigma from various practitioners, previous employers and in personal relationships, it was difficult for me not to essentialize common experiences. It was also disheartening to listen to other similar stories in younger participants,

as it was my hope that social stigma may not be as prevalent now as it was when I was first diagnosed and experiencing stigma. Also, I found myself comparing my story to the participants' story in terms of the degree to which stigmatizing experiences impeded on their recovery process. This likely interfered with my ability to accurately interpret the participants' accounts of the effects of stigma on life satisfaction (LaSala, 2003). Finally, it is quite possible that full exploration of participants' experiences was not examined given my possible assumption that the outcome and impact of these experiences would be the same for them as it was for me.

Strategies utilized to maintain an 'outsider' identity upon approaching the qualitative interviews included practicing compartmentalization as a temporary coping technique that enabled me to focus all of my attention, both intellectually and emotionally, on the participants' stories. Centering myself for a pending interview, I attempted to re-frame my mind to that of a researcher and academic as opposed to an individual with a history of mental illness. In maintaining non-disclosure of my mental health status, I was cognizant of the fact that disclosing my disability might place some participants at ease, I did not want the interviewing process to become reciprocal with me offering my story in any way. I attempted to maintain a 'position of not knowing' with the knowledge that coping with mental illness is a self-evolving process and respecting the position of each participant in 'starting where they are at' in their journey in living with mental illness. I also maintained the understanding that times may have changed and the stigma that was so prevalent when I was growing up may not for these participants be quite as intense; the age and the social-historical context in which their symptoms emerged may be relevant to their experiences. Upon reflection, these various coping mechanisms and practices, although not entirely effective, did help to establish appropriate boundaries with each participant.

As previously discussed, I do recall mentally comparing my personal experiences to those of the participants. Nevertheless, I managed not to qualify my experiences with theirs by respecting and validating each of their experiences as unique to them.

Findings

The following findings consist of a reporting of the data collected utilizing two qualitative methods. Qualitative findings consist of interview content and data collected during the photo elicitation portion of the study.

Qualitative Findings

The qualitative component of this study incorporates individual interviews, as well as responses to a photo elicitation exercise. I will first address the prevailing themes that emerged from analysis of the interviews and where applicable, combine them with the photo elicitation themes. Participants were asked to bring in two photos – one of a “good time” in their lives, when they felt a higher degree of life satisfaction and one representing a difficult, and less satisfying period– and these were discussed at the end of the interviews. Often times, photographs elicited more than one theme.

From an analysis of the 8 interview transcripts, 5 themes emerged surrounding the stigmatization of mental illness and life satisfaction: impact of stigma – selective disclosure, disruption to life course, forms of stigma – what does it look like?, and sources of stigma. The themes have been categorized as either positive or negative influences on life satisfaction.

Negative Influences on Life Satisfaction

Impact of Stigma – Selective Disclosure

According to the participants of this study, the prevailing impact of stigma was participants’ perceptions that disclosure of mental illness must be made selectively. In all 8 cases, participants severely limited the number of people to whom they disclosed their diagnosis and/or their use of related medications. For example, Participant W felt that there was such

stigma towards the addictive qualities of his/her medication for anxiety that s/he only disclosed the medication s/he was taking to two of his/her sisters and his/her partner. W elected to keep his/her reliance on medications from his/her father (who works as a physician) and her/his mother (who has a graduate degree in social work). W stated: “There is a conscious decision for me not to tell people”. Later on, W said: “My dad said: “suck it up” at his practice; he’s not into mental health. My mother would go crazy. She’d say: “you’re addicted” and she’d freak out”. Meanwhile, Participant A confided: “I avoid disclosing mental health problems. I do. As I said, I worry about the judgement and evaluation of others and what they may think of my level of competency”. B, who has been diagnosed with post-traumatic stress disorder (PTSD)¹, stated: “I didn’t tell my friends about the hospitalizations. I knew they wouldn’t want to talk to me anymore. Or they would think I’m very strange. Like I have schizophrenia or something like that”. Similarly, Participant C, who has been diagnosed with paranoid schizophrenia, commented: “I didn’t tell them [*job agency*] what my diagnosis was because every time I do it’s like suicide”. Finally, M revealed his/her trepidation in discussing his/her diagnosis of depression and alluded to his/her internalized stigma:

She is a very close friend but I don’t know how she would react. She’s a medical type [*nurse*]. So maybe when I accept myself more, I will tell her. But we are close. I can tell her anything but not that right now.

In five cases, participants’ disclosure to people outside of family was made only to others who had revealed mental illness themselves. Still, the idea of disclosing mental illness to others for all 8 of the participants was met with the fear of harsh judgement, rejection, avoidance,

¹For more information on the various diagnoses mentioned in this study, please consult the current Diagnostic and Statistical Manual of Mental Disorders by the American Psychiatric Association.

and/or not being accepted by others. Upon asking Participant G what his/her worst fear would be upon disclosing his/her mental illness, G confided:

I suppose maybe rejection and losing that relationship and that full acceptance of who I am: that there is a part of me that they reject and they don't want a relationship, or I guess the fear of them feeling like they can't trust me or that I'm going to let them down.

Five individuals conveyed that disclosing their mental illness conjured up additional concerns related to disappointing others; that the validity of the condition would be questioned; that they would not be taken seriously; that they would be looked at differently; possibly losing others' respect; or that it would make things worse for them. For example, M spoke of his/her experience in divulging his/her diagnosis of depression to a couple of his/her friends: "And they don't acknowledge me. So then I end up feeling worse sometimes talking to these people. So why would I tell these people that I'm depressed? They say: "Oh, you don't have to be depressed"". Participant W, who works in the child welfare industry, spoke about his/her fear that s/he would be deemed a bad parent, declaring: "So, does this prevent me from being a good parent? No, but I've worried about that sometimes. What if someone found out, would they think I'm neurotic and crazy? And call CAS?" W addressed the fear of a potential discovery of his/her reliance on a highly stigmatized anti-anxiety medication by his/her employer. W admitted to taking his/her daily medications in the workplace setting in private to avoid exposure. In summary, all 8 participants limited the number of people to whom they disclosed their mental illness diagnosis and medication use as a result of the fear that the anticipated impact of such would have on their relationships and/or reputation.

Disruption to Life Course

Another theme that emerged for all participants was the experience of a temporary or permanent disruption to their life course during the time period that they were initially diagnosed; seeking treatment; and/or trying various medications in an effort to stabilize their symptoms. For all but one participant, this meant taking a leave of absence from university, dropping out of university, or graduating later than anticipated (note: most of the participants were first inaugurated into the mental health care system during that time in their lives).

Participant W commented: “They [*medications*] made me non-functioning for 2 years. I took a leave from school. I was just not in a good place”. Participant A spoke of the negative impact of his/her diagnosis on his/her self-esteem and how this functioned to disrupt his/her education trajectory stating: “... the impact of the diagnoses on my self-esteem affected my decision to withdraw from [one university program] and concentrate on [another university program].”

Meanwhile, Participant C appeared to have experienced a permanent disruption to his/her life course after being diagnosed with paranoid schizophrenia. C, who reported the lowest satisfaction with their present life situation, admitted that s/he would currently be homeless without the support of his/her mother who houses him/her. During a particularly difficult time in his/her life, C discusses his/her initial experiences with the mental health care system:

I was discharged. I was homeless. I had no place to go; I had no food, no friends, and no money, no job, no shelter. I was out on the street. I went to a homeless shelter. People wanted to fight me because of my skin colour. So, after being homeless for 2 weeks I went back home and I was arrested by the police and taken to hospital for 6 months.

Participant C is currently unable to function adequately with the medication that s/he is obligated to take in order to continue living with his/her mother. The result is that s/he currently

wishes for a life that has eluded him/her: “I want to get away from it [*therapy*]. I want to have a life but I have no life. I want to have a career”. C revealed that s/he has never had a partner, a career, or felt as if s/he was a part of his community. C profoundly articulated his/her opinions of the mental health care system:

The way they treat the mentally ill - it's not right. They've got to do more for these kind of people. Recognizing it's a disability, having someone to talk to, getting active employment, becoming a contributing member of society, getting involved in the community. It's very important for someone with a mental illness. They've got to be stable and they can't get stable because people don't respect them enough. Just medicating these people is not a good way to treat someone with mental health.

Participant C feels that his/her experiences with the system have ruined his/her life and is unwilling to accept his/her diagnosis of paranoid schizophrenia. In conclusion, each of the participants delayed attainment of their educational pursuits and/or career aspirations to focus on the pressing urgency of reducing the symptoms associated with their mental illness.

Forms of stigma – what does it look like?

From the perspective of the participants in this study, the stigma associated with mental illness most often manifested itself through comments and jokes made by friends, family, coworkers, peers and members of the medical community. Each of the 8 participants spoke of instances where offensive remarks about mental illness were made by others, either directly towards them or in ignorance of their diagnosis. One participant, S, who had a diagnosis of bipolar II with rapid cycling (at the time), spoke of a joke s/he overheard his/her cardiologist telling the ICU nurses after his/her suicide attempt: “It made me want to kill myself all over again. They were laughing about rapid cycling and making jokes about bicycling. It was so inappropriate.” Another participant, V, spoke of how his/her brother often jokes about the period

s/he spent at a facility for the treatment of anorexia, referring to it as his/her time in the “loony bin”. V feels that his attitude is a “symbol” of greater societies’ ignorance and prejudice against those with mental illness. V states that he is a typical person who does not understand mental illness and conveys prejudice without realizing he is doing so. Derogatory comments regarding dependence on medication were also described by G. For this participant, stigmatizing comments from his/her brother equated medication use with being “less of a [person]”; reliance on medications “equals weakness”.

Often times, comments were perceived as designed to minimize the validity or impact of the illness on the participants. For example, participants were offered solutions such as “walking it off” and “exercising more,” or told to “think about people suffering in Africa whenever you get depressed.” The main message that these stigmatizing comments offered participants was the sense that there is a clear lack of understanding about mental illness and its’ effects on individuals.

Sources of Stigma

Social Stigmatization

The main source of stigma was perceived to be previous, current and potential employers. The majority of participants (7 of 8) spoke of the experience and/or fear of losing a job and the concern that their competency and mental stability would be questioned should a current or future employer discover their diagnosis.

Participant B, who had been admitted to hospital by police after threatening suicide, was told by a potential employer that his/her criminal record had to be cleared for him/her to work at respite services. B said:

I got a letter from them [*respite services*] saying that I had a positive criminal record and that they couldn't hire me. I didn't know that until then and I made the connection that because the policemen checked me in, they had put it in the record as "other".

Upon returning from a long term leave from his/her previous employment, Participant S was told by his/her supervisor: "You're not my problem; you're the insurance company's problem". S added: "I didn't expect that from him. I didn't think he was that type of person." S revealed that this supervisor and several other co-workers wanted nothing more to do with him/her after his/her return to work from long term disability. However, as time has passed since this incident, S claimed that "I have no problem now disclosing that I have a mental health illness. And partly it's about education". S was the only participant who expressed comfort in disclosing his/her mental illness for educational purposes. W spoke of his/her fears about revealing his/her diagnosis to his/her employer stating: "Somehow I wouldn't be able to do the job. I'd be seen as less competent. Maybe the concern [is that] I wouldn't be able to manage or handle a situation even though I can handle all sorts of things". W felt that should s/he divulge his/her mental illness s/he would be terminated from his/her current position.

Other participants echoed the concern about being seen as less competent by an employer upon disclosing their mental illness. M, who is a recent graduate, spoke of his/her fears concerning being hired stating: "Because to find a job; people aren't going to hire me if I'm depressed. If I have depression, they'll say that I'm unstable... You have a mental illness, who is going to hire you?" Meanwhile, G, fearing that his/her medical records would be requested for a position in his/her field, spoke of equal opportunity policies stating:

They [*society*] give the impression that it's accepted and that we will accept disability in some form but, for me, I just feel that's more lip service and the actuality is "no"...

I wish I had never gone on medication or received this diagnosis because how is this going to affect me in a professional sense?

Participant G felt that a potential employer in his/her area of interest would require stability in the job and that a diagnosis and reliance on medications would be perceived by an employer as the inability to tolerate or handle stress. This, s/he believed, would result in his/her elimination from the competition for the position.

Another identified source of stigma was medical practitioners, hospital staff, and/or emergency services personnel (e.g., police and paramedics). The majority of participants (7 of 8) spoke of being seen by some of their practitioners, not as a person but as their diagnosis, a patient, or just a number. One participant, C, who has been diagnosed with paranoid schizophrenia, spoke of his/her numerous hospitalizations asserting s/he would never go to hospital again: “I was just embarrassed about the way I was treated. It hurts when I talk about it; it makes me very frustrated because people don’t understand where I’m coming from”. C claimed that all of his/her civil rights have been violated by the mental health care system and the police and that s/he was treated like an animal, mass murderer and terrorist. Participant C no longer discusses his/her experiences with his/her practitioners for fear of “being locked up”.

Both M and G also spoke specifically about being treated only with a prescription and receiving little emotional support. For example, G described his/her interaction with his/her initial diagnosing psychiatrist as an “impersonal transaction”, where the psychiatrist stated: “this is a formal diagnosis, here you go, here’s your prescription.” G continued: “I never really felt any sort of connection. I just felt this is the aspirin, whatever antibiotic I need to take to feel better”.

Participant W, who finally found the right medication after 7 years of trying various psychotropic drugs postulated: "...there's very few doctors who get it. They think: "Oh anti-depressant, give it to you and it'll work and if it doesn't, there's another one"". One psychiatrist's solution for W when s/he was attending university was to advise him/her to reduce his/her stress by getting "rid of my cats" and working in a variety store. W states: "That wasn't an option; my cats were my family... I thought: "Variety store? Why am I going to university?""

Half of the participants presented pictures of a challenging period that occurred during a time in which appropriate treatment had yet to be secured. They reported that they were waiting to access appropriate treatment that had been approved; or not accessing any treatment services; or not taking medications for their mental illness. In some instances, there was seemingly a long wait time to access services. In the case of Participant M, a search for a psychiatrist in his/her region was met with a one year waiting list. For Participant V, this meant waiting over 6 months to attend the facility for the treatment of anorexia. Participant B discussed a time period during which s/he was weaning off of medications related to depressive episodes:

I was sad, I guess. I was just really overwhelmed with school work and time lines and when I had those pressures and school, it mimicked how I felt when I was going through all the stuff when I was in the hospital; so it re-triggered.

Participant S, who experienced stigma from an acquaintance who was a police officer, claimed:

I was talking to one guy who was a cop and when I revealed that I had PTSD, it was like he blew up, [and said] "that's a cop out!" The only real people with PTSD were soldiers and people who had been through a life threatening situation; that type of trauma.

Other sources of stigma included family members, previous and current partners, friends, acquaintances and various cultural and social sources.

The majority of the participants (7 of 8) discussed instances of stigma from family members and/or current and previous partners. For example, G discussed how his/her brother was previously taking medications for his depressive symptoms but elected to become chemical free. G's brother would often question G's decision to rely on anti-depressants to manage his/her symptoms stating: ““You should get off of that [*medications*]” or in asking: “Why are you on that? Do you really need to be on that?” sort of thing.” Meanwhile, Participant V discussed his/her father's “repulsion” for “eating disordered behaviour” and, upon my questioning whether his/her father would have a different attitude towards him/her if s/he was not currently in recovery, stated:

He would be frustrated with me and I think he would like me less. He would always love me but I think he would keep his distance from me. I just feel like he can't handle it. It just touches him and he doesn't have the stomach for it.

Friends or friends' parents were often identified as stigmatizing towards participants upon learning of their mental health diagnosis. Most participants (7 of 8) relayed experiences of being stigmatized by these individuals. In some instances, this resulted in participants ending relationships or becoming estranged from friends. Participant W explained:

I let go of a couple of friends because they were horrible. One said to me: “Why don't you go out and walk it off, exercise.” And I said: “I don't feel like it, I can't leave my home right now.” That was really hard. They didn't understand; they didn't get it. That was a shift where I did let go of some friends. It was a very lonely time.

The same was true for Participant S whose relationship ended with a friend and fellow colleague when she cancelled a long weekend trip with S. S recalled: “She called me one day

and said: ““I’m afraid of you and I don’t want to go.” I had to pay for the down payment and I didn’t go.”

The majority of participants (7 of 8) revealed that stigmatization of mental illness in the form of social and cultural forces affected them. Participant S, who is financially dependent on Canada Pension Plan (CPP) and other income support programs, explained that s/he is unable to live with or marry his/her partner because they are receiving Ontario Disability Support Program (ODSP) supplements. S stated that with his/her Registered Retirement Savings Plan (RRSP) assets, his/her partner would: “...automatically be knocked off ODSP if we even tried to live together”; later adding: “There’s so many complications – even with residence – with the government rules that they don’t even want to have people with mental health to have relationships.”

Similarly, the rules surrounding Ontario Student Assistance Program (OSAP) for students with mental health issues were often restrictive. Participant W, who took a 60% courseload over 18 years of post-secondary schooling claimed:

OSAP does not view or consider mental health as permanent or severe enough and therefore, would not consider me a person living with a disability at the time I attended school. And therefore would not forgive any or all of my loans as they would a person with MS [*Multiple Sclerosis*] or another valid disability.

Internalized Stigma

Internalized (or self) stigma was also found to be another source of stigma for several participants. However, internalized stigma appeared to be a concern for Participant M in particular. Of all the participants, M spoke the most about his/her issues around acceptance of

his/her diagnosis of depression and how s/he refuses to take prescribed anti-depressant medications because s/he “would have to accept that I am depressed”. M stated:

You see, because it's [*stigma*] social and because we grow up in this kind of society... And then when it happened to myself; when it happened to me; I can't accept myself because I don't accept others. That's the way things are.

Later on, M discussed how s/he is often in denial of his/her diagnosis and has not achieved self-acceptance as a result.

Participant W discussed his/her view that others would stigmatize him/her due to the medications that s/he is required to be the “best” that s/he can be: “It makes me sad that my most immediate family, most [of] the people I meet; that I feel it's my perception that I would be stigmatized.”

Finally, Participant S reflected on his/her experiences with internalized stigma at an earlier time in his/her life:

I think the big part of self-stigmatization comes from the people around us. In mental health, a lot of us identify with our illness. The way I say: “I am borderline” rather than “My name is S and I've been diagnosed with...” That's big because we don't walk around and say: “I am cancer”. That's a big thing that came from the medical community... I think it comes from guilt and shame too. When I carried a lot of guilt and shame, I'm more self-stigmatized because I thought everything was my fault.

Mental Illness and Identity: Hiding and Secret Keeping

The majority of the participants (7 of 8) indicated that they considered their mental illness to comprise part of their identity. All of these individuals also indicated that resorting to ‘hiding’ a part of their identity because of experiences or anticipated fear of stigma elicited feelings of shame, loneliness, and sadness, all of which impacted negatively on their life satisfaction.

Participant G revealed the sense of indignity that s/he associated with keeping a secret from others declaring: "...it's almost this shameful part of myself that I have to hide and so having to live your life, kind of in this secret, spy-like fashion is stigmatizing in and of itself". Participant W stated: "I feel like I have to keep a part of me secret...and that's a part of who I am. Why should I have to hide that? But, I see that there could be consequences". W expressed sadness about the inability to "be open" with most family members and friends. Similarly, V said: "I feel like I've lived some other secret life a little bit. And a lot of my good friends now, I've made in recovery, like post recovery; and they have no idea."

Feeling the need to hide a mental health status often produced a sense of isolation and loneliness amongst some participants. In 4 instances, participants brought photographs that depicted a time where there was an intense sense of isolation and loneliness. For example, Participant V presented a picture of a family vacation overseas after s/he had just been discharged from the facility for the treatment of his/her anorexia. V stated:

[My counsellor] didn't think we should go on the trip because it would just ruin all my routines that have started to develop. But my parents really wanted to go and they thought it would be good for me. I remember struggling the whole time because of all these things I wasn't used to... And I remember thinking: "You don't understand" ... I just remember thinking like: "I'm still so sick" ... I knew I had a lot of work to do, I guess; that's what I was thinking at that point".

V had a difficult time especially during family meals where s/he would be crying and feeling terrible that s/he could not enjoy the trip. In describing the scenarios that participants interpreted as representing a difficult period in their lives, participants revealed stories that demonstrated a lack of understanding by others about their mental illness. This often compounded their feelings of alienation and marginalization from people in their lives. For

Participant W, the sense of isolation was ever present in each photograph s/he presented, regardless of framing it as a good or difficult time period.

Fake it until you make it!

The final theme related to a difficult time, involved the idea of “faking it until you make it.” Strongly reflecting the notion of performance, half of the participants described these periods of having to force a smile or put on a fake persona. In each case, participants were on the verge of an impending breakdown – or ‘crash’ – or having difficulty in managing their mental health symptoms. Participant W discussed a picture of him/her on a scooter during a trip out to the West Coast. Admitting to having high anxiety levels and suffering from depression, W stated:

It was one of the worst times of my life because of all these horrible things [*death of childhood friend, father had heart attack, quit job*]. This was a couple of months just before the worst time of my life; this was the summer before I crashed... Even though I’m smiling happily there – “fake it ‘til you make it”.

Maintaining a ‘secret’ identity for fear of being stigmatized often resulted in participants resorting to hiding problematic symptoms and feeling that they must “fake it ’til you make it”. Participant G referred to this as “performing” and said: “You have to act a certain way so that they don’t pick up on, you know, suspicious behaviour of you potentially have a mental health issue.” For G, this was further compounded by feeling compelled to prove him/herself to his/her partner and in-laws. This was to the detriment of identifying and meeting his/her own needs. G states:

I think I definitely struggle with assertiveness because I feel like I want to convince other people that they can depend on me, and so I want to meet other people’s

needs and I sort of lose track of, okay: “What are my needs? What do I want?” Just because I am busy, busying myself with convincing other people that I’m okay.

Six of the participants revealed that as symptoms became increasingly unmanageable, they felt it necessary to occupy themselves by keeping busy (such as excessive exercising), withdrawing from social situations, and/or isolating from others including close family and friends. The task of ‘performing’ became apparent again at these times. Participant M, for example, spoke of “a disconnect” between who s/he is in his/her “dark place” of depression and what s/he portrays to everyone stating: “Like I have this identity that I’m hiding from the real world and that’s where the problem is”. M’s current treatment is focussed on accepting and embracing him/herself and not repressing his/her true feelings. Participant G also described a sense of detachment from his/her diagnosis: “So I guess what I mean by detach – where it’s almost like where I put it to the back of my mind and I don’t really think about it. Or try not to think about it.” The notion of performing or not being true to one’s self contributed negatively to the participants’ life satisfaction. G verbalized:

When I got tired of performing, I would just completely isolate myself all together from social situations. So there was no performing I had to do. I could just feel. So that there was a match between how I felt and how I acted.

In each instance, participants’ relationships with their partners and family declined due to an increase in symptomatic behaviour, as well as the act of isolating once performing was no longer possible.

This notion of performing was also revealed by Participant M who stated: “I have to be smiling”. Participant M discussed how his/her therapist spoke of the mental exhaustion that

accompanies M's expectation of "forcing a smile" and how "the energy that it's taking you just to cover it and repress all those feelings are causing you to be tired".

Participant S confided that although the trip s/he took with his/her former friend and colleague was a good event in his/her life, the realization that characteristics of a potential mental health issue were apparent to others made it a difficult time as well: "She [former friend and colleague] made me realize that I could be mean and make it look like someone else was being mean, manipulating. Years later when I got the borderline diagnosis, it made so much sense". In one other case, the participant reported the period depicted in the photographs as being both a good and bad time. Both instances entailed periods of transition and self-awakening for each of the participants. Participant G presented a photograph of his/her brother's wedding and described:

That was around kind of a good time and a bad time. A bad time in the sense that I was mourning the loss of a relationship – a dysfunctional relationship – but at the same time, that resiliency, I guess; getting back on my feet again into a healthy place. So kind of in transition; kind of healing; in healing mode.

Positive Influences on Life Satisfaction

For the majority (6 of 8 participants), positive influences on life satisfaction were experienced once diagnosis and symptom management had been achieved. Based on the interviews with the majority of participants, positive influences on life satisfaction consisted of a combination of symptom stabilization, effective practitioners, helpful therapy and supportive relationships. Most of the participants considered themselves to be on a journey towards mental well-being and recovery.

Naming it

In half of the instances, being formally diagnosed was reported as a positive influence on life satisfaction. Each of these individuals experienced a sense of relief or hope upon diagnosis. For example, W said: “In some ways there was relief to put a name to what was happening to me.” Participant G commented about his/her diagnosis at the age of 17: “So I felt, I guess a sense of relief. Not necessarily relief, but hope. I guess that this was something that would work and I could actually feel different than I had been feeling previous.” Participant V also expressed feelings of relief and hope upon being diagnosed with anorexia in his/her statement: “I wasn’t crazy because other people were doing exactly what I was doing.... I was like: “Okay, there’s help and hope for us somewhere and I’m not the only person that’s going through this. I’m not some medical mystery...””

Medication and Therapy

For three participants, taking prescribed medication to ensure symptom management increased life satisfaction. For example, in the case of Participant W, finding the ‘right’ medication and achieving the realization that “this is how life should be” was pivotal to his/her recovery. Similarly, although G resents his/her dependence on medication, s/he acknowledged that the medications give him/her a dimension to life that s/he was missing – “to feel more”.

Six of the participants spoke specifically of the benefits of various therapies that they were able to access as the result of their diagnosis. Therapy helped participants to do a number of things: to understand themselves better; manage and cope with their symptoms more effectively; move forward; set and attain realistic goals; forgive themselves and others; develop self-acceptance and increased self-respect; become more assertive about their needs and wants;

and let go of what other's think. V was perhaps the most grateful for his/her journey in battling anorexia stating:

So I'm moving on and I think about my eating disorder all the time because it's a big part of my life and I've learned so much. But now I think about it kind of fondly in a way. It was awful and I wouldn't want somebody to go through it but I'm glad I went through it. And I'm glad about everything it taught me. I think that I just care more about myself than I used to.

Effective Practitioners

All participants had worked or are currently working with at least one practitioner or outreach worker who they felt understood, listened, and were supportive in their journey to recovery. For M, this meant finding a psychologist who incorporated the macro elements that come to play in his/her depressive episodes, recognized that his/her depression is something bigger than him/herself, and that s/he is not to blame.

Supportive Family and Friends

In terms of supportive relationships, participants discussed the importance of their accepting and sympathetic family members and friends, who, even on their most difficult days, were comforting, reliable and loving towards them. Participants recognized that, for loved ones who persevered even at times when they wanted to completely withdraw (which was, often times, upon hospitalization) that they were not completely alone despite feelings of isolation and that they did have someone they could count on. Some described it as unconditional love.

Of those pictures capturing a good period in participant's lives, half depicted celebrations or trips with family members. For Participant S, taking annual Christmas trips with his/her father as a child formed happy memories and were cherished after his death from cancer when S

was only 17. Although Participant W suffered from food poisoning on a trip with his/her family, a photograph showing W spending time with his/her partner and children in a bathing suit on the beach represented “an awesome time”.

In Recovery – Life After Labelling

In a few instances, participants brought photographs that depicted them in recovery.

Participant V showed a picture of him/herself at the beach with friends:

We just went to the beach and it was really fun. Like, I would never be able to stay over at someone’s house [*before recovery*]. I needed to be home. I needed to eat my own food... I would’ve been too tired to do everything that we were doing. I wouldn’t have wanted to spend time with a bunch of other girls.

Participant A spoke of a time following completion of very effective therapy and stabilization with medications:

I had obtained a job - I had worked in the summer as a Support Worker. I went from a summer work to a full time employee...things were going extremely well in my life. Like, I was managing, I was happy. I was smiling everyday.

Empowerment and Resiliency

When prompted to discuss feelings of resiliency and empowerment, 6 of the 8 participants indicated that their sense of resiliency had grown with the journey towards recovery. The majority of participants (6 of 8) identified feeling empowered to take control of their own lives and referred to the idea of standing up to social injustice. Half of these participants were enrolled in or had recently completed degrees in areas of social work. In one instance, the participant was working in the child welfare industry. Many participants described a sense of

resiliency. For example, participant W referred to themselves as the “[queen/king] of resiliency” adding: “I definitely feel much more confident in my ability to bounce back”. S/he later comments: “I’m at a point where I have the power to say: “F%\$# you”; that’s pretty empowering. I think I feel I have justice issues”. Participant S stated: “I not only fight hard for social justice and advocate for myself; which is what I started doing for myself, but it became not only for myself but for other people”. Finally, participant V said: “I’ve become more satisfied with myself and my life... I’ve learned a lot about myself and it makes me want to help people.” Later stating: “So I guess I feel empowered and I feel knowledgeable and I feel grateful that I know who I am now.” Each of the participants who attested to feeling a strong sense of empowerment and resiliency had also reflected on the positive influences on life satisfaction in association with their journey.

Discussion

Based on a current (although somewhat limited) review of literature, information on the various forms of stigma and the perceived and actual experience of such on previous and current life satisfaction appears to be scarce. Moreover, in reviewing the few studies that I did consult, I was unable to locate research that posed questions directly related to any positive outcomes of diagnosis in current literature. To begin to address this gap, I explored both positive and negative experiences in living with mental illness and navigating the system during the qualitative interviewing process and photo elicitation piece which are analyzed in this discussion. Although some studies did investigate alienating experiences of being diagnosed, the handful that I referred to did not ascertain if these events had lasting negative effects on individuals. Therefore, in an effort to build on existing literature, I posed interview questions to ascertain the degree to which stigma affected the participants over time. This was accomplished by inquiring about the impact that the experience of stigma played on them at the time they occurred and in the present day. These findings are elaborated on in the discussion that follows. Finally, the idea of recovery, based on my interpretation and analysis of the data gathered during interviews, became evident as an important part of many participant's stories. Research surrounding the notion and process of recovery will be discussed throughout this section.

Initial Experiences with the Mental Health Care System

Common to all participants was the initial, often arduous experiences of acquiring emotional and practical support from practitioners upon coming to the realization that medical intervention was required. In most cases, seeking treatment was a voluntary choice initiated by the participant or a concerned family member. Based on the participants' accounts of their initial

dealings with the mental health care system, in addition to the difficulty finding effective medications, the lack of access to effective treatment and disruption to academic or professional endeavours required in order to pursue treatment became barriers to leading full and productive lives. In addition, navigating the system to receive a formal diagnosis further marginalized the participants due to long waiting lists for treatment, ineffectual and insensitive practitioners, and misdiagnosis. In support of modified labelling theory, participants appeared to encounter poor treatment and experienced discrimination and marginalization based on being reduced to their diagnosis. The scenario of waiting for effective treatment was often contextualized in photographs the participants described as depicting a difficult time period.

Many individuals come away with feelings of being devalued by medical professionals in the form of negative judgement or not being heard (Woodgate, 2006). The common theme amongst the participants in this study was the lack of understanding on the part of medical practitioners and, sometimes, family members at the onset of seeking appropriate treatment. This issue, along with the difficulty in exercising autonomy over the direction and course of treatment that comes with dismissive practitioners, left the participants describing experiences of stigma compounded by feelings of isolation during their initial dealings with the mental health care system. These feelings were often reflected upon by the participants in the photo elicitation piece of the interview, when discussing the images highlighting a difficult time period.

Leavey (2005) suggests that treatment of mental illness within the existing system is often a lengthy process in terms of time, access and accurate diagnosis. Often times, individuals with mild to moderate mental illness are treated by general practitioners who may lack the expertise and time to deal with psychiatric concerns (Davis, 2006). Initial recommendations from various practitioners often endorsed pharmacological measures as opposed to therapy or

other solutions for the participants who further reported that they did so in a paternalistic manner. Significant side effects (such as weight gain) of some medications can erode self-esteem and potentially discourage individuals from leading healthy and socially relevant lives (Arboleda-Flórez & Stuart, 2012). These potential complications are generally not taken into consideration or communicated by practitioners (Arboleda-Flórez & Stuart, 2012). Responses from medical practitioners that elicited feelings of being punished, patronized, demeaned, undermined and humiliated were reported to be recurrent themes amongst most studies investigating the stigmatization of mental health care practitioners (Arboleda-Flórez & Stuart, 2012). One participant in particular from this study spoke of the humiliating experiences involved in being involuntarily hospitalized. Furthermore, Davis (2006) contends practitioners may play a role in contributing to the stigma of mental illness through an attitude of clinical pessimism and insensitive use of diagnostic labels. The majority of participants (approximately 6) spoke of receiving several inaccurate diagnoses. One participant had been diagnosed with twelve different anxiety related diagnoses from his/her attending psychiatrist during their first 40 minute appointment.

Hinshaw (2005) professes that social stigma, as evidenced by demeaning attitudes from practitioners or dehumanizing hospital experiences can have lifelong implications for individuals. Several participants in this study were still profoundly impacted by their initial experiences with various members of the health care system even after many years of receiving effective and life changing therapies. Some of the participants reported their non-compliance with recommended medications or treatments during these initial stages as a reaction to poor relationships with consulting practitioners. This common reaction of nonconformity was highlighted in a study by Wisdom and associates (2006), who found that there was a more likely

chance that participants would not comply with recommended treatments if they: did not receive feedback from service providers, were judged by them as “abnormal” or “mental”, or prescribed medications without discussion of other options. Each participant of this study shared a difficult story regarding medical practitioners who elicited or contributed to feelings of marginalization, differentiation and loss of power.

In the majority of cases, participants of this study were experiencing symptoms in late adolescence or early adulthood and as such, were compelled to take a leave of absence from school or reduce workload demands. Findings regarding the process of recovery do acknowledge that individuals diagnosed with mental illness often experience a delay in reaching typical milestones (Leavey, 2005). However, most of the participants in this study were able to regroup after a significant period of time in treatment and fulfill their pre-existing life ambitions. This occurred once symptom management had been attained and intensive therapy completed. Finding the right medication and practitioner was fundamental to recovery for the majority of participants – and often took several years to achieve – but ultimately resulted in a positive influence on life satisfaction and is elaborated on in the “Life After Labelling” section of this discussion.

Stigma

Sources of Stigma: Social

For the participants of this study, experienced social stigma took the form of jokes or comments of a deprecating nature surrounding mental illness. The source of social stigma most commonly identified by the participants of this study was employers. Participants anticipated that they would be subject to discrimination – and some were blatantly discriminated against – if

or when their diagnosis was revealed. Stigma often dissuaded participants from actively competing in the job market, eroding their confidence in their abilities to meet job demands, or ensuring that they did not let employers become aware of any mental health conditions. Existing research by Draine, Salzer, Culhane and Hadley (2002) found that the symptoms associated with mental illness over the course of an individual's life may have an impact on educational attainment, which also affects employment. The majority of participants had experienced a delay in their graduation dates from post-secondary education in order to concentrate on treatment. For the two individuals who had established careers, both had experienced disruption in service due to long term medical leaves.

The role that systemic and social stigma plays, particularly with respect to employment opportunities and career advancement, cannot be underestimated. Stuart (2004) addresses the higher likelihood of unemployment and underemployment within the populations of mental illness due to social stigma which then leads to the presence of internalized stigma thereby resulting in increased psychiatric disability. Stuart (2004) contends that most studies report unemployment rates between 80% and 90% amongst severely mentally ill individuals, identifying employment discrimination as the most frequently identified stigma experience.

Sources of Stigma: Internalized

A second theme related to the power of stigma in living with mental illness that participants described was the influence of internalized stigma. Based on modified labelling theory and, building on the stage model of awareness of prevailing stereotypes, agreement with these often derogatory beliefs and application to oneself upon diagnosis, Corrigan and Rao (2012) describe the internalization of stigma as culminating as “harm” and a sense of

unworthiness to pursue life goals – such as finding meaningful employment or achieving independent living. MLT postulates that the manifestation of internalized stigma upon diagnosis serves to diminish confidence and self-efficacy which thus impacts the achievement of life goals. Corrigan and associates, (2009) discuss this phenomenon as the “why try” effect that augments modified labelling theory discussed in the theoretical framework section of this thesis. As a barrier to positive life satisfaction, internalized stigma fosters a sense of unworthiness and insufficiency (Corrigan & Rao, 2012). One participant in particular clearly conveyed a lack of self-acceptance at the present time that impacted his/her current life course and potential for competency in his/her chosen field of work. The “why try” effect was evident in his/her lack of confidence and pessimism in achieving his/her goals.

However, the “harm” stage and subsequent “why try” effect was not apparent in the majority of participants at the time of my study as many had moved on to pursue life goals. These findings also challenge Corrigan’s (2004) research that indicated that the likely emergence of internalized stigma in relation to one’s diagnosis results in low self-efficacy and demoralization that can significantly, and possibly permanently, interfere with a person’s goals and quality of life.

Elsewhere, Corrigan and associates (2009) contend that those who reject the prevailing societal stigma with respect to mental illness demonstrate a sense of empowerment to resist the stereotypes and social constructions associated with mental illness. In these instances, for those who have strong self-efficacy and self-esteem, internalized stigma is replaced by a need to seek social justice and equality (Corrigan & Rao, 2012). Corrigan and Rao (2012) describe a strong sense of empowerment as the direct opposite of internalized stigma and conceptualize internalized stigma along a continuum. Identified as the stigma “paradox” (which is discussed in

the literature review section of this thesis), for those participants who revealed a lower level of self-acceptance and eluded to the presence of internalized stigma, disruption to their life course had become permanent at the time of the study. These individuals could potentially fall on one end of the continuum. Whereas the majority of participants (6 of 8), that is, those who expressed a higher degree of self-worth and acceptance, spoke of their resiliency and sense of empowerment as a positive influence in their life. Based on these findings, this majority were functioning more towards the other end of the spectrum. Each of these individuals were in the process of recovery, took the initiative to seek out treatment or at least expressed a willingness to accept treatment at the onset of illness and reported more positive benefits in seeking and receiving treatment.

In summary, it appears that my study supports the idea of a continuum associated with internalized stigma as the majority of participants, while experiencing internalized stigma and the “why try” attitude during initial experiences with the mental health care system, had a more vested interest in achieving equality for themselves and others impacted by mental illness at present day. It would appear that the majority had moved from internalization of stigma to empowerment as a result of several beneficial facilitators that sought to elicit positive feelings associated with life satisfaction and acted to challenge and possibly reduce internalized stigma.

Impact of Stigma

Selective Disclosure

Each of the participants revealed the practice of selective disclosure, in terms of their diagnosis and the use of psychotropic drugs, as a result of the social stigma surrounding mental illness. Corrigan and Matthews (2003) define the application of selective disclosure behaviours

when: “there is a group of people with whom private information is disclosed and a group from whom this information is kept secret” (p. 243). Selective disclosure is thought of as the strategic decision of when, where and to whom one would reveal their mental illness diagnosis (Olney & Brockelman, 2003). Every participant had chosen who they would disclose their mental illness based on their level of trust and comfort with the individual. As well, if individuals in their lives were the sources of stigma through jokes and comments, participants were on guard to conceal their diagnosis.

Covert measures and acts of secrecy were also discussed by each participant. In most cases, disclosure of their mental illness was selectively limited to close family, friends and service providers. Basically, individuals in their lives were told on a “need to know basis” (Dindia as cited in Olney & Brockelman, 2003). Often times, participants would agree, when prompted during the qualitative interviews, that they considered their mental illness to be a part of their identity and as such, many people in their lives did not really know them. Keeping diagnoses and medication reliance from others was a source of shame and contributed to feelings of isolation for most participants. This theme of isolation and loneliness was also a primary subject in the photographs that were presented as representing a difficult time period. Pachankis (2007) notes that prolonged concealment of one’s mental health status may result in associating their diagnosis with shame, which could result in diminished self-acceptance.

Meanwhile, Olney and Brockelman (2003) state that “people with disabilities seek to control the perceptions of others so that they have the opportunity to interact on an equal footing” (p. 36). The authors identify three practical reasons that individuals conceal their disabilities: 1) since mental illness is an “invisible” disability, study participants felt that they would not be believed if they disclosed; 2) participants feared they would be perceived as less

than competent or completely incompetent and; 3) they wanted to be viewed as consistent and trustworthy and disclosure may be discrediting (Olney & Brockelman, 2003). Each of the participants in my study expressed identifying with one or all of these reasons during the qualitative interviews. Participants were particularly concerned about being deemed incompetent by their existing or future employer.

Therefore, acts of social withdrawal, social avoidance, passing and covert measures (with respect to medication ingestion) were often associated with feelings of shame amongst the participants. Holmes and River (1998) describe these tactics as coping mechanisms to avoid social stigma.

Coping Mechanisms for Social Stigma

Social Withdrawal

Social withdrawal, described as retreating from social interaction by Holmes and River (1998) took place, on the most part, for participants who were symptomatic and unable to maintain appearances with anyone in their life. Many of the difficult periods described by the participants through the use of photographs were directly preceding a “crash”. A possible reason behind the absence of photos capturing those participants who had “crashed” or retreated in acts of social withdrawal, was that there were no longer any opportunities or social events taking place in that participant’s life for fear that their mental health status would be discovered. However, this is just a supposition on my part.

Avoiding Social Interaction

Social avoidance is defined as a protective factor where individuals with mental illness circumvent any social situation where others may discover their diagnosis (Corrigan & Rao, 2012). These individuals tend to only associate with others who identify as mentally ill (Corrigan & Rao, 2012). Several participants in this study acknowledged that most of the individuals in their lives who were privy to their diagnosis were also labelled as mentally ill. One participant in particular, only interacted socially with members of a support group for individuals living with mental illness.

Passing and Performing

Passing, a term first coined by Goffman (1963) with respect to “spoiled” or “discredited identities”, is a technique implemented by various stigmatized groups of individuals to hide or “pass off” and disguise their disability from others (Barga, 1996). Information is controlled in an effort to manage any shameful information that may result in rejection (Barga, 1996). This negative coping practice serves to maintain status quo amongst peers and ensures a position within the dominant social status (Siebers, 2004). One participant described this act of passing as “performing” and when they were no longer able to uphold their public façade due to the emergence of symptomatic behaviour, retreated in social withdrawal and isolation. However, in each case, participants identified that their feelings did not correspond to behaviours. This resulted in participants expending a lot of energy to maintain appearances which, in some instances, resulted in ambivalence about their identity. Many of the participants brought photos to the interview that portrayed a difficult time period where they had to “fake it ‘til you make it!” alluding to the idea of passing or performing.

In support of MLT, negative and maladaptive coping mechanisms, practiced to reduce the possibility of social stigma, culminated in acts of withdrawal and avoidance. This, in turn, resulted in threats, disruption or loss of important relationships which ultimately impacted negatively on life satisfaction. Several participants vocalized tensions within their previous and existing relationships specifically around the time that they were facing a ‘crash’. In most cases, these estrangements affected relationships with participants’ current and/or ex-partners and those close family members and friends to whom they had not disclosed their diagnosis. Pachankis (2007) identifies the strain close relationships can suffer when individuals become preoccupied, vigilant, and suspicious with respect to being “outed” in social situations. Each of the participants engaged in acts of hiding and isolating from the public and discussed aversion to social events during the times they felt their symptoms were not under control. As a result of these stress-inducing concerns, affective states like increased anxiety, depression, hostility, demoralization, guilt and shame increase or emerge (Pachankis, 2007).

Moreover, the continual threat of exposure in various social situations can challenge individuals to question their identity (Pachankis, 2007). This is when participants would resort in acts of passing and performing in an effort to conceal their true feelings and often brought about confusion surrounding their sense of self. The idea of identity ambivalence - where there is an inconsistent view of oneself across space and time is important but beyond the scope of this thesis. In conclusion, the impact of stigma and resulting negative coping mechanisms culminated to shape negative self-evaluations, important relationships and potentially, negatively influenced life satisfaction.

Positive Coping Mechanisms

The literature, however, points to other coping mechanisms that are described as positive. These include: indiscriminate disclosure, where secrecy is abandoned in an effort to normalize the prevalence of mental illness; broadcasting, where one's experiences are shared to educate others about mental illness and; social action, which involves lobbying for change on a systemic level (community, government) (Corrigan et al., 2009; Holmes & River, 1998). In this study, one participant, who took a leadership role in a community mental health agency, identified that s/he practices indiscriminate disclosure, as well as broadcasting to fight the stigma that is so prevalent within society. However, in accordance with MLT and the prevalence of social stigma during initial experiences with the mental health care system, the majority of participants continued to engage in acts of limited disclosure and continued to practice negative coping mechanisms.

Life After Labelling

On the basis of questions posed during the interview, although social and internalized stigmatizing influences impacted negatively at the time they occurred, 6 of 8 participants reported several positive influences on life satisfaction as the result of being diagnosed. Many participants spoke to the importance of being appropriately labelled as the gateway to self-discovery once symptom stabilization had been achieved and effective treatment underway. Since the mental health care system is predicated on the social construction of mental illness where diagnosis is required to gain accessibility to services and treatment, participants recognized the importance of labelling to access treatment opportunities designed to promote their mental well-being. Some felt the diagnosis to be difficult to accept initially, others spoke of

their reluctance to disclose it even today, and all shared experiences of misdiagnosis and marginalizing experiences within the mental health care system in the initial phases of treatment. Yet, for most participants, once an effective practitioner and ‘proper’ diagnosis was in place, the knowledge and skill set achieved through beneficial therapy was identified as a positive impact on their life satisfaction. For these participants, being properly diagnosed resonated with feelings of hope and relief. Hope was synonymous with possible release from troublesome symptoms while relief was instrumental in lessening the feelings of isolation and marginalization brought upon diagnosis by practitioners. Participants were able to identify with others who had received similar diagnoses and experienced a sense of normalcy with respect to their experiences and feelings associated with mental illness. However, for those two individuals who had not fully accepted a diagnostic label at the time of the interviews, the negative effects of internalizing stigma as predicted by MLT and the “why try” effect had become part of their mindset and identity.

The primary facilitators to positive life satisfaction for majority of the study participants appear to include a combination of controlling or managing symptoms through effective medications, valuable treatment methods, engagement with a helpful therapist, and supportive social relationships.

Those participants who claimed to be stabilized on their medications and spoke highly of the positive experiences that resulted from seeking treatment identified with the journey towards recovery. The ongoing process of recovery, as conceptualized by Markowitz (2001), incorporates: “controlling symptoms, regaining a sense of self, dealing with stigma and discrimination and trying to lead a productive and satisfying life” (p. 64). Everett (2006) claims:

Recovery is a process of living well despite challenges. It is an individual journey characterized by personal growth, empowerment, better management of troubling symptoms and healthier choices, thereby improving one's quality of life. As people take control of their lives, they build self-esteem and reject internalized negative stereotypes. They also gain the confidence to confront or counteract others' attitudes and discriminatory behaviours (Everett, p. 25).

For those participants who reported positive accounts within the system, most extolled the virtue of finding the “right” medication. Relief from problematic symptoms associated with their various diagnoses allowed participants to confidently rejoin the social world and refocus on their future with a sense of hope. Although the process of finding the most effective medications was arduous and time consuming, participants spoke of the benefits that symptom management brought to their improved life satisfaction. Leavey (2005) describes the stage where one's symptoms are under control and the subsequent journey associated with understanding that their mental illness is not their “fault” as acceptance. The majority of the participants in this study expressed that they were in the process of or had already achieved a strong sense of self-acceptance in their journey to recovery.

Distinguishing between the concept of self and the illness was often associated with adapting to a new sense of identity which evolves, at the recovery stage, into their social identity (Leavey, 2005). Meanwhile, a sense of hope for the future was facilitated by gaining knowledge about various coping skills, insight into strengths and limitations, establishing goals to strive towards and returning to academic or vocational responsibilities (Leavey, 2005). Many of the participants expressed that the most effective therapies involved goal oriented treatment such as cognitive behavioural therapy (CBT), developing coping mechanisms to effectively deal with emotions and education about their mental illness. Other advantages of effective therapy common to many individuals living with mental illness include personal growth, self-acceptance

and the discovery of resiliency (Webster & Harrison, 2007). All of these benefits were predicated upon the acceptance and successful treatment intervention in association with that diagnosis. For the majority of the participants (6 of 8), these benefits had become a reality.

Of potentially equal importance was working with an effective therapist. Many participants described the most influential therapist in their journey to recovery as one who understood them, accepted them for who they were, actively listened and offered constructive and goal oriented solutions to their various issues. Leavey (2005) notes the importance of a “good” doctor in the process of recovery who is equipped to explore problem solving and strength-based therapies. Webster and Harrison (2007) underscore the importance of supportive and empathic interactions in the development and growth of personal attitudes and self-coping practices where trust and reassurance is abundant. Moreover, according to Rosenfield (1997), enhancing confidence and a sense of autonomy over one’s life is fundamental in treatment providers to promote higher levels of satisfaction with life. The impact of normalizing experiences, establishing rapport and a collaborative relationship with therapists has also been found to have a positive influence on therapeutic relationships especially amongst young adults living with mental illness (Wisdom et al., 2006).

Rogers, Anthony and Lyass (2004) stress the importance of perceived social support and a sense of belonging for individuals labelled with mental illness and how they can positively influence symptom management. The authors conclude that higher perceptions of social support by individuals living with mental illness may aid in helping to reduce the significance of life stressors, helping to apply coping skills, enhancing a sense of self-efficacy and contributing to problem solving techniques (Rogers et al., 2004). All of these factors positively influence life satisfaction for individuals living with mental illness. The majority of participants of this study

spoke of the importance of having loving and understanding family members and friends in their lives to whom they could approach should they need additional support. For the remaining two individuals, a lack of social support magnified the sense of isolation that is commonly encountered by individuals living with mental illness due to the stigma that is so prevalent in our society. In addition, Corrigan and Phelan (2004) found that those who reported strong social support networks also reported better recovery efforts especially if the focus was on hope and goal orientation. Hope was often elicited through the positive and empowering attitudes of effective practitioners, family members and friends and, accompanied with the application of skills associated with goal setting (such as CBT), likely contributed to positive life satisfaction for participants.

It should be noted that, given the limited scope of this thesis, one cannot infer from this study the degree to which these facilitators exist to promote positive life satisfaction. Moving towards improved mental health likely encompasses many factors to achieve optimal life satisfaction that were not explored in this study. Moreover, it does not go unnoticed that, based on my interpretation of the data gathered from the participants, the pursuit and achievement of mental well-being and positive life satisfaction is largely placed on the individuals' shoulders. With the social construction of mental illness, the focus of intervention on individual 'weakness' and fault serves to 'correct' or rehabilitate individuals to comply to 'normal' thoughts and behaviour patterns. As a result, treatment regimens rarely acknowledge a systemic or societal element in the emergence of mental illness.

Only one participant described the process of undergoing treatment as exploring the structural contributors that have come to play in the social construction of mental illness. Moreover, learning that the "undesired differentness" (Goffman, 1963) associated with mental

illness was not attributable to a personal deficit on his/her part but the result of the ignorance of prevailing social and structural systems elicited hope in achieving a positive sense of self-worth and identity apart from diagnosis. Given the ignorance surrounding the common prevalence of mental illness, (which is largely undetected due to the ability to hide or conceal diagnosis from the general public), any deviations from what is determined to be ‘proper’ conduct in terms of behaviour is socially differentiated and unfavourably categorized (Link & Phelan, 2001). As such, individuals diagnosed with mental illness are required to either take personal accountability for their own recovery or engage in maladaptive coping strategies to avoid being ‘outed’ as mentally ill. Many individuals are deterred from seeking treatment as the collective belief that seeking treatment in association with a possible mental illness will result in being ‘othered’ and marginalized due to stigma (Corrigan, 2004). If they do seek therapy, based on the findings of this study, most will encounter stigmatizing forces in the mental health care system. However, the structural ineptitudes of the system serving those with mental illness are rarely addressed as contributing to the stigma encountered by individuals. Focusing recovery efforts towards the individual instead of macro and mezzo level systems, fails to recognize the social construction that mental illness has on individuals so labelled.

Limitations

Several limitations apply to this study. Given that the study was limited to just 8 participants, it cannot be inferred that these findings are representative of all those with a mental health diagnosis. Data specific to each of the participant's experiences was gathered and therefore, not transferrable to the entire population of those living with mental illness.

Secondly, although photographs did aid in assisting participants to recall previous memories, the participants' ability to recall past events could be considered a limitation in this study based on the differences in the length of time since diagnosis as people's perceptions of their experiences can change over time.

A third concern is that those with mental health disorders typically face higher rates of unemployment or underemployment, poverty, poor physical health, homelessness, alcohol and drug abuse (including higher smoking rates), and incarceration (Davis, 2006). However, each of the participants taking part in this research project had already claimed to attain, or were in the process of attaining, a university degree and thus may not necessarily be representative of the greater population of those living with mental illness.

Fourth, although numerous attempts were made to ensure the confidentiality and comfort of the participants, some participants may not have felt comfortable revealing or discussing particularly difficult experiences and, therefore, may not have been completely open and/or honest in their responses.

Finally, the quantitative tool (Appendix G) was developed by me based on other scales in existing literature. Therefore, the tool was not tested and there is nothing to support its' validity or reliability. Moreover, since the various measures of life satisfaction was only incorporated into the interviewing process if the participants recorded a low score, only this data is meaningful

to the findings and analysis. Any findings from the quantitative tool that were not incorporated in the qualitative piece cannot be applied to this study. With a small sample size, results from this tool cannot be used for the purposes of comparison or explanation. This issue reflects the inexperience surrounding and poor design and execution of quantitative measures in research.

Implications for Practice and Future Research

Mental Health Education in Schools

Although public knowledge surrounding the social stigma associated with mental illness is improving, education and promotion related to mental health is still not a fundamental part of educational curriculum within Canadian elementary and secondary level schools. In addition, stigma research concerning adolescents only accounts for less than 4% of stigma research (Link et al., as cited in Dalky, 2012). Accordingly, research studies on effective approaches to reduce stigma in school settings is limited and has resulted in a lack of literature on effective programs or interventions in young populations, especially at primary level educational settings (Dalky, 2012).

Given the possibility that primary and secondary school aged students are experiencing symptoms and potentially experiencing the stigma associated with perceived difference based on mental health, researching and addressing the enactment and experience of stigma associated with mental illness within academic settings is fundamental to early detection, chronicity, impact and intervention into mental illness. Most of the participants of this study experienced their initial symptoms during this time period (elementary and secondary education) and reflected on how there was a lack of awareness and education surrounding mental illness. This issue intensified the feelings of marginalization and alienation that are implicit in the stigmatization of mental illness. Public education and community resources that directly support the youth culture are essential to the possible prevention of mental illness and the stigma that surrounds it.

Merging a more general approach to inclusion by implementing contact-based activities and in-class instruction that serves to prevent or eliminate negative thought processes towards ‘others’ based on difference could seek to alleviate elements of discrimination in many other respects besides mental illness (Schachter, Girardi, Ly, Lacroix, Lumb, van Berkmand & Gill, 2008). Contact-based interventions are found to be more effective in changing negative beliefs and attitudes as well as considerable behavioural change in the long term as opposed to education-only strategies (Schachter et al., 2008). Pettigrew and Tropp (as cited in Schachter et al., 2008) found: “Intergroup contact typically reduces intergroup prejudice across a broad range of groups and contexts” (p. 8). Personal stories from individuals, ideally peers, living with mental illness have been found to quite effective in serving to reduce the stigma and fear associated with mental illness (Swaim; Rickwood, Cavanaugh, Curtis & Sakrouge as cited in Schachter et al., 2008). An all-inclusive approach within the school setting will likely foster a more supportive and caring environment thereby contributing to positive influences on life satisfaction for those who are navigating mental health issues. Meanwhile, combatting the stereotypes and social constructions associated with mental illness will seek to potentially eliminate future generations from discriminating against those with mental illness (Schachter et al., 2008). As a result, the social stigma affiliated with mental illness could potentially be eradicated in the future.

Challenging Social Stigma on a Macro Level

With insufficient federal mental health care policy and the lack of attention by all levels of government towards people with mental illness both in the community and in institutional settings, government has clearly been an active instigator in the prominence and prevalence of stigma associated with mental illness in Canada. Canada continues to be the only country in the

G8 (Kirby, 2008) and the Organization for Economic Cooperation and Development (OECD) that does not have a national mental health care policy (Lurie, 2005). However, after the release of the *first* national report on mental health (compared to over 300 reports on the physical health system) entitled “Out of the Shadows at Last” by the Standing Senate Committee on Social Affairs, Science and Technology in 2006, the prime minister announced the creation of the Mental Health Commission of Canada (MHCC) (Kirby, 2008). The MHCC’s mandate is to become “a catalyst for a national discussion about mental health in Canada” (Kirby, 2008, p. 1320). At that time, the federal government agreed to fund the commission \$17 million over a 10 year period (2007 to 2017) (MHCC, 2011). The MHCC (2011) has several initiatives underway to fight stigma in schools, workplaces and communities through the “Opening Minds” program established in 2009. The commission initially had 3 strategic initiatives based on the 2006 recommendations: develop a national mental health strategy, conduct a 10 year anti-stigma campaign, and build a national knowledge-exchange centre (Kirby, 2008).

However, although the federal government has invested heavily in this initiative, the commission will operate at an arm’s length from all levels of government and will not have the power to impose their vision or strategy (Kirby, 2008). Kirby (2008) contends: “the commission is neither a service delivery organization nor an advocacy group. It provides jurisdictions and stakeholders with the necessary tools and information needed to improve the quality of and access to mental health services and support” (p. 1322). Practitioners working with people labelled mentally ill must support and contribute to mental health care policy development and are encouraged to become accountable for implementing those tools into their clinical practice. The MHCC offers the opportunity for social workers to contribute their visions and ideas to the various committees and advisory boards.

Meanwhile, individuals with mental illness are becoming active partners in the fight against stigma. However, there is still so much that could be improved with respect to the systems and policies that supposedly care for and treat those with mental illness. It will take an active and committed government and ongoing advocacy measures at the grass roots level to address and help eradicate the stigma associated with mental illness. Lobbyists and social workers must look outward at the structural stigmatization that has been imposed – and inward towards their own implications in such - and address issues related to income, housing, health care and education to help individuals with mental illness achieve a better quality of life and greater life satisfaction. This study supports the requirement for existing advocacy measures on micro and macro levels.

Assessing the Presence and Impact of Internalized Stigma

Although it is not conclusive, based on the results of this study, the degree to which internalized stigma exists may determine the rate at which one progresses through the various stages of recovery. Measuring the presence of internalized stigma and how it changes or does not change over time (at onset of symptoms to recovery) could be facilitated through more extensive longitudinal studies.

In terms of future research directions, findings of this study suggest the two eldest participants seemed to express a great deal of internalized stigma and its' negative impact on their life satisfaction during the interviews. These individuals not only vocalized intense feelings of internalized stigma but also indicated a lower level of life satisfaction as evidenced by their scores on the Life Satisfaction Exercise (see Appendix G, Table 2). Although the scope of this research cannot conclude that internalized stigma was more prevalent in the older participants, it

does warrant future studies on the effect that one's age and their social-historical context plays on individual's life satisfaction as related to a mental health diagnosis. Also, the presence of internalized stigma may be connected to the length of time since diagnosis as experiences of internalized stigma were more often affiliated with the initial stages of medical treatment.

Assessing Common Practice Approaches in Individual Treatment

Camp and associates (2002) recommend that future research should focus on what mediators or practice approaches are effective in minimizing the internalization of stigma. Half of the participants extolled the virtue of various therapies to challenge their internalized perceptions of their illness and suggested that cognitive behavioural therapy (CBT) was most effective. Based on those participants who spoke of treatments incorporating an active, directive therapy, such as a CBT clinical approach, all reported outcomes and acquired skills that contributed positively to their life satisfaction. Cognitive behavioural therapy supports evidence based practice and is a common tool for mental health practitioners in the treatment for various mental health disorders (Davis, 2006).

However, CBT frames mental illness as a problem of faulty thinking processes pathologized to the individual. Individuals are taught to correct their 'faulty' thinking processes by replacing negative self-talk with more positive and a more 'realistic' view of the world in which they live (Teghtsoonian, 2009). This method of treatment requires adjustment of people to their circumstances expecting them to change their 'defective' thought patterns instead of addressing the impact of stigma and negative reaction from society or focusing on greater structural forces that marginalize people identified as mentally ill from becoming fully

functioning members of society (Teghtsoonian, 2009). Meanwhile, attention is diverted from the inadequacy of social policies and the focus of the problem directed towards the individual.

Pathologizing practice approaches must be scrutinized and replaced – or at least augmented by (if possible) – those frameworks that incorporate an ecological systems approach. Moreover, focusing on the strengths of the individual and empowering them to challenge some of the stereotypes that exist surrounding mental illness will aid in breaking down some of the stigma inherent in their diagnosis.

Exploring Stigma on a Mezzo Level

On a mezzo level, counteracting internalized and social stigma through acts that empower and educate (such as participation in self-help and peer support groups where individuals who have been diagnosed are able to talk openly among themselves without judgement) can act to alleviate some of the marginalization that many individuals experience as a result of stigma (Everett, 2006). Most of the participants revealed that they had participated in self-help and/or peer support groups during various stages of treatment. In all instances except one, the experience was positive and helped to normalize the prevalence of mental illness surrounding them. One participant had assumed a leadership role in his/her local peer support mental health program. Such groups seek to limit acts of social withdrawal, promote self-disclosure in a safe environment and minimize feelings of isolation. Possessing supportive relationships in one's life was found to be quite important in the recovery process thereby contributing to positive life satisfaction for the participants of this study.

Meanwhile, social workers supporting those living with mental illness must consider their own position regarding the pathology and individualism of mental illness in association with

their clients. Educating social workers about the social construction of mental illness and the impact of such on those who are labelled is important to recognizing the lived experience of stigma and its' consequential effect on life satisfaction. Social workers should be vigilant about the medicalization of mental illness and the impact and implications that being labelled holds on individuals particularly within a clinical setting. In addition, social workers should practice reflexivity in determining their own social misconceptions, perceptions, attitudes, prejudices and discriminatory behaviours. Social workers must assess their implications in the perpetuation of derogatory stereotypes and the social construction of mental illness in order to effectively address the impact of social and internalized stigma on their client's lives.

Supporting Clients' Decision to Disclose

Self-disclosure, which may be essential to self-acceptance and the journey to recovery, acts to eradicate the prevalence of stigma in our society (Arboleda-Flórez & Stuart, 2012). As Hyman (2008) summarizes: "The more contact and openness on the topic of mental health in our society, the more people who receive mental health services will be able to avoid the stigma and discrimination" (p. 37). Social workers and mental health care practitioners working with people with mental illness are encouraged to facilitate interventions that challenges internalized stigma. A study by Corrigan, Morris, Larson, Rafacz, Wassel, Michaels, Wilkniss, Batia and Rüschi (2010) found that those who disclose their diagnosis may experience a less negative impact on their quality of life. Being transparent about ones' mental illness may diminish the affective conditions related to the shame that may emerge with concealing a secret and passing. Fighting social stigma utilizing strategies of indiscriminate disclosure, as well as broadcasting can also foster feelings of empowerment and control over ones' life (Corrigan, Rao & Tsang, as cited in Corrigan & Rao, 2012). Finally, positive reactions to disclosure may also generate

feelings of self-efficacy in meeting life goals (Corrigan et al., 2009), promote recovery (Arboleda-Flórez & Stuart, 2012), afford additional options in terms of treatment, increase social support (Pachankis, 2007) and provide opportunities to educate others about and normalize the existence of mental illness (Hyman, 2008).

Social workers employing strategies like role play can effectively support their clients in disclosing a mental health diagnosis. Social workers offer an opportunity for a safe space to navigate various reactions to self-disclosure. The application of role play where various positive and negative reaction scenarios are facilitated between social workers and their clients can attest to their willingness to disclose (Hyman, 2008). Helping clients to educate themselves on the frequently asked questions and concerns that result from self-disclosure can help equip individuals living with mental illness to express themselves in a confident and informed manner. This applies to the etiology of mental illness (Hyman, 2008). Social workers can also provide client facilitation of weighing the costs of disclosing versus the benefits to them personally, as well as assessing the strength and level of support of their existing social contacts to help them manage negative reactions (Corrigan & Matthews, 2003).

However, Hyman (2008) cautions that: “Self-disclosing is a complex and personal issue that individuals must address only when they feel strong and ready to do so” (p. 37). Social workers can help to assess clients’ emotional readiness to come out about their diagnosis as timing is an important consideration in disclosing. Although the majority of participants in this study spoke of feeling empowered to challenge the inadequacies of macro systems and discriminatory attitudes, all were continuing to engage in acts of selective disclosure. This exemplifies the perceived risk that comes with indiscriminate disclosure.

Corrigan and Lundin (as cited in Hyman, 2008) note that the ability to exercise indiscriminate disclosure first requires an attitude change where talking about one's mental illness no longer induces feelings of hesitancy or shame. Social workers can help their clients to determine whether they are prepared to potentially face social stigma or rejection should they decide to disclose. Other variables that social workers can identify in facilitating client self-disclosure include discussions surrounding: appropriate setting, quality of the relationship to whom they are disclosing a diagnosis, and coping strategies to effectively deal with the possibility of rejection (Hyman, 2008). Mediating factors that social workers could broach with clients in order to assess whether the risk associated with indiscriminate disclosure is feasible include: client confidence in the ability to cope with the possibility of rejection, previous experiences of discrimination and subsequent reactions to such, client level of self-esteem and sense of self-identity, current degree to which secret keeping and hiding impacts on mental well-being, necessity in accessing available resources and client sense of empowerment.

Not only assessing client personal readiness to disclose but also being acutely aware of the current social discourse and climate surrounding mental illness is important to discuss prior to making the decision if and when to disclose. For example, being cognisant of any recent media attention that contributes to the derogatory stereotypes surrounding mental illness or public education campaigns that seek to raise awareness about the struggles associated with stigma and mental illness (such as the "Bell - Let's Talk" campaign, 2013) (Hyman, 2008). Public education campaigns which challenge negative and prevailing social constructions of mental illness afford a safer space for individuals to disclose. Albert (n.d.) suggests providing literature and information brochures to individuals to whom one discloses that help to dispel the myths associated with mental illness.

Each of the participants of this study had practiced selective disclosure within their social circle but expressed a strong aversion to disclosing to a wider social network, particularly employers. According to Hyman (2008), for those who wish to disclose to their employer (likely for reasonable accommodations), there are a number of considerations to take under advisement such as:

- the individual's employment history and professional status level with their employer;
- the type of employer (e.g., male dominated industry may be more subject to discriminatory practice);
- the size of the employer (larger employers will likely have established policies and procedures in place for reasonable accommodations);
- whether other's have disclosed disability and if so, reactions by the employer;
- whether it appears that the employer has adequately accommodated other people with disabilities; and,
- whether social stigma associated with mental illness has been witnessed by other staff.

Hyman (2008) notes that there appears to be little to no centralized resource on promoting and educating the mental health population about disclosure. One strategy she suggests is to for individuals to determine when and how to disclose by joining a mutual support group to learn about others' experiences in disclosing and receive advice on the most appropriate ways to educate others about mental illness (Hyman, 2008). Meanwhile, Lang (as cited in Albert, n.d.) supports disclosure based on individual's specific character, that is, if they are normally private about other issues, then disclosing a mental illness may be intrinsically uncomfortable for them to pursue. Lang (as cited in Arthur, n.d.) underscores two choices when faced with someone who reacts negatively to disclosure: they can agree to disagree or they can

try to educate that person. For those clients who have experienced a negative response to self-disclosure, social workers can aid in reconstructing the conversation their clients engaged in when disclosing thereby debriefing the situation and reassessing a more effective way of disclosing to others. Social workers should be vigilant about stressing that negative reactions are due to the social and systemic ignorance and blind acceptance of society to the prevailing social constructions and stereotypes of mental illness and not a weakness or fault on their part.

Future Directions: Exploring a New Sense of Self within the Context of Mental Illness

Aneshensel and Phelan claim that the evidence is compelling that: “being identified as mentally ill is itself a social transformation. One’s identity is altered, often irrevocably, and this transformation has profound repercussions for one’s subsequent social relationships” (as cited in Gove, 2004, p. 365). Although the stages of recovery in terms of accepting and living with mental illness have been well researched, reports from studies concerning the possible exploration of a new identity are limited. What is the impact of selective disclosure and acts of passing on the individual’s sense of self? How does the social stigma associated with mental illness affect a potential discrepancy between social and self-identity? How does internalized stigma inhibit self-awareness and self-acceptance? How does the emergence of a new sense of self impact on life satisfaction? The evolutionary process towards self-acceptance for the majority of participants was diminished by acts of secrecy, withdrawal and passing, yet, coming to terms with their diagnosis often included reassessing and exploring a new sense of identity. Perhaps treatment designed to navigate identity development can mitigate the impact of internalized stigma. Corrigan and Matthews (2003) extrapolate the process of identity development related to sexual minorities and apply it to mental illness. Future studies could

explore the idea of new sense of self-discovery and formation specifically with populations who are diagnosed with mental illness.

Conclusion

The purpose of this study was to elicit personal accounts of the experiences of stigma associated with mental illness in various social contexts and how those experiences influence life satisfaction. Each of the participants had been labelled with a mental illness and reported they were functioning at various stages of recovery from said illness. All participants of this study revealed experiences of stigma from a number of different sources that adversely impeded on their life satisfaction at the time and in some cases, had a lasting negative impact on their life satisfaction. Furthermore, based on the findings of this study, for those who remained unaccepting of their diagnosis, levels of life satisfaction were negatively impacted to a greater extent than those who were accepting of their illness and had participated in effective treatment.

In those cases where positive life satisfaction was achieved (often during the individual's personal journey to recovery), internalized stigma was minimized or non-existent and self-acceptance and a strong sense of empowerment prevailed. This highlights the "paradox" of stigma where application of societal stereotypes and attitudes become applied to oneself upon diagnosis resulting in reactions of diminished self-esteem and self-efficacy (as stipulated by MLT) or are rejected (immediately or after time) thereby promoting feelings of righteous indignation and empowerment. Possible variables in these scenarios is the extent to which prevailing, derogatory stereotypes related to mental illness were internalized upon being labelled and the degree to which social stigma was perceived and/or experienced upon inauguration into and subsequent navigation of the mental health care system. For those on the journey to recovery and hence, improved life satisfaction, participants recognized the benefits and rewards of undergoing effective treatment where self-awareness and self-acceptance was achieved. The main facilitators to recovery emerging from this study were stabilization of symptoms due to

medications, effective and appropriate treatment, supportive medical practitioners and a strong, social support system.

However, achieving higher levels of self-acceptance and reporting positive results in terms of proper diagnosis did not prevent participants from engaging in behaviours of selective disclosure and passing in an effort to circumvent possible experiences of social stigma. This is a testament to the intolerance that is still conveyed by greater society and the systemic oppression associated with mental illness and how influential social stigma can be on one's level of life satisfaction.

Policies relating to health care, income security, public education, and social housing as it relates to people identified as living with mental illness are insufficient and deficient. As such, stigma also works to limit research and program funding and ultimately, access to effective, integrated inpatient and outpatient treatment and services (Sartorius, as cited in Hinshaw, 2005). Undergoing treatment for mental illness can result in loss of citizenship rights forcing those to rely on inadequate social services and limiting individuals from making valuable and satisfying contributions to social and cultural life (Morrow, 2004). Prevailing negative associations with mental illness have proven to make individuals with mental illness subject to vulnerability and extortion. The participants of this study revealed their fears concerning the consequences of perceived and experienced social stigma on their personal and financial well-being and their overall life satisfaction.

The multifaceted concept of stigma can be applied to mental illness on every level: differentiation based on a negative, attributed label; prevalence across time; an 'us' against 'them' mentality; tolerance of unjust and discriminatory treatment; and structural oppression

(Link & Phelan, 2001). Until the stigma associated with mental illness is diminished and rectified, those diagnosed with mental illness will continue to suffer from the consequences of being diagnosed in demeaning and perhaps permanent ways. So much is at stake for individuals who have been diagnosed or “suffer in silence” and since mental illness knows no bounds - that is, mental illness does not discriminate across ethnic, racial, socioeconomic status, and other demographic dimensions - we all have a vested interest in the fight against stigma. For those who continue to function without medical intervention due to the fear inherent in facing stigmatizing forces, the consequences could be fatal.

My hope is that my future career will involve addressing the structural ineptitudes of the educational and mental health care system in educating young populations about mental health and mental illness. I believe that incorporating mental health education into scholastic curriculum will have a large impact on discriminatory views thus reducing the stigma associated with mental illness. We need to create a discourse in society that challenges existing stereotypes and creates a safe space for children and young adults to feel empowered to discuss their feelings and concerns. My career plans endeavour to provide that space for the youth of our society who wish to disclose their thoughts and feelings; thoughts and feelings that I was discouraged from voicing.

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Appendix A

A Study about the Effects of the Stigmatization of Mental Illness on Life Satisfaction



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Purpose of the Study: As the Principal Investigator, I am trying to gain an understanding of how the experience of the stigmatization of mental illness has been for those diagnosed/labelled with a mental illness and the associated effect on actual and perceived life satisfaction. I am doing this research for my Master Social Work thesis requirements.

You are invited to take part in this study on stigma and life satisfaction. My research will seek to identify prevailing themes amongst individuals diagnosed with a mental illness with respect to the experience of stigma by family and friends, medical practitioners, the mental health care system, public and private agencies, and society in general and the effect that such experiences have had on the individual's satisfaction with their life. My research will explore the lived experience of stigmatization and the negative and/or positive effects that such experiences have played in individuals' lives.

What will happen during the study? You will be asked to complete a life satisfaction exercise (attached) before the interview. The exercise will take 5-10 minutes to complete. At our interview, we will review the consent form and discuss confidentiality and the option to withdraw from the study. We will then review some of the answers to your exercise. Following this, you will be asked several questions related to your experiences of being diagnosed with a mental illness (attached). Two sample questions in the attachment are: *Can you tell me about your initial experiences with the mental health care system and being formally diagnosed with a mental illness?*

Can you tell me about any experiences you have had where others have treated you differently when they learned that you were diagnosed with a mental illness or upon hospitalization for a mental illness? How did this affect your satisfaction with yourself and your life situation?

With your permission, this interview will be audio recorded and notes taken. The interview will take approximately 90-120 minutes. The interview location will mutually agreed upon by you and me. If there are portions of your taped interview that are unintelligible or require additional information, I will contact you via phone or email but only with your previous consent.

Are there any risks to doing study? The risks involved in participating in this study are minimal. *Due to the emotional sensitivity of the information you choose to share, there is the possibility that you may become upset, nervous or feel vulnerable in sharing your personal experiences. It is recommended that you have identified supports available to you (for example, family, friends, community resources) that you might contact should you wish to seek emotional support after the interview. If you would like, a list of various community resources specializing in mental health will be provided to you after the interview.* You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. Also, you can withdraw (stop taking part) at any time. I describe below the steps I am taking to protect your privacy.

Are there any benefits to doing this study? You will have the opportunity to tell your story and educate others about the experience of being diagnosed with a mental illness and how it has affected or currently affects you and your life satisfaction. This could help others to understand the difficulties individuals face when living with mental illness. I hope to break down some of the stigma associated with mental illness.

Payment or Reimbursement: Bus tickets will be provided if transportation is required.

Confidentiality: You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. No one but me will know whether you participated unless you choose to tell them.

The information/data you provide will be kept in a locked cabinet where only I will have access to it. Information kept on a computer will be protected by a password. Three years after my degree has been conferred, I will securely destroy all data.

Legally Required Disclosure: Although I will protect your privacy as outlined above, if the law requires it, I will have to reveal certain personal information (e.g. intent to harm self or others).

What if I change my mind about being in the study? Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study,

you can decide to stop (withdraw), at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. Bus tickets, if required, will still be provided. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

Information about the Study Results: I expect to have this study completed by approximately September 2012. If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study: If you have questions or need more information about the study itself, please contact me at: codlinja@mcmaster.ca or 905-464-4778.

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat

Telephone: (905) 525-9140 ext. 23142

c/o Research Office for Administrative Development and Support

E-mail: ethicsoffice@mcmaster.ca

CONSENT

I have read the information presented in the information letter about a study being conducted by Jennifer Codlin of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw* from the study at any time. I have been given a copy of this form. I agree to participate in the study.

Signature: _____

Name of Participant (Printed) _____

1. I agree that the interview can be audio recorded.

a) Yes

b) No

2. a) Yes, I would like to receive a summary of the study's results.

Please send them to this email address _____

or to this mailing address: _____

b) No, I do not want to receive a summary of the study's results.

3. I agree to be contacted via phone or email for any issues with my transcription (i.e., helping the researcher to understand any portions of the audio-recordings that may not be clear and/or be difficult to understand, or for any further clarification on statements I have made as required by the researcher). I understand that I may always decline the request.

a) Yes, Please contact me at: _____

b) No

**Please note that withdrawal from the study is no longer possible after submission of my thesis to the McMaster School of Social Work.*

Appendix B**Email Recruitment Script****Jennifer Codlin, BA, BSW,****Masters Candidate in Social Work****A Study about the Effects of the Stigmatization of Mental Illness on Life Satisfaction**

E-mail Subject line: Have you been labelled or diagnosed with a mental illness and want to share your story?

As part of graduate program in Social Work at McMaster University, I am carrying out a study to learn about the experiences associated with the stigmatization of mental illness has had on individuals with a mental illness diagnosis or label and the how these experiences have affected their life satisfaction. Stigmatization is formally defined as the assignment of negative perceptions to an individual because of perceived difference from the population at large (The Free Online Dictionary by Farlex).

I am interested in learning about common experiences and feelings of people diagnosed with a mental illness with respect to the experience of stigma by family and friends, medical practitioners, the mental health care system, public and private agencies, and society in general *and* the effect that such experiences have had on the individual's satisfaction with their life. My research will seek to explore the lived experience of stigmatization and the negative and/or positive effects that such experiences have played on individuals' lives.

I am inviting you to complete a brief exercise that will take about 5-10 minutes each and participate in a private 90-120 minute interview with me. Some of the questions that you may be asked include:

Can you tell me about your initial experiences with the mental health care system and being formally diagnosed with a mental illness?

Can you tell me about any experiences you have had where others have treated you differently when they learned that you were diagnosed with a mental illness or upon hospitalization for a mental illness? How did this affect your satisfaction with yourself and your life situation?

It is expected that there will be minimal risks to you in taking part in this survey. You may feel some discomfort in discussing this topic but you can stop at any time. You will be provided with bus tickets to and from the interview location if required. I have attached a copy of a letter of information about the study that gives you full details, as well as, the questionnaire and interview guide. This study has been reviewed and cleared by the McMaster Research Ethics Board. If

you any have concerns or questions about your rights as a participant or about the way the study is being conducted you can contact:

The McMaster Research Ethics Board Secretariat

Telephone: (905) 525-9140 ext. 23142

c/o Office of Research Services

E-mail: ethicsoffice@mcmaster.ca

I would like to thank you in advance for your time and consideration. Please contact me or Dr. Ann Fudge Shormans with any questions.

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Appendix D

Life Satisfaction Exercise *(to be distributed prior to interview)*

A Study about the Effects of the Stigmatization of Mental Illness on Life Satisfaction

Jennifer Codlin (Master of Social Work Candidate)

(School of Social Work – McMaster University)

NB: The items below are subject to change based on input from the focus group

Please note that this is an anonymous exercise and answering any of these questions is optional. These answers should be based on your current situation (present day).

How satisfied are you with your current situation with respect to the following?

Please scale these items between 1 and 10 where:

1 = completely dissatisfied and 10 = completely satisfied or put N/A if not applicable (ie. If you don't work or don't volunteer)

Number of supportive and caring relationships _____ (between 1 and 10)

Frequency of contact with these individuals _____ (between 1 and 10)

Occupation _____ (between 1 and 10)

Income _____ (between 1 and 10)

Volunteering _____ (between 1 and 10)

Residence _____ (between 1 and 10)

Time spent doing leisure activities _____ (between 1 and 10)

NB: I will then probe into those that are on either end of the spectrum. ie. "I see you scored 2 out of 10 for annual income. Can you tell me why are not satisfied with your annual income?"

How important are each of these items to your life satisfaction and mental well-being?

Please rank these items from 1 to 7 (or 8) where:

1 = most important to my life satisfaction and 7 = least important to my life satisfaction or put N/A if not applicable (ie. If you don't work or don't volunteer)

____ Number of supportive and caring relationships

____ Frequency of contact with these individuals

____ Occupation

____ Income

____ Volunteering

____ Residence

____ Time spent doing leisure activities

____ Other (please specify) _____

Appendix E

Interview Questions *(to be discussed in person with researcher)*

A Study about the Effects of the Stigmatization of Mental Illness on Life Satisfaction

Jennifer Codlin (Master of Social Work Candidate)

(School of Social Work – McMaster University)

Information about these interview questions: This gives you an idea what I would like to learn about your experiences. Interviews will be one-to-one and will be open-ended (not just “yes or no” answers). Because of this, the exact wording may change a little. Sometimes I will use other short questions to make sure I understand what you told me or if I need more information when we are talking such as: “*So, you are saying that ...?*”), to get more information (“*Please tell me more?*”), or to learn what you think or feel about something (“*Why do you think that is...?*”).

Interview questions:

1) Can you tell me about your initial experiences with the mental health care system and being formally diagnosed with a mental illness?

These are potential follow up questions if the following are not discussed in the initial response:

Probe: How soon did you seek treatment after the onset of symptoms? If delayed, why?

Probe: Did you have to see more than one practitioner? Why?

Probe: Did you receive more than one diagnosis from these practitioners? If yes, specify.

Probe: Did you agree with the suggested treatment made by your practitioner(s)? If no, specify.

Probe: What were the positive and/or negative experiences as a result of your experience in being diagnosed? **Or** Did you experience anything helpful in the process? Unhelpful?

Probe: How did those experiences impact you at the time?

Probe: Did these experiences have a lasting effect on your satisfaction with yourself and your life situation? If so, to what extent and how?

NB: Transition statement and discussion of the concept of stigma

2) Did you understand any of these experiences to be stigmatizing?

Probe: Tell me more.

3) Did being diagnosed as mentally ill affect your life plans/goals and/or day to day life? If yes, how so and why?

4) Can you tell me about any experiences you have had where others have treated you differently when they learned that you were diagnosed with a mental illness or upon hospitalization for a mental illness? (for example: avoided you, degraded you, discriminated against you, made you feel inferior, acted as though they were uncomfortable around you, ended your relationship, treated you unfairly)

Probe: How, if at all, did this/these experience(s) affect your satisfaction with yourself and your life situation?

Probe: Does that experience still impact you today? If so, to what extent and how?

Probe: Did you change your behaviour towards others upon diagnosis or hospitalization? (I.e. Isolate self, avoid certain people, wait to disclose or did not disclose mental illness to others?)

5) Can you tell me about a time when you have experienced stigma (if applicable) associated with your mental health diagnosis? This could be the result of interactions with your family, friends, medical practitioners, community agencies, others in society, your previous/current employer(s), the mental health care system?

Probe: How, if at all, did that/those experience(s) affect your satisfaction with yourself and your life situation?

Probe: Do(es) that/those experience(s) still impact you today? If so, to what extent and how?

6) How did these experiences of being stigmatized affect how satisfied you are with your life overall?

NB: If the interview has focused mainly on the negative aspects so far, I may discuss the possibility of positive outcomes from such experiences including defining what is meant by sense of empowerment and resiliency and ask the following:

7) How have stigmatizing experiences impacted on your sense of empowerment and resiliency?

8) What do the pictures/memorabilia you brought represent to you? Can you tell me what was happening for you during these times?

9) Is there something important we forgot? Is there anything else you think I need to know about you and your experience?

Appendix F



Oath of Confidentiality

I understand that as:
[X] transcriber

for a study being conducted by Jennifer Codlin of the School of Social Work, McMaster University, under the supervision of Professor Ann Fudge Schormans, confidential information will be made known to me.

I agree to keep all information collected during this study confidential and will not reveal by speaking, communicating or transmitting this information in written, electronic (disks, tapes, transcripts, email) or in any other way to anyone outside the research team.

Name: _____ Signature: _____
(Please Print)

Date: _____

Witness Name: _____ Witness Signature: _____

Appendix G

Table 1

Ranking of Measures of Life Satisfaction

Measures of life satisfaction	Importance - ranked from 1 (high) to 7 or 8 (low)								
	V	A	W	S	M	B	C	G	Average
# Supportive/caring relationships	1	2	4	3	6	4	1	2	2.9
Frequency of contact/relationships	2	3	5	2	4	5	4	3	3.5
Occupation	3	4	2	n/a	5	1	3	4	3.1
Income	4	6	3	6	3	2	2	5	3.9
Volunteering	7	8	8	1	8	n/a	7	8	6.7
Residence	6	5	7	4	2	3	5	6	4.8
Time for leisure activities	5	7	6	5	7	6	6	7	6.1
Other - specified by participant	n/a	1	1	n/a	1	7	n/a	1	2.2

Table 1 summarizes participants' responses to the Ranking of Measures of Life

Satisfaction tool, in which they were asked to rank the importance of a series of measures of life satisfaction. In addition to ranking seven preselected measures, participants were given an option to add and rank an additional life satisfaction measure of their own choosing and this, in the above chart, is captured in the category 'other'. Any 'n/a' responses indicated that that particular measure of life satisfaction was deemed by the participant to be not applicable or relevant to their present life satisfaction.

Table 2

Current Level of Satisfaction with Measures of Life Satisfaction

Measures of life satisfaction	Current level of satisfaction (1 low to 10 high)								
	V	A	W	S	M	B	C	G	Average
Participants									
# Supportive/caring relationships	8	7	10	9	5	9	2	9	7.4
Frequency of contact/relationships	8	10	8	9	4	7	1	7	6.8
Occupation	5	n/a	1	n/a	n/a	5	n/a	6	4.3
Income	3	1	8	5	n/a	8	1	6	4.6
Volunteering	8	n/a	5	5	n/a	n/a	n/a	7	6.3
Residence	8	10	7	5	7	7	3	8	6.9
Time for leisure activities	10	4	3	3	5	9	1	1	4.5
Average	7.1	6.4	6.0	6.0	5.3	7.5	1.6	6.3	

Table 2 identifies each participant's overall satisfaction with their present life circumstances, as well as their responses to each individual measure of life satisfaction. Those participants reporting 'n/a' for any of the categories explained that they were not currently engaged in those activities (e.g., not currently employed, receiving an income, and/or volunteering).