

**THE INFLUENCE OF STIGMA ASSOCIATED WITH BEING OLDER
AND MENTALLY ILL ON SELF-IMAGE**

Noga Ziv-Yodelevich

School of Social Work

McGill University, Montreal

August, 2008

**A thesis submitted to McGill University in partial fulfillment of the requirements of the
Degree of Masters of Social Work**

Copyright 2008 by

Noga Ziv-Yodelevich



Library and Archives
Canada

Published Heritage
Branch

395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque et
Archives Canada

Direction du
Patrimoine de l'édition

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file *Votre référence*
ISBN: 978-0-494-66932-7
Our file *Notre référence*
ISBN: 978-0-494-66932-7

NOTICE:

The author has granted a non-exclusive license allowing Library and Archives Canada to reproduce, publish, archive, preserve, conserve, communicate to the public by telecommunication or on the Internet, loan, distribute and sell theses worldwide, for commercial or non-commercial purposes, in microform, paper, electronic and/or any other formats.

The author retains copyright ownership and moral rights in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

AVIS:

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque et Archives Canada de reproduire, publier, archiver, sauvegarder, conserver, transmettre au public par télécommunication ou par l'Internet, prêter, distribuer et vendre des thèses partout dans le monde, à des fins commerciales ou autres, sur support microforme, papier, électronique et/ou autres formats.

L'auteur conserve la propriété du droit d'auteur et des droits moraux qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

In compliance with the Canadian Privacy Act some supporting forms may have been removed from this thesis.

While these forms may be included in the document page count, their removal does not represent any loss of content from the thesis.

Conformément à la loi canadienne sur la protection de la vie privée, quelques formulaires secondaires ont été enlevés de cette thèse.

Bien que ces formulaires aient inclus dans la pagination, il n'y aura aucun contenu manquant.

■ ♦ ■
Canada

ACKNOWLEDGEMENTS

The completion of this thesis would not have been possible without the help and support of the following people: First, I would like to thank my thesis advisor, Dr. Amanda Grenier, for her ongoing guidance, encouragement and support throughout the journey of writing this thesis.

My sincere gratitude goes to the ten participants in this study. Their generosity and insight comprised the foundations on which this thesis was built. I would also like to thank my colleagues at the Cummings Jewish Centre for Seniors for supporting me and believing in my abilities. A special thanks goes to Harriet Tobman, Carole Klein, Estie Kleinfeld and Maria Mendoza for their valuable advice and assistance and to Prof. Bendayan for his help with the French translation.

Finally, and most importantly, I would like to thank my extended family, my husband and my children for standing by me and encouraging me throughout this project-thank you.

ABSTRACT

The purpose of this qualitative study was to explore and better understand the stigma experienced by a specific subgroup of the population experiencing mental illness—*older adults*. Using the framework of the Modified Labelling theory, the effect and significance of stigma on their self-image was investigated. Semi-structured interviews were conducted with ten seniors who participate in the Community Mental Health Program at the Cummings Jewish Centre for Seniors in Montreal, Quebec. Using a purposive sample, study participants were included according to: age (i.e., 50 plus), participation in a mental health program in a community center, and having a diagnosis of a mental illness. Interviews were analyzed according to individual coping strategies as well as thematic content across interviews. Study results enhance understandings of how older people resist dominant discourses of stigma attached to mental illness and how personal perceptions on mental illness, age and health influence self-image.

ABSTRACTION

Le but du présent travail fut d'étudier et d'apporter une meilleure compréhension aux stigmatisations éprouvées par les personnes âgées souffrant de maladies mentales et les avenues par lesquelles elles influencent leur perception d'eux-mêmes.

Des rencontres et entrevues semi-structurées ont été menées sur dix personnes âgées faisant partie du programme de Santé mentale communautaire au Centre Juif Cummings pour personnes âgées de Montréal (Québec).

Nous avons travaillé sur un échantillonnage sélectionné. Les participants ont été choisis d'après les critères suivants: leur âge (entre 58 et 87 ans), leur participation au programme de santé mentale d'un Centre communautaire et le fait qu'ils souffrent de maladie mentale. La variété des diagnostics incluait: affection bipolaire, dépression, schizophrénie et anxiété.

Les entrevues ont été analysées selon la thématique et la façon personnelle de chacun à faire face à l'entrevue.

Les résultats obtenus contribuent à notre compréhension sur la façon que les personnes âgées résistent à la voie prépondérante sur la stigmatisation des maladies mentales et comment la conception personnelle des maladies mentales, de l'âge et de la santé influencent la perception de soi.

TABLE OF CONTENTS

Chapter 1: Introduction

Introduction.....	1
Historical perspectives on mental illness.....	3
Deinstitutionalization.....	4
Community based care as connected to stigma.....	6
Theoretical framework.....	6
Biological approach to mental illness.....	8
The modified labelling theory.....	8

Chapter 2: Literature Review

Public stigma	10
The impact of public stigma.....	11
Self-stigma.....	12
The consequences of self- stigma.....	13
Recent studies on stigma experienced by people who live with a mental illness.....	14
Summery.....	18
Older adults and mental health.....	18
Co-morbidity of physical and mental health needs.....	20
Masked depression & anxiety among older adults.....	21
Stigma attached to mental illness and old age.....	21
Policies and services for older adults with mental health needs.....	22

Chapter 3: Methodology

Objectives	25
Conducting research with older people.....	26
The semi-structured interview.....	27
Interviews.....	27

Setting.....	29
Subject population.....	30
Sample.....	30
Specific sample.....	31
Recruitment.....	32
Sample description.....	33
Table one: Sample description.....	37
Data collection.....	37
Data analysis.....	38
Organization of findings.....	39
Ensuring trustworthiness.....	39

Chapter 4: Findings

Theme One – Illness.....	42
Becoming ill.....	42
Making meaning- Dealing with a psychiatric diagnosis.....	44
Negotiating labels.....	45
Managing the illness.....	46
Coping strategies.....	46
When mental and physical interact.....	48
Theme Two - Stigma.....	49
The image of mental illness.....	50
Comparing mental illness to physical illness.....	51
Living a secret.....	53
Communicating the illness.....	55
Theme Three – Self-Image.....	58
Perception on self.....	58
The role of mental illness.....	60

Perceptions on age.....	61
Perceptions on resilience and despair.....	62

Chapter Five: Discussion

Illness.....	65
Stigma.....	68
Self image.....	71
Summery discussion.....	74

Chapter six: Conclusions

Cautions and limitations.....	77
Conclusions.....	78
Social work implications.....	79

References	80
-------------------------	-----------

List of appendices

Appendix A-McGill Ethics Approval.....	85
Appendix B- Cummings Jewish Centre for Senior Ethics Approval.....	86
Appendix C- Interview Guide.....	87
Appendix D- Consent Form.....	88

Chapter 1:

INTRODUCTION

Older adults who live with mental illness are a diverse population with complicated needs. As the elderly population in Canada and in the world is rapidly growing, and life expectancy is increasing, questions regarding the quality of life of this population emerge (Sivis, McCrae, & Demir, 2005). It is well established that during the process of aging, people encounter stressors such as decline in health, independence and the loss of loved ones (MacCourt, 2004). While most of the elderly population manages to adapt to these changes and to maintain their mental health, seniors who suffer from a mental illness can face a unique threat on their ability to maintain a good quality of life. Yet, research indicates that factors such as stigma and denying the symptoms of older people create barriers that result in the underutilization of mental health services by elderly mentally ill people (Halpern, 2001).

Stigma attached to mental illness is recognised by numerous studies as a persistent and significant contributor to the marginalization of people who suffer from a mental illness (Corrigan & Kleinlein, 2005; World Health Organization & World Psychiatric Association [WHO-WPA], 2002; Link & Phelan, 2001). However, the negative image of mental illness in the public has not changed much throughout time. To this day there are people who consider a person who is diagnosed with a psychiatric illness as dangerous, unpredictable and potentially violent (Guimon, Fischer, & Sartorius, 1999). It is safe to say that a person who lives with a mental illness needs not only to deal with symptomatic challenges but also with society's reactions toward him/her (Hayward & Bright, 1997; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001).

To date, most studies have focused on the existence and impact of stigma towards younger adults with mental disorders (WHO-WPA, 2002) and explored the ways the public perceives people who are diagnosed with a psychiatric illness (Hall, Brockington, Levings, & Murphy, 1993; Purvis, Brandt, Rouse, Vera, & Range, 1988; Guimon et al., 1999). This thesis aims to apply the concept of stigma to older adults and to explore how the stigma associated with mental illness influences their self- image. At a stage where physical and mental challenges interact, participants who live with a mental illness were asked to express their opinions and insights regarding their own perception on stigma, age and concept of self. In order to do so, the modified labelling theory developed by Link, Cullen, Struening, & Shrout (1989) was chosen as a theoretical framework. Modified labeling theory is concerned with how the self- identity and behavior of an individual is influenced by how that individual is perceived by others. A qualitative study was conducted in order to illuminate the subjective interpretations of ten seniors who live with a diagnosed mental illness. Their experiences regarding stigmatizing reactions, mental and physical challenges were explored within the context of their age. Their life stories contributed to the understanding of the way these seniors make meaning of their life and the way they interpret their realities.

This chapter will situate the historical roots of stigma associated with mental illness back to ancient civilizations (Goffman, 1963; Szasz, 1972; Guimon, 2001). It will also describe the deinstitutionalization of people with mental illnesses in the 1950's from psychiatric hospitals to alternative facilities in the community and will discuss the connections between stigma and community based care as it is known today (Thornicroft & Bebbington, 1989; Warner, 1995; Lamb & Bachrach, 2001).

Historical perspectives on mental illness

The phenomenon of stigma has existed in society since the early ages. The Greeks were the first society to initiate the term stigma. Ervin Goffman, (1963) who defined stigma as, “The situation of the individual who is disqualified from full social acceptance” (p.1), explained that the Greeks used the term stigma as visually apparent signs, burnt or cut into the body. “These signs advertised that the bearer was a slave, a criminal, or a traitor - a blemished person, ritually polluted, to be avoided, especially in public places” (p.1). During the Middle Ages, mentally ill people were regarded in the same way as those suffering from the plague or syphilis. They were held in facilities occupied by those who suffered from contagious diseases. People with mental illnesses were persecuted, witch hunted and accused of being dangerous, violent and immoral. Throughout the centuries, the concept of “stigma” shifted from an actual mark of inferiority to an act of social labelling (Porter, 2004).

In the age of Enlightenment, with the decline of the power of the Church, mentally ill people were placed in hospitals and doctors were expected to restore their patients into good health and protect society from them. Since then, and until the 1950's, people who had mental illnesses resided in asylums, separated from the community (Guimon, 2001). Tomas Szasz (1972), highlighted the link between witch hunting of the mentally ill and the stigmatizing of the ‘mad’. Both were seen by him as strategies to enhance social control through victimization and enhancing the psychiatric empire. To this day, mental institutions, or psychiatric hospitals, have a negative reputation among the public. Not surprisingly, the negative images of forced treatment given by psychiatrists and oppressive control over subordinate patients contributed to activist involvement in the form of the

anti-psychiatry movement as well as the deinstitutionalization of people with mental illness to community care (Banton, 1985).

Deinstitutionalization

Deinstitutionalization of people who suffer from mental illness started to take place in the 1950's, and is considered a revolution in mental health care.

Deinstitutionalization consisted of three component processes: The release of patients from psychiatric hospitals to alternative facilities in the community; the diversion of new admissions to alternative facilities; and the development of specialized services in the community for the mentally ill population. The rationale for deinstitutionalization was based on the assumptions that community based care would be more humane than hospital based care, and would be more therapeutic and more cost-effective (Thornicroft & Bebbington, 1989). The deinstitutionalization of people with mental illnesses and their integration into community is regarded as one of the most significant shifts in the way we, as a society, view and treat this population. There are however, positive and negative aspects to this policy (Lamb & Bachrach, 2001).

Research has shown that in communities where all three elements have been implemented, people with mental illnesses have benefited from an improved quality of care and, in some cases, were able to live independently (Warner, 1995). People with mental illness have achieved significant gains in their attempt to live as independent lives as possible. However, the benefits of deinstitutionalization do not apply to all mentally ill individuals. In some cases, people with severe mental illness have found it extremely difficult to sustain themselves in the community. In addition, community resistance,

fragmentation of services and insufficient housing opportunities have created barriers in the integration of people with severely mental illness into the community. In some cases, inadequate resources were made available to implement community care policy. As a result, programs and services were expected to operate and implement this policy without the funds to do so (Lamb & Bachrach, 2001).

The implementation of deinstitutionalization was further criticized in terms of the execution of the ground level policy—in particular, the way health professionals treated people within the community. For example, Ragins (2007) claims that, “some of the failure of deinstitutionalization may well be because professionals have never been deinstitutionalized themselves” (p.6), meaning that assumptions and stigmas regarding people with a mental illness continued to create barriers to incorporating concepts of empowerment and collaboration between service providers and the consumers.

Deinstitutionalization involves more than changing the geographical location of people who live with mental illnesses. It is an ongoing conceptual change that requires insight and understanding from those who plan and implement community based care (Lamb & Bachrach, 2001). In order to be able to continue creating appropriate community based services tailored to the individual’s needs, age and clinical state, there is a need to first acknowledge and appreciate the diversity within the population known as the “mentally ill”. This would allow consumers of community based care to voice their opinions regarding services and interventions. These changes in concept are important not only within the context of providing services, but also as a way to shift stigmatizing public assumptions regarding people who live with a mental illness.

Community based care as connected to stigma

According to various studies, deinstitutionalizing people with mental illness from psychiatric hospitals to community based care exposed the public to direct contact with patients, which potentially elevated negative perceptions and rejecting stereotypes (Eker & Oner, 1999; Depla, Graaf, Van Weeghel, & Heeren, 2004). Research has shown that stigmatized reactions are produced when the public is exposed to people who display symptoms that indicate deviant behaviours such as inappropriate behaviour, language irregularities, and talking aloud to themselves (Corrigan & Kleinlein, 2005). The responses of people with mental illness to ordinary social cues and expectations are deemed strange and unpredictable. As a result, family members, neighbours and friends can no longer understand them and lose their ability to identify or empathise with them (Kendell, 2004). In these cases, the general public showed fear and dislike towards people with mental illness, and tried to avoid being in contact with them (Corrigan & Kleinlein, 2005; Link & Phelan 2001). Common beliefs about people with mental illnesses reported in the literature included that they are dangerous, responsible for their condition, that their condition is chronic and difficult to treat, and their behaviour disrupts the normal social interaction (Hayward & Bright, 1997; Guimon et al., 1999).

Theoretical framework

The modified labelling theory developed by Link et al. (1989) provides a useful framework to understand the complicated reasons and ways that negative stereotypes and stigma are created. Modified labelling theory is concerned with the self-identity and

behaviour of an individual and how he/she is influenced by the perceptions of others.

According to this theory, “people develop conceptions of mental illness early in life from family members, personal experiences, peer relationships and media portrayals of people with mental illness” (p.1622). People who live with a mental illness are exposed to the same perceptions and can internalize negative ideas about themselves and start to believe in them (Link et al., 1989; Link et al., 2001).

Labelling theory and mental illness

During the 1960s, questions regarding stigmatized reactions towards people who are mentally ill emerged. Research opinions were divided. Some claimed that medical conditions cause symptoms and deviant behaviours and others claimed it was the label attached to mental illness that caused the problem (Corrigan & Kleinlein, 2005). These debates divided researchers and health professionals into supporters of the medical model verses supporters of the labelling theory. The modified labelling theory offers a middle ground between the two extremes. It can best be understood within the debate between those who believe that sociological influences alone contribute to the stigmatization and rejection of people who suffer from a mental illness (e.g., social constructionists) and those who claim that medical origins are responsible for deviant behaviours among the mentally ill.

Thomas Scheff (1968) was the first to apply labelling theory to the mentally ill by claiming that mental illness manifested itself solely as a result of societal influence. The key principle in labelling theory is that the label “mentally ill” or “deviant” leads the public to treat the person as mentally ill, triggering responses such as fear and disgust and leading to modified behaviours such as minimizing contact with the labelled person. This causes

the mentally ill person to exhibit continued deviant behaviour, thus, fitting himself into the label. Such theories suggest that both the behaviours and responses to behaviours are social in nature (Scheff, 1968; Corrigan and Kleinlein, 2005).

Biological approach to mental illness

As a main supporter of the medical model, Walter Gove (1975) claimed that society had no influence on mental illness. Drawing on a biological approach to mental illness, Gove claimed that the disabilities associated with mental illness originated entirely from medical conditions. This theory suggests that negative responses are a result of the bizarre behaviours displayed by persons with mental illnesses rather than a consequence of negative stereotypes or labels. Gove's medical model theory claims that behavioural disturbances produce symptoms, and that these symptoms make it possible for psychiatrists to apply diagnostic labels and to treat patients with appropriate medication (Guimon et al., 1999).

The modified labelling theory

The modified labelling theory is an attempt to find a middle ground between the medical model and the labelling theory. Link et al. (1989) concluded that aberrant behaviours cause negative reactions from society, which lead the public and the individual to label mental illness in a negative way. This theory claims that, "even if labelling does not directly produce mental disorder, it can lead to negative outcomes" (p.400). In other words, the modified labelling theory acknowledges that biological roots cannot be dismissed in connection with mental illness. However, social reactions toward people who

suffer from mental illness are seen as a significant source of stigma and rejection which can cause serious outcomes. Such outcomes could be low self-esteem, and feelings of failure and shame. Social rejection of people who are mentally ill can influence the way patients perceive their disease. A person's behaviour toward the mentally ill would thereby reflect the person's assumptions about them. Through a self-fulfilling prophecy process, the mentally ill person may subsequently behave in a way that confirms the perceived expectations (Goffman, 1963; Hillet et al., 1999; Link et al., 1989).

Chapter 2:

Literature Review

There is an abundant body of research concerning stigma and mental illness. The data collected from the literature indicates that stigma to mental illness exists and manifests itself in different ways. The following review will examine different types of stigma, (i.e., public stigma and self-stigma), it's possible consequences and the impact on the lives of people diagnosed with a mental illness. It will also attempt to provide a brief overview of the research on stigma as experienced by mental health consumers, thus providing an opportunity to hear their opinions and voices regarding their own realities.

Public stigma

In the literature, a clear distinction is made between public stigma and self-stigma (Link & Phelan, 2001; Corrigan & Kleinlein, 2005; WHO-WPA, 2002). Public stigma is defined as the reaction the public has to people with a mental illness (Corrigan & Kleinlein, 2005). According to these authors, there are three components, which create public stigma: stereotypes, prejudice and discrimination. Social stereotypes are viewed as knowledge structures that are efficient means of categorizing information about social groups. Stereotypes represent collectively agreed upon notions of groups and are considered efficient because they provide quick impressions and expectations of individuals who belong to a stereotyped group. Stereotypes about people with a mental illness include dangerousness, incompetence and character weakness (Hamilton & Sherman, 1994). Prejudice occurs when people endorse these negative stereotypes and generate negative emotional reactions as a result. Emotional reactions could include fear, anger, pity and withdrawal and could lead to discrimination. Discrimination could be

defined as any distinction, exclusion or preference that has the effect of withholding services or impairing equal rights (WHO- WPA, 2002).

The impact of public stigma

There is a body of research that highlights the different ways that public stigma could influence the life goals of people with mental illness (Link et al., 2001; Guimon, 2001; Wahl, 1999). Proprietors, employers, health care providers, family members and friends, involved in the lives of those with mental illnesses, can be impacted by public stigma. They could, for example, be involved in the loss of rightful life opportunities such as meaningful employment and decent housing conditions. In terms of obtaining competitive employment, surveys consistently show that less than fifteen percent of people with a serious mental illness are employed (Anthony & Blanch, 1987). In terms of housing, it is estimated that in the United States, more than two million people with severe mental illness live in inadequate housing, lack needed support or are homeless (Corrigan & Kleinlein, 2005). While likely lower in Canada as a result of welfare state protections, many homeless people are known to have mental health issues (Canadian Mental Health Association [CMHA], 2003).

The literature also addresses the impact that a psychiatric label has on people in terms of discrimination. A person who has suffered from mental illness is liable to be discriminated against - this means being subjected to prejudice that could lead to difficulty in achieving life goals (Kendell, 2004). When referring to life goals, the literature emphasizes basic civil rights such as obtaining competitive employment, adequate housing,

getting married or obtaining education (Corrigan & Kleinlein; 2005, Kendell, 2005; Guimon et al., 1999).

Stigma has also been seen as contributing to the underfunding of services for the mentally ill (Barchas et al., 1985). In a competitive market, funds are designated to sectors that the public perceives as “deserving”, such as children with life threatening diseases, or people who suffer from cancer. Mental illness is not perceived as “attractive” and the public finds it hard to empathise with it (Kendell, 2004). Discrimination towards marginalized and stigmatized groups such as the mentally ill affects not only the person himself, but also his family and the people who care for him. Most of the time, it is the family members, or close friends, apart from the person himself, that first become aware of the mental problem. Caring for the mentally ill person puts a significant amount of strain on the family. Negative attitudes and stigma could lead to denial, or result in the family’s hesitation to ask for professional help. Inner relationships in the family are affected and the family members can themselves experience diminished self-esteem (Eker & Oner, 1999).

Self-stigma

Self-stigma on the other hand, is used by theoretical frameworks such as the modified labelling theory to argue that stigma can be internalized and cause serious harm. It is defined as the acceptance of stigmatizing images towards one’s sense of self (Link & Phelan, 2001). According to these authors, “consumers develop stereotypic understandings about mental illness through their socialization and membership in the broader culture, and apply these negative stereotypes to themselves after they are formally labelled” (p.1621). From an early age, people are influenced by personal experiences, parent’s views and the

media's portrayal of mentally ill people. People living in societies that endorse such stigma may internalize the negative stereotypes and perceptions, and start to believe that these assumptions are true. A person who suffers from a mental illness and accepts these concepts may fear rejection and develop self- prejudice and low self-esteem (Corrigan & Kleinlein, 2005; Link & Phelan, 2001). A vicious circle of withdrawal and rejection could occur when a person acts on the anticipation of rejection, even if the rejection does not actually occur (Angell, Cooke, & Kovac, 2005).

The consequences of self-stigma

The consequences of self- stigma may differ in occurrence and significance. According to labelling theory, three main responses may occur: secrecy, withdrawal and education. First, in the case of secrecy, a person could choose to keep his mental illness history from employers, relatives and loved ones (Link et al., 1989), or choose not to seek help because of the fear of being identified with this stigmatized group (Corrigan & Kleinlein, 2005; Hayward & Bright, 1997; Hillert et al., 1999). Second, in the case of withdrawal, the person may limit his social interaction to people who know about the illness and are supportive, thus reducing the risk of being rejected or judged by others (Link et al., 1989). Finally, in the case of education, the person may attempt to change views about mental illness by educating himself and others about the illness (Link et al., 1989; Guimon et al., 1999).

Critics of this theory argue that although most people with mental illness are aware of the stereotypes and stigmas that are associated with mental illness, they do not necessarily agree with them (Hayward & Bright, 1997; Gregoire, 1990; Quadagno &

Antonio, 1975). Research has shown that despite an awareness of stigma, some people did not experience a decline in self – esteem (Crocker & Brenda, 1989). Depending on their identification with their stigmatizing group and their positive self-esteem, people could also view mental illness stereotypes as unjust, leading them to feelings of anger and non-compliance with society’s expectations and stereotypes (Corrigan & Kleinlein, 2005). Furthermore, Weinstein (1983) reported that in many cases, those who suffer from mental illness evaluated themselves more positively than do the “mentally ill” in general, suggesting that negative labels attached to mental illness were not seen as personally relevant. Research on empowerment supports this concept, and suggests that being stigmatized can produce reactions of positive self-perception as a way to oppose and reject negative evaluations (Rogers et al., 1997).

Recent studies on stigma experienced by people who live with a mental illness

Numerous research studies have attempted to explore and demonstrate the possible consequences of mental illness labelling. Most of the studies involved reports from the general population, asking people to express their opinions regarding people with mental illnesses (Corrigan & Kleinlein, 2005; Guimon et al., 1999; Hall, Brockington, Levings, & Murphy, 1993; Purvis et al., 1988; Farina & Felner, 1973).

What are not yet widely explored are the views, experiences and opinions of stigma from the perspective of persons with mental illness (Garf et al., 2004; Wahl, 1999). The following review intends to provide a brief summary of the few studies that attempted to examine the significance and impact of stigma by asking people who live with a mental

illness to voice their opinions regarding their perceptions on the significance and impact of stigma.

In an attempt to find out more about the extent in which people who live with a mental illness encounter stigma in their daily lives, and about the possible impact of stigma experiences on their quality of life, Wahl (1999) conducted a nationwide survey of 1,301 mental health consumers. In this survey, 100 respondents were requested to describe specific incidences where they experienced stigma and the emotional reactions and coping strategies that were used to deal with the situations.

Survey results and follow-up interviews revealed that the experiences of stigma emanated from a variety of sources which included family, community and health care professionals. In fact, 80% of the respondents reported that they witnessed stigmatizing comments or depictions of mental illness; 70% reported that they were at least sometimes treated as less competent by others once their illnesses were known; and 74% indicated that they had often avoided telling others outside their immediate families about their mental illness. Feelings of anger, hurt and lower self-esteem were reported by 57% of the interviewees (Wahl, 1999).

The influence of stigma on the self-esteem of people who live with mental illness was explored further by Link et al. (2001), who conducted a three-stage study with a group of mentally ill persons by assessing the levels of discrimination, devaluation and social withdrawal at a base line and follow up session. In this study, 88 members of a clubhouse program for the mentally ill were randomly assigned to either an intervention group or control group. Baseline responses indicated that low self-esteem was significant in

determining perceptions of stigma and discrimination (54%) and that 74% believed that mentally ill people were experiencing discrimination. The results were consistent at both the six and 24-month follow up sessions. The study design however, consisted of a self-report questionnaire and did not take into account the symptomatic state or personality orientation of the participants.

Similar findings were reported in a study conducted by Garf et al. (2004). This study compared the public's views of people with a mental illness and how psychiatric patients view themselves. This representative population study in Switzerland went a step further by examining the impact that perceived stigma had on the quality of life of mentally ill people (N=124). Study results confirmed the researchers' original hypothesis that psychiatric patients and the public did not differ in their beliefs that most people reject people with mental illness. Furthermore, this study showed that these beliefs could also influence the decision of a mentally ill person to seek help due to the fear of being labeled. Their measurement tool however, measured assumptions about how other people would react to mentally ill people and did not measure respondents' actual behaviors.

Self-perceptions of people with severe depression were explored in a study conducted by Yen, Chen, Lee, Yen, and Ko (2005). This study examined the relationship between self-stigma and severity of depressive symptoms, socio-demographic characteristics and the course of the illness. The authors' hypothesis was that patients with major depression would have greater self-stigma than patients with non-depressive minor mental disorders. A sample of 247 patients with diagnoses of depression disorders from an outpatient psychiatric setting was chosen. A self-stigma assessment scale was used to measure the patient's own attitudes towards their mental illness. The findings of the

research were congruent with the results of previous studies. Twenty five percent of the patients had high levels of self-stigma. Patients who had more severe depression had higher levels of self-stigma. These findings support the evidence that people who are severely depressed are under-treated. This could provide a possible explanation as to why self-stigma is one of the barriers to sustaining psychiatric treatment. This study did not compare levels of self-stigma between patients with clinical depression and those patients with other mental illnesses in terms of their level of self-stigma and also relied only on the patients self report.

Finally, treatment discontinuation is another major concern among professionals as well as family members. Sirey et al. (2001) examined two groups of younger and older psychiatric patients in her research about perceived stigma as a predictor of treatment discontinuation in outpatients with depression. The hypothesis was that older adults would report higher levels of perceived stigma and would be more likely to discontinue treatment. A two stage sampling design of 92 new admissions of outpatients with major depression was administered. Sixty-three of the patients were 18-64 years old and twenty- nine were 65 and older. Perceived stigma was assessed at admission. Discontinuation of treatment was recorded at a 3-month follow up. The findings of the research showed that in older adults greater perceived stigma was associated with greater likelihood to discontinue treatment. The study emphasized the impact that stigma has on the treatment process itself. The study, however, did not account for other treatment factors such as doctor patient relationships.

Summary

The reviewed scholarship provided a foundation for the understanding of the phenomenon of stigma associated with mental illness. As this review indicated, the roots of this phenomenon are deeply embedded in the way that society views and treats people and groups who demonstrate behaviors considered different and/or judged as deviant. It is safe to say that people who suffer from mental illness are exposed to a variety of stigmatizing reactions from the public. The question of internalizing these concepts into one's sense of self is complicated and is not yet clear. The ways that people who live with mental illness chose to interpret stigmatizing reactions and how they make meaning of their reality needs to be further explored.

Older adults and mental health

Older adults who suffer from mental illnesses are exposed to similar stigmatizing reactions as younger adults (MacCourt, 2004) but may also face additional challenges related to their age, health and life circumstances. This section will explore the impact of stigmatization towards older adults.

Canada's population, like other countries around the world, is aging. In 2001, 1 in 8 Canadians were aged 65 years and over (Turcotte, & Schellenberg, 2007). Within this, it is estimated that 1 in 5 people aged 65 years and over have a mental disorder, including dementia, depression, psychosis, bipolar disorders, schizophrenia, and anxiety disorders (Sullivan, Kessler, La Clair, Stolle, & Whitney, 2004). The significant increase in the number of older adults raises important questions regarding their health and their needs for

(Sullivan, Kessler, La Clair, Stolle, & Whitney, 2004). The significant increase in the number of older adults raises important questions regarding their health and their needs for specialized services (Sivis, McCrae, & Demir, 2005). This is especially the case when mental health concerns are considered. In Quebec, 2-3 % of the adult population including older adults have a serious mental illness and this rate is estimated to double by 2030 due to the aging of the population (Bartels, 2004). As a result, community health and social services will face unique challenges of how to best address the mental health needs of the aging population.

Older adults vary widely with respect to their mental disorders. An important distinction is between those who are aging with mental health needs and those who develop a mental health need in late life. Some seniors have suffered from chronic, severe mental illness across the life course; others have experienced periodic episodes; and a substantial number of older adults experiences mental illness disorders for the first time in late life (Halpern, 2001). There are also differences in relation to the type and severity of the mental health need, and the questions with regard to co- morbidity between physical and mental health needs. However, in order to diagnose, treat and develop specialized services, there is a need to acknowledge the diversity in the elderly population who suffer from a mental illness. A major step toward acknowledging the mental health issues of older people was achieved in the 1996 collaboration between the World Health Organization and the World Psychiatric Association's technical consensus document on mental health and aging. As Sullivan et al. (2004) states, " For the first time, opinion leaders from across the world collaborated to acknowledge specialty psychiatry for the elderly, the characteristics of psychiatric morbidity in old age and their treatment, the

organization of multidisciplinary services, the need for training schemes across health and social care workers, and the benefits of research activities” (p. 459). There is however, still a good deal of work to do in relation to our understandings of mental health needs of older people. Three of the key challenges include: 1) those raised by the combination of physical and mental health needs; 2) the masking of depression and anxiety; and 3) the stigma attached to being an older person.

1) Co-morbidity of physical and mental health needs

Older adults face a variety of challenges that are specific to their life stage. These could include physical problems, mobility and medical conditions, retirement, and changes in income level. Seniors may respond to these events in different ways. Research has shown that in some cases, stressful life events could trigger depression and anxiety among seniors or contribute to an existing mental health condition (Sivis et al., 2005; Sullivan et al., 2004; Halpern, 2001). Seniors who live with a mental illness have a high prevalence of concurrent major medical disorders such as cardiovascular disease, gastrointestinal disorders, skin infections and acute respiratory ailments (Dickey, Normand, & Weiss, 2002). Research suggests that co-morbidity among this population can be associated with a variety of risk factors such as unhealthy life styles, metabolic and neurological side effects of psychiatric medications as well as poor health care (Bartels, 2004). According to a study by Kramer, Simonsick, Lima, & Levav (as cited in Halpern, 2001) co- morbidity of physical and mental health conditions is not only considered a key risk factor for maintaining mental health, but can also contribute to masking mental health symptoms

and/or their dismissal as a natural part of the aging process by health professionals, care givers and the seniors themselves.

2) Masked depression & anxiety among older adults

According to research, there are significant numbers of masked depression and anxiety disorders among older adults (Preville, Cote, Boyer, & Hebert, 2004). Masked depression refers to the ways in which the older adult would focus on his/her physical symptoms, rather than on his/her mental health problems. Older adults with mental disorders may present with different symptoms than younger adults, thus making accurate diagnosis and treatment difficult (Sullivan et al. 2004; McCourt, 2004). In many cases, older adults and their families tend to consider psychological disorders stigmatizing and tend to deny their existence. In some cases, when a person reports his /her symptoms to his doctor, the doctor tends to normalize the symptoms of the mental illness, especially in cases of depression and anxiety, thus leaving many seniors under- diagnosed and untreated (Preville et al., 2004).

3) Stigma attached to mental illness and old age

Stigma attached to mental illness and old age can also cause a significant barrier to receiving adequate services. Seniors may feel embarrassed to acknowledge their mental health symptoms and seek help (Canadian mental health Association, 2008; Sullivan et al., 2004). According to the Technical Consensus Statement regarding stigma and discrimination against older people with mental disorders that was released in 2002, there are adverse interactions between the stigmatizing attitudes towards mental disorders and towards old age (WHO- WPA, 2002). Depression and anxiety are seen as personal

weakness, by others and by the seniors as well. Additionally, age-based stereotypes, by which all old people are considered odd to some extent, can result in low levels of recognition and treatment by health care professionals. For example, professionals may believe that older people are inflexible and unable to change, and as a result, reinforce stereotypes and beliefs that their mental illness is incurable and/or dismiss or ignore complaints made by older people. This phenomenon may contribute to a difficulty in accessing physical health care as well as proper mental health care services (WHO-WPA, 2002; Halpern, 2001). It is estimated that only half of older adults in the U.S.A who acknowledge their mental condition receive treatment from any kind of health care provider. In Canada, only one third of older people with mental illness living in the community receive mental health services (Sullivan et al., 2004). The reasons behind this phenomenon include reluctance to self-refer, access and availability barriers, as well as the failure of professionals to identify the signs and symptoms of mental illness (Halpern, 2001).

Policies and services for older people with mental health needs

The services within the Canadian health care system fall under provincial jurisdiction. The system is mainly public, with extensive private sector collaboration. This means that while the federal government can provide guidelines and initiatives related to mental health, the provincial governments are responsible for implementing actual programs and services (Fleury, 2005). In June 2005, the Quebec Government produced the 2005-2010 Quebec Mental Health Action Plan (PASMQ). The plan is part of the major

transformation of the Quebec health and social network initiated by Bill 25 in 2003 (Lesage, 2007).

The reform of health and social services made major recommendations in relation to mental health programming across the life course. The Quebec Mental Health Plan recommended an organization of first, second and third line mental health services and a development of mental health clinical and organizational plans for each of the CSSS (Centres de sante et de services sociaux). The reform suggested that first line mental health teams would serve populations across the life course with a distinction being made between teams for adults and children/youth. As a result, this organizational structure could leave older adults with mental illness without specialized services targeted to their needs and age-related challenges (Moscovitz & Regenstreif, 2007). One of the strengths within the plan however, is that it not only focuses on people with severe mental illness (i.e., schizophrenia and psychosis) as has been the case in the past forty years, but also prioritizes common mental disorders such as depression and anxiety which are significantly more prevalent within the senior population (Lasage, 2007).

When compared to the federal report, one can see that the 2005-2100 Quebec Mental Health plan follows the recommendations of the federal report “Out of the Shadows at Last- Transforming Mental Health, Mental Illness and Addiction Services in Canada” (2006). Specifically, it recognizes that older adults are an emerging, growing population with complicated specific mental health needs. Contrary to the report however, the Quebec Plan does not specify any type of interventions for seniors. The Standing Senate Committee recognized that seniors with mental health issues should be provided treatment

and support services within their communities and homes, and that they should receive services across the continuum of care from specific, specialized programs designed for them (Kirby & Keon, 2006). However, despite this recognition of the importance of mental health services to the elderly, there is still a division between physical and mental health services. In order to receive public homecare services, seniors need to be suffering from loss of autonomy related to physical health, and likewise, to receive mental health services, they must have a diagnosed mental health problem. Seniors who suffer from both find it difficult to access services that address their specific needs (Moscovitz, & Regenstreif, 2007). Stigma associated with mental illness, physical difficulty in accessing services, denial of symptoms and mental health needs which are often viewed as secondary to and disconnected from their physical needs, can all contribute to the underutilization of mental health services by older adults. This phenomenon raises concerns when the numbers, diversity of needs and vulnerability of this population is considered. Neglecting mental health needs could lead to additional physical health concerns such as malnutrition and/or premature hospitalization (Sivis et al., 2005; Halpern, 2001).

Chapter 3:

Methodology

There is growing recognition that stigma related to mental illness impacts the ways the public perceives and treats people who live with a mental illness (Link et al., 1989; Graf et al., 2001; Kendell, 2004). Drawing on modified labelling theory, the theoretical framework for this thesis, concepts of internalized negative assumptions and self-stigma were explored. Ten older adults who live with a diagnosed mental illness were asked about their opinions and perceptions regarding their personal experiences with stigma as it related to mental illness.

Objectives:

This thesis aimed to explore and better understand the stigma experienced by older people who suffer from a mental illness and understand how these experiences impacted their self- image. The specific research question was: How do stereotypes and stigma associated with old age and mental illness impact self image?

I used qualitative research to explore and understand the social phenomena of how seniors lived and experienced their mental illness. Qualitative research was chosen as a method of inquiry, in order to allow me to better understand situations within their context (Strauss & Corbin, 1990). The design of this study aimed to capture rich and detailed local narratives embedded within individual perceptions expressed by the respondents. "Human actions are based upon, or infused by, social meaning: that is, by intentions, motives, beliefs, rules, and values" (Hammersley & Atkinson, 1995, p. 8).

Qualitative research assisted me to present these subjective experiences as a valid, significant source of data and enabled me, as a researcher, to provide insights into their stories from their individual points of view.

Conducting research with older people

Older adults who suffer from a mental illness are considered to be vulnerable and tend to be exposed to negative stigma and stereotypes. The stereotypes could lead to exclusion from regular activities and community events (WHO- WPA, 2002). In this research I was interested in hearing the seniors' voices, and in particular, giving them a chance to express their opinions as well as learn about access to services. The seniors were interviewed and expressed personal views about stereotypes associated with mental illness and old age. Considering that these topics could create discomfort to some seniors, clear guidelines were discussed over the phone and repeated before the beginning of each interview. These guidelines included the possibility of stopping the interview at any stage, choosing not to answer a question that caused discomfort and/or asking to erase part or the entire recorded interview.

Ethical approval was received from the Ethics Committee for Human Subject Research at McGill University (See appendix A). In addition, I received approval from the Cummings Jewish Centre for Seniors, where the research was conducted. This allowed me the opportunity to interview seniors who are already part of the existing Mental Health Program at the Centre (See appendix B).

The semi-structured interview

The semi-structured interview was chosen as the primary method of inquiry for this research. A semi-structured interview was intended to maintain a balance between open – ended questions, which allow the respondents to express their thoughts without any guidelines, and a more structured approach by which the wording of the questions and the themes that are explored are predetermined (Bogdan & Biklen, 1982).

Recognising the limitations of conducting only ten interviews, I decided to use a more structured approach than typically used in narrative interviews. This allowed me to focus on the ways that participants saw themselves and their experiences of stigma as it related to their mental illness. The use of semi-structured interviews allow a balance between open-ended questions, where participants would pursue themes of importance, and more focused questions where I, as an interviewer, could ensure that all respondents are asked about similar topics (Rubin & Babbie, 2005).

Interviews

Interviews were loosely structured around exploring the experiences of mental health and illness. The interview guide consisted of six items which served as a reference point. The interview guide was designed to ensure that respondents were asked about similar topics, yet allowed room for me to probe emerging topics (Lofland & Lofland, 1984). Interviews were intended to capture three main themes: 1) the ways that seniors see themselves and their realities; 2) the stereotypes and stigma associated with mental illness and old age; 3) and the ways that these stereotypes and stigmas influence self-image (See appendix C for interview guide).

Interviews were organized around six key questions: The first question (i.e., Tell me about yourself) included probes regarding age, family status, and living arrangements and enabled the respondent to provide personal and family background about him or herself. This served two purposes. First, it enabled us to establish a rapport, and second, by asking the respondent about himself/herself, the respondent was given the message that he/she, rather than the illness, was the focus of the interview. The second question (i.e., How do you see yourself?) gave the respondent the opportunity to describe him/herself in depth, including characteristics, strengths and limitations, and provided an entry point to further explore self-image. The third question (i.e., Would you consider yourself to be older?) elicited reactions concerning age, personal interpretations of one's place within the life cycle and connected the respondent with the second question (i.e., How do you see yourself). The fourth question (i.e., What is a mental illness to you?) was designed to prompt reactions concerning mental health issues, diagnosis and medical history. The use of a generalized question regarding mental illness provided a comfortable entry point for the respondents to talk about mental illness in general and to relate to their own mental illness and their medical experiences. The fifth question (i.e., How do you think other people see you?) explored the different ways the respondents perceived other people's perceptions of them. This question was asked in order to explore the respondents' reactions regarding stigma experiences, stereotypes, family issues and resistance and was more generally connected to being an older person who lives with a mental illness. The sixth question (i.e., What, if anything, would you change about yourself?) was asked in order to bridge the issues that were discussed and summarize the interview. Respondents were

asked to reflect about their lives, the way they are seen by others and how they see themselves in light of their age and mental health conditions.

Setting:

This study was conducted at the Cummings Jewish Centre for Seniors in Montreal. This Centre is a non-profit community agency for predominately Jewish Seniors that provides services to seniors living throughout the city. The Centre's mandate is to help seniors maintain their independence and promote their quality of life. A full range of social, recreational, educational and financial programs and services are offered to meet seniors' needs. The Support Services Department provides services that help seniors remain in their homes for as long as possible and offers homecare, meals on wheels, and transportation to medical appointments to its clients.

The Mental Health Program, which is part of the Support Services Department, has an objective of integrating seniors who live with a mental illness into the mainstream of the Centre by offering courses, volunteer opportunities, exercise, and art programs. It also provides the opportunity to participate in social groups. Social workers offer ongoing follow-up and support, and work with the seniors to design individual intervention plans tailored to their interests and needs. This program's philosophy and core values stem from the wellness approach found within the recovery model. The perspective is that people with mental illness may never be cured and will face a lifelong challenge of managing their illnesses and trying to have a meaningful quality of life. Achieving this type of equilibrium requires ongoing professional support in the form of counseling and multi-disciplinary

programs which facilitate the recovery process. The core values of the program relate to personal wellness and the fight against the stigma of mental illness.

Subject population:

The subject population for this study are Jewish seniors who have been diagnosed with mental illness, live in the community and are a part of a Community Mental Health Program in a community Centre for seniors. Members of this program must be at least fifty years of age, live independently or in foster homes, and be capable of participating in courses and activities in the Centre. In my experience as a social worker with the Mental Health Program, I had several questions about attitudes and self-image of seniors with mental health issues (e.g. depression, anxiety, and bipolar disorder). In particular, I was struck by the way that social stereotypes can impact the professional practices and interactions with the 'mentally ill' as well as the way these seniors see themselves. As one of the key English language community-based programs that address mental health for older people, I felt that selecting a sample from this community centre would allow me to investigate and answer my research question. Interviewing seniors diagnosed with mental illness but who are not my clients and do not associate me with service delivery, enhanced my ability to research and understand their views, opinions and life experiences. It provided the closeness that a researcher hopes to gain in qualitative research and also provided a good entry point in terms of familiarity and trust that seniors felt toward me.

Sample:

The Mental Health Program consists of forty clients. In this program, I work with half of the clients, and another worker is assigned the primary responsibility for the other

half (i.e., 20 seniors). All of the seniors in this program have been diagnosed by a psychiatrist as suffering from mental illness. Mental illnesses of the members include depression, schizophrenia, bipolar disorder, and anxiety disorder. The seniors are community-residing, independent and competent people who manage to live with their illnesses and cope with them to the best of their abilities. They are followed by a psychiatrist and are compliant with their medications. Each senior has a case manager who is a social worker at the Centre. After building a rapport, the client and the social worker decide on an intervention plan tailored to his/her needs. This can include registration for courses, participation in social groups, obtaining services such as home care, meals, or attending ongoing meetings for support and follow up. The intervention plan is dynamic and flexible and can be re-negotiated. In order to avoid potential coercion, the seniors who participated in this research study were not my clients and do not associate me with their cases or service delivery.

Specific sample:

Purposeful sampling was employed in order to choose my specific sample (Please refer to Table One for the details of the sample). Within purposeful sampling, a maximum variation sampling was used as a way to capture and describe the central themes that cut across the participants of the Mental Health Program. By using this sample strategy, I was able to study a small sample of ten seniors with heterogeneous psychiatric diagnoses. This method of qualitative inquiry holds that common patterns emerging from within variations can be of particular interest in capturing core experiences and shared impacts (Patton, 1990).

Since the focus of this thesis was to explore the influence of stigma experiences on the self-image of older adults, I approached eleven English-speaking seniors who were members of the Mental Health Program. Out of eleven seniors asked to participate in the study, ten agreed. One senior declined and expressed concerns that my questions could trigger undesired memories regarding her past life experiences. The inclusion criteria were: age (i.e., 50 plus), being a member of a Mental Health Program in a community centre and diagnosed with mental illness. The official diagnosis of those interviewed included persons with bipolar disorder, depression, schizophrenia, and anxiety disorder. Out of the ten seniors interviewed, eight were women and two were men and had a range of ages from fifty eight to eighty seven. Six of the respondents were divorced, two were single and two were widows. Since all the seniors in this program are Jewish, ethnicity served as a homogeneous factor for this sample.

Recruitment:

Each of the seniors was initially contacted by telephone. I introduced myself and explained my role as a graduate student at McGill University. I explained my reason for calling and the subject of my research. Most of the seniors were familiar with me and knew that I worked as a social worker at the Centre. This familiarity contributed to a feeling of openness in the conversations and enabled the seniors to comfortably ask questions regarding the study. The issue of confidentiality was discussed at length and the process of audio-taping and transcribing for the purposes of transcription was explained.

Sample Description

The following short segments individually introduce each participant of the study by drawing on the key life experiences and statements of each. (Note that the names have been changed to ensure confidentiality). Following this, Table One provides a table view of the 10 participants for comparison purposes.

1. Bella: “They call me a rapid cyclor”

Bella is sixty one years old. She is well groomed, presents herself in a very articulate manner and is very social. She was born in Canada and has three sons, aged thirty one, thirty three and thirty five, all of whom live in Montreal. Bella worked as a teacher until she became ill and was diagnosed with bipolar disorder twenty five years ago. When her mental health state became evident, she was asked to take a leave of absence and eventually left her position as a teacher. She opened a computer store with a partner where she applied her skills and taught computer courses. Bella separated from her husband nine years ago after being married for twenty five years. When she felt that she could no longer work, she applied for Welfare benefits and has been receiving them ever since. She is currently in a relationship and lives with her boyfriend.

Bella is diagnosed with bipolar disorder. When asked about her diagnosis, she replied, “They call me a rapid cyclor”. Bella experiences manic episodes which can last a few weeks. These episodes are usually followed by a major depression that prevents her from getting out of bed. She is hospitalized several times a year in order to have her medications adjusted. When she feels up to it, Bella participates in art courses and in a social group at the community centre for seniors and sees a social worker there on a regular basis.

2. Elaine: “You are not sick. Get over it.”

Elaine is fifty nine years old. She was born in Canada. She is very creative and spiritual. “I consider myself a very social person but also an introvert”. She has been divorced for many years and has three grown children who live in Montreal and has one granddaughter. A year ago, Elaine decided to pursue an old dream: she went back to school and became a full time student. She lives on her savings and on student loans.

Elaine was diagnosed with bipolar disorder four years ago and was hospitalized for several months. In the midst of her depression, Elaine sold her house and moved to a rental apartment—she later regretted this decision. Elaine is struggling to maintain a close relationship with her children. When asked to describe her family’s reaction toward her

illness, Elaine was surprised to hear from her daughter that, “You are not sick. Get over it”. She sees her psychiatrist and social worker on a regular basis.

3. Mindy: “I am better off than my mother”

Mindy is sixty one years old. She was born in Canada, is divorced, and lives in a rented apartment with a roommate. She receives Welfare and works a few times a week in a community organization. She volunteers in the Jewish community and is an advocate for people who receive Welfare. Recently, Mindy recovered from breast cancer. She also suffers from epilepsy.

Mindy was hospitalized when she was fifteen years old and was diagnosed with schizophrenia. Mindy’s mother left her when she was fourteen years old at which point she went to live with her grandparents. Shortly after this event, she was hospitalized. Her relationship with her mother to this day is shadowed by the mother’s decision to leave; she is still struggling to maintain a relationship with her mother and expresses ambivalent feeling towards her. Mindy describes herself as a fighter and a survivor and expresses herself through poetry. As a child, her mother used to refer to her as ‘retarded’, and predicted that she will turn out to be, “Just like her father—No damned good!”

4. Ruth: “I do the best I can”

Ruth is eighty years old. She was born in Russia and came to Canada in 1939 as a young girl. She was born with congenital dislocation that caused her to be physically disabled. Since her husband died four years ago, she has been living in a low rent building for Jewish seniors. Ruth has one daughter who lives in Vancouver. She supports her daughter financially because her daughter is married to a man who has a gambling problem. Ruth worries about her daughter and the financial burden of supporting her add to her feelings of anxiety, since she herself is living on a low income. However, she stated that, “I do the best I can”.

Ruth was diagnosed with clinical depression from an early age. She sees a psychiatrist on a regular basis. She also suffers from mobility problems and from carpal tunnel syndrome. Her health problems cause her severe chronic pain and sometime prevent her from going out. When asked about her life, Ruth replied, “I have to be strong for my daughter”. When she feels physically up to it, Ruth participates in courses & social activities in a community center for seniors and sees a social worker every week.

5. Rona: “Depression gets in the way”

Rona is sixty three years old. She was born in Canada and has three sisters who live out of town. Rona is single and lives alone. She worked for a few years in a bank and describes this period in her life as very productive and positive. Since she was released from this job, she has not been able to hold any job for a significant amount of time. She lives on her savings and is constantly worried about her financial situation.

Rona was diagnosed with clinical depression when she was in university. Since then, she sees a psychiatrist on a regular basis in order to obtain her medications. She says, "I have been unhappy since the age of ten". Rona stays home most of the time. Several times she has attempted to join activities and social groups, but found that she was unable to attend on a regular basis. Rona struggles to find additional sources of income, and is currently searching for a computer teaching position. She worries that "depression will get in the way and defeat me".

6. Carole: "I'm very strong minded"

Carole is seventy nine years old. She was born in Romania where she went through the Holocaust. She arrived in Canada with her husband in 1950. She has three daughters who live in Montreal. She has been divorced for twenty five years, and describes this decision as, "the best decision [she] ever made". Carole lives alone with her cat in a small apartment. She relies on Old Age Pension and her income is very limited.

Carole was diagnosed with clinical depression many years ago. She is regularly followed by a psychiatrist and is on medication. She is also seeing a social worker. Carole also suffers from fibromyalgia, a disorder that causes chronic pain and limited mobility. As a result of this, Carole finds it hard to participate in social activities. "Sometimes I get so exhausted that I can't talk to anybody or do anything".

7. Hilda: "I want to cry but I smile"

Hilda is eighty seven years old. She was born in Romania and moved to Canada after surviving the Holocaust and spending one year in Israel. She was married for forty eight years and does not have any children. Hilda's husband passed away nine years ago. She described her husband as a very jealous and possessive man and her marriage as a constant struggle to please him. She moved to a seniors' residence three years ago but does not feel that this is her home. She says, "I didn't like it here from the first moment". Since her move, she has undergone both heart surgery and hip replacement surgery.

Hilda was diagnosed with clinical depression many years ago and is seeing a social worker and a psychiatrist. She has not disclosed this information to anyone in the residence since, as she says, "it is not anybody's business". Hilda does not take part in social activities in her residence and does not have friends there. She participates in activities in a Jewish community centre when her health permits it.

8. Miriam: "I'm coping with things"

Miriam is sixty four years old. She was born in Canada. She is single and lives alone in a seniors' residence. Miriam worked as a secretary and lived with her parents most of her life. She took care of her mother who suffered from lung cancer and moved to a residence only after both her parents passed away. She went through a period of adjustment in her new apartment since she is the youngest resident and is surrounded by elderly people with different mobility and health conditions. "I'm learning to more or less live with, well,

live with people, in the residence, that ninety percent of them have Alzheimer's and... I'm coping with things".

Miriam was diagnosed with anxiety disorder after her mother passed away. She experienced several panic attacks which began when her mother became sick. In addition, she is struggling with different health issues: Crohn's disease, arthritis and osteoporosis. Miriam participates in social activities and courses in a community center for seniors. She sees a social worker on a regular basis and perceives the activities and meetings with her social worker as an important way to structure her week and reduce feelings of anxiety and isolation.

9. George: "I don't want people to see me this way"

George is sixty one years old. He was born in Canada. He has been divorced for twenty five years and has one son who lives in the United States. George worked as an accountant for a large company but left his position fifteen years ago due to problems with his mental health. He then proceeded to work as an independent accountant. For the past four years George lives in a supervised apartment and receives Welfare.

When George was a teenager, he was diagnosed with severe anxiety disorder and clinical depression. He has struggled with his illness for many years and was hospitalized for long periods of time. He does not participate in social activities and stays in his apartment most of the week. "I don't want people to see me this way". He is very isolated and expresses feelings of despair towards the future. He says, "I'm existing. I'm not living." His psychiatrist stopped seeing him because according to George "there is nothing he can do for me". His medications are monitored by his pharmacist. Recently George has requested to change his psychiatrist and is waiting for the hospital's response. He sees a social worker every two weeks.

10. Shimon: "I am not my illness"

Shimon is fifty eight years old. He was born in Morocco and moved to Canada as a young child. He is divorced and has four children. He holds a Master's degree in biology and worked in research for several years. He then worked as a sales person for a large company. He stopped working ten years ago due to his illness and is receiving Welfare. Since his divorce, Shimon lives alone in a small apartment. He volunteers in a community center for seniors and plays music for seniors who suffer from Dementia. He sees a social worker and a psychiatrist on a regular basis.

Shimon experienced his first manic episode when he was twenty five years old and was diagnosed with bipolar disorder at thirty one. He was hospitalized many times throughout his life and each time his medications were adjusted. Shimon has published two books about his mental illness. He advocates for people with mental illness in different community organizations and feels strongly about demystifying stigma and stereotypes associated with mental illness.

Table one: Sample description

Name	Age	Gender	Family Status	Place of Birth	Income	Diagnosis
Elaine	58	F	Divorced	Canada	Savings	Bipolar
Bella	61	F	Divorced	Canada	Welfare	Bipolar
Mindy	61	F	Divorced	Canada	Welfare	Schizophrenia
Rona	63	F	Single	Canada	Savings	Depression
Miriam	64	F	Single	Canada	Savings	Anxiety
Ruth	80	F	Widowed	Romania	Pension	Depression
Hilda	87	F	Widowed	Romania	Pension	Depression
Carole	79	F	Divorced	Russia	Pension	Depression
Shimon	58	M	Divorced	Morocco	Welfare	Bipolar
George	64	M	Divorced	Canada	Welfare	Anxiety & Depression

Data collection:

Face to face interviews comprised the strategy of data collection. Interviews were conducted in the senior's home or at the community center, according to the preference expressed by the interviewee. Each senior was interviewed once. As previously mentioned each respondent was informed that he/she would be able to stop the interview, chose not to answer a question that makes him/her uncomfortable or ask to erase part or his/her entire recorded interview. Confidentiality was ensured and a consent form was read by the respondent, discussed and signed by each of participant before the beginning of the interview (see appendix D for a copy of the informed consent form). The interview guide provided a general map for the interviews. Questions were asked according to the natural flow of the interview with the duration of each interview varying and determined by each

senior. Some interviews lasted an hour while others lasted between thirty to forty minutes. I respected the wishes of my respondents to pause, rest and terminate the interview when they felt it was time. Each interview was recorded verbatim and transcribed for analytic purposes.

Data analysis:

The first stage of the analysis began by getting a sense of the person and his story. This analysis resulted in longer versions of the stories used to present each of the ten participants. After this initial analysis, interviews were analyzed according to themes which emerged from each of the interviews, using key words and concepts. This analysis is best described as working within each of the narratives or within-case analysis (i.e., not yet looking for the relationship with other interviews). During the later process, which is known as open coding, the data from each interview was identified and grouped into categories. These categories comprised the preliminary framework for analysis (Strauss & Corbin, 1990).

After the data was grouped into categories, it was re-examined, linked and compared to data from other interviews in order to obtain a better understanding of the full picture. Here, the analysis is more of a thematic analysis focus running across interviews. Throughout this process the data was revisited and regrouped. An audit trail was devised in order to be able to track the different speakers and sources of data (Strauss & Corbin, 1990). A decision was made as to which themes were to be included in the final report and which concepts were not relevant to the immediate focus of this study. My supervisor was involved at all stages of the analysis and read my stages of analysis to help guarantee the

validity of my interpretations. In the final stage, themes from the ten interviews were brought together to form a clear and informative account on the lives of older adults who live with mental illness.

Organization of findings

The findings of this study are organized into several categories which represent a common phenomenon expressed by the respondents. Three major themes were identified. They include: (1) illness, (2) stigma and (3) self-image. Within these major themes, subcategories were identified and explored. Within the first theme of 'Illness', the different aspects of becoming, negotiating, and managing illness are identified and discussed. Mental and physical illnesses are explored within the context of age, psychiatric diagnosis and life circumstances. The second theme of 'Stigma' explores the ways seniors see the concept of stigma as related to their mental illness, the ways they see the image of mental illness in society, and the ways they choose to communicate their illness to others. Theme three, 'Self-image', explores the ways seniors see themselves and their lived experiences. Self-image is explored in light of their perceptions of themselves, their age, and their health conditions.

Ensuring trustworthiness

This study integrated several procedures in order to ensure trustworthiness. My familiarity with the respondents and prolonged engagement served to increase credibility of the study. "In order to be able to fully understand the research subject's world, the researcher is expected to connect with the person or group that he is studying, to use this closeness as a way that involves the researcher in prolonged immersion in a life of a group,

community, or organization in order to discern people's habits and thoughts" (Punch, 1998, p. 258). My familiarity as a social worker in a community center for seniors helped me to secure access to this otherwise, difficult to reach population. By using familiarity, I was able to ensure positive rapport with the participants. Furthermore, my familiarity with the respondents and with the challenges they face also increased my theoretical sensitivity which derived from professional literature, and personal and professional experiences (Patton, 1990). By interviewing seniors who were known to me, but not my clients, I was able to decrease coercion and increase trustworthiness.

Transferability was addressed by creating an audit trail. A system was developed to identify different sources of data. The research design, process and analysis were recorded so that others who read this study will be able to have enough information to judge and draw conclusions about the findings (Rubin & Babbie, 2005).

I was aware of the potential for bias throughout the design and implementation of the study. By using critical reflections, I examined my own assumptions and stereotypes regarding mental illness and old age and attempted to use these reflections when writing my final report. "Investigators seek ways of demonstrating to their audiences their historical and geographical situations, their personal investments in the research, various biases they bring to the work, their surprises and un-doings in the process" (Gergen & Gergen, 2000, p.274). This process increased my consciousness of my role as a researcher while conducting the interviews. I was aware of the effects of my presence as a researcher during the interviews and acknowledged the possibility of reactivity. By recognizing that I

could not eliminate reactivity, I chose to be cognizant of it. As a result I was also able to position myself within the process of analysis and interpretation.

Chapter 4:

Findings

The key themes that emerged from this study illuminate the subjective life experiences of ten seniors who are living with a diagnosed mental illness. Their opinions regarding their illness, self-image, stigma experiences and age, provide the opportunity to better understand the challenges they face and the individual ways by which they chose to make meaning of their lives. Although divided into separate themes for the purpose of presentation in this thesis, the experiences of the ten participants intertwine and interact in the everyday lives of the respondents.

THEME ONE: ILLNESS

The theme of 'Illness' emerged in each of the ten interviews, suggesting that dealing with an illness is a challenging task for these respondents. This multilayered concept entails different aspects of becoming, negotiating, and managing illness. In these accounts, the concept of illness is given a personal meaning, and is interpreted differently by each of the seniors. In the course of identifying themes it became apparent that many of the seniors associated mental illness with a psychiatric diagnosis, and that senior's reactions to their diagnosis varied from acceptance to the rejection of their illness. Furthermore, physical pain emerged as an important factor by many of the seniors who suffer from co-morbid health conditions, creating a complicated picture of struggle and resilience.

Becoming ill. Accounts on becoming ill and dealing with the challenges of a mental illness emerged from many of the interviews. Becoming ill was seen as a significant

experience and discussed in detail throughout the interviews. In many cases, the participants could identify the exact year and circumstances regarding their first experience with mental illness. Consider the following illustrations where two of the respondents recalled their first experiences of mental illness:

“Well the first time I got ill was after the birth of my eldest son. That was post partum depression but in those days they didn’t know what it was. So I was ill with him until I became pregnant with my second son, that was 9 months later, they were born very close to each other. And as far as teaching goes, I became ill in 1986, and I was sick on and off for the whole year.” (Bella)

“I was hurting from the inside. You know, your mother is going away, walking out on you, and I’m like “please mommy, take me with you, take me with you” and you beg and plead with her .And she said oh no, no, no, you have to stay here and get an education... And it’s like; Bubby, when am I going to live with mommy? So between 14 and 15 that’s when the break down happened. And then I was hospitalized.” (Mindy)

While for some the onset of the illness was clearly marked by one event, others respondents described ongoing feelings of unhappiness throughout their lives without being able to identify the cause of their despair. Consider the following illustrations where two of the participants describe their struggle to understand what they were going through:

“When I was in high school, I used to cry myself to sleep every night. I asked my mother-surely there is somebody I can speak to, a rabbi, a minister, I didn’t know anything about therapists, and in those days they didn’t have many therapists. It was a terrible thing”. (Rona)

“I was diagnosed when I was 31. I had my first episode when I was 25....I was diagnosed 7 years later. And then at that time I was depressed for a long time. My ex wife and I knew there was something wrong but we did not know what”. (Shimon)

In these cases, being diagnosed with a mental illness was seen as a way to understand ongoing feelings of despair.

Making meaning – Dealing with a psychiatric diagnosis. Making meaning of the illness emerged as an ongoing, personal negotiation with one's concept of self, which involved coping strategies, external validations from professionals and support from family members. One of the key moments in the process of "making meaning" of mental illness, was receiving and struggling to accept the psychiatric diagnosis.

According to research, receiving a formal diagnosis brings with it a professional recognition of the existence of an illness as well a variety of labels and stigma (Hayward & Bright, 1997). Professional recognition usually entails a treatment plan, which can include a combination of medications and psychotherapy. It also gives a uniformed definition to medical and psychiatric terms (Karis & Wandrei, 1996). Consider the following illustrations, where receiving a formal diagnosis is seen as a way to increase the understanding of the respondents' mental state:

"I have been unhappy since the age of ten. I didn't have a label for it until I was in university and I thought I had to speak with somebody." (Rona)

"It (The diagnosis) helped me to understand the illness better. The mechanisms of the cells...that kind of thing." (Shimon)

In many cases, psychiatric terminology was used to describe and make sense of what they were going through. This terminology seemed to provide a sense of understanding of the course of the illness, thus enhancing the respondents' abilities to control their realities.

"I was suffering from manic depression at the time, that's what they called it. The last three years I've been hospitalized four or

five times. They call me rapid cyler which means that I'll go in and out of them very quickly". (Bella)

"I've been well for a year now. I'm 57. I had a two year episode and a one year episode of.... ahh depression. That's what it was. And I had only been diagnosed with bipolar syndrome about a year and a half ago". (Elaine)

Negotiating labels. While in some cases having a formal diagnosis was accepted, others negotiated the illness and reframed the labels. Although for some, receiving a formal diagnosis for their illness helped understand what they were going through and increased their sense of control over their life, for others, having to live with a psychiatric diagnosis was hard to accept. A formal diagnosis also entails a variety of labels attached to it; having a diagnosis brings personal relevance to other people's attitudes and beliefs about mental illness. In some cases, accepting the diagnosis, could mean that these beliefs become applicable to one's self (Link et al.,1989). Consider this quote, where one of the respondents felt that she could not relate to her formal diagnosis, suggesting that for her, the word schizophrenia was detached from her identity. When asked about her diagnosis (i.e., What does your diagnosis mean to you?) she indicated that she will have to look it up in the dictionary:

" Well, I grew up with it, so...what do I think it is? This big word. You mean schizophrenia? I would have to look it up in the dictionary. I know it's a mental illness. You know, it has to do with the inside of your brain. How it functions." (Mindy)

When asked the same question, another respondent echoed feelings of rejection towards her psychiatric diagnosis. Consider this quote which illustrates this respondent's feelings:

"I can't really accept it (the diagnosis). I know, I read and I heard about it and maybe it is with other people but I can't accept it in

me because I am a perfectionist and need to be able to just get up and go.” (Rona)

As illustrated by these quotes, some of the respondents seem to consider the rejection of their psychiatric diagnosis as a way to resist their reality and renegotiate their sense of self.

Managing the illness. Being able to manage the illness was brought up by majority of the respondents. In particular, participants discussed the expectation of being able to control mood shifts and depression after years of suffering. As illustrated by the following quotes, the struggle to control and manage the illness is described as challenging and ongoing:

”I am afflicted with bipolar disease, disorder, I learned after many years to control it, not really control it but to manage it most of the time, like 99% of the time, but it is the road back that is difficult, like coming back from an episode, from depression, irritability, hypo mania.” (Shimon)

” With as many times as I’ve been depressed, you would think that by now I could’ve worked that through knowing that my low self-esteem comes with the depression. Never happened yet that I have been able to straighten that out. (Bella)

In some cases, the expectation to be able to manage the illness yourself, created a barrier to admitting and receiving help:

”I haven’t even gotten treatment for a year and a half. I was struggling to get out of it myself....I thought I could get out of it and I had the same attitude that I could get out of it myself with effort. That’s misleading eh?” (Elaine)

”My feeling is that I had depression all my life and that it became worse and worse and it is always a head of the medication and the treatment. I think I got a lot of help from talking therapy and from the medication but it never quite caught up. I always felt at least slightly depressed. I never felt that the depression was gone. And then I had to increase the medication.” (Rona)

Coping strategies. In order to manage and cope with the illness, the respondents reported using various coping strategies to overcome periods of depression. These ranged

from educating one's self about the illness to receiving family and professional support. Taking steps to manage and control symptoms have been described in the literature as an important way to increase the sense of control over the illness and to enhance healing and empowerment (Jacobson & Greenley, 2001). For some, educating themselves about the illness provided a sense of control over their life. Consider the following quote where one of the respondents described what helped her to cope with her illness:

"...It made me feel very depressed. I was crying a lot, I was very depressed. I took some courses a long time ago at McGill University...I took a course in psychology when I was young....because you know, I didn't have a father to talk to, my mother was working, so I had nobody. And the course gave me knowledge with a good professional. I wish I could go to more lectures now." (Ruth)

For another respondent, being with other people who also suffer from a mental illness and receiving help from professionals assisted her to receive the support she needed:

"You need a lot of energy to communicate with people. Small doses, one on one is better. Support groups where everyone is mentally ill that helps. Like in the Day Hospital". (Elaine)

For others, family was seen as an important source for support. Consider this quote where one of the seniors describes the importance of family support especially while a person is in the midst of a depression:

"Well depression doesn't happen just like that. The hospital has a history of the illness and people need to do follow up. I know that sometimes even making an appointment could be very hard. Somebody needs to support the person and do it for him. A sister, or a mother or a family member. This support is even more important than the medications, or from support from a doctor or a nurse." (Shimon)

Another respondent echoed the need for family support, in this case her partner, who took care of her when she had depressive episodes:

"I like to have my privacy. And especially when I'm depressed, I like to be alone, I like to sleep and I don't want anybody telling me what to do. Even in the hospital this time I slept away the morning, I didn't even go to occupational therapy and I don't want to go to a group home where they tell you what to do. I like to be by myself and having a live-in boyfriend was terrific because he did all the cooking and I didn't have to worry about that and all the shopping. So what do I need a group home for? I don't need the support, I don't need the moral support and I can be in my own space, I like that." (Bella)

When Mental and Physical interact. When asked to describe their health condition (i.e., Tell me about your health condition) four of the seniors focused on their physical health rather than their mental health. This phenomenon was apparent especially in cases where seniors were older (i.e., in their seventies and eighties) or suffered from co-morbid health conditions (i.e., physical ailments as well as a mental illness). This phenomenon is supported by the literature. According to research, many seniors tend to focus on their physical symptoms rather than their mental health symptoms in order to normalize their feelings of depression and anxiety (Preville et al., 2004; Sivilis et al., 2005). Consider the following ways the participants described their health conditions:

"At the age of 21 I was diagnosed with Crohn's disease which more or less turned my life and my health upside-down in the fact that my, I had no, I had a very weak immune system and hence I developed arthritis, osteoporosis, and many other life-threatening diseases which are now under control". (Miriam)

"Right now my health condition I hope should be better, I've been for an MRI and I have a lot of trouble with my lower back.....I have fibromyalgia, which is ...sometimes I get so exhausted that I can't talk to anybody I can't do anything..." (Carole)

“My health, I had a heart operation...not heart, my heart is okay but I had a valve, a valve which didn't work. And I fell on the street ... I lost my balance and broke my hip, last year in the 2nd of November.” (Hilda)

In these cases, physical pain was mentioned as a barrier for being able to function and retain positive mental health. In some cases, physical pain over shadowed other ailments such as depression and anxiety and was seen as overwhelming physically and mentally. Yet the seniors seemed to have different ways of coping with these ailments. Where Hilda has a strategy of coping with the pain *“It hurts like hell but I walk, thank God. That's how he should take me if he takes me”*, Ruth and Carole describe how pain prevents them from being mobile and active as they would want to be:

“I want to do things with my life. I don't want to be a handicap. I want to be healthy. But now the pain is all over my body and it's just too much.” (Ruth)

....” I think my mental health is o.k. it's just the pain that I am having a lot. It makes me feel anxious sometimes, not depressed but worried, because when I don't feel good I get really fed up with it ...with the pain”.... (Carole)

THEME TWO: STIGMA

The stigma attached to mental illness was experienced by the majority of the respondents at different levels and manifested itself in a variety of ways. Some of the seniors felt they could not disclose their mental health condition to others because they would be seen and treated differently. Some of the seniors however, felt the need to educate and communicate their illness to others, as a way to cope with their situation. In these accounts, stigma was explored on a continuum from subtle to blunt comments

regarding a person's mental health condition. Within the theme of 'stigma', the image of mental illness was explored, as well as accounts on 'living a secret' and different ways that seniors chose to communicate their illness to others.

The image of mental illness. In each of the interviews, seniors discussed the negative image of mental illness among the general population. This negative notion of mental illness is supported by research. Studies that compared social conceptions on mental illness among the general population and psychiatric patients found that both psychiatric patients and members of the general public believed that mentally ill people suffer from a negative image and are rejected by most people (Garf et al., 2004; Link et al., 1989). The following quotes illustrate the image of a mentally ill person as described by two of the seniors.

... "I think that people think that mentally ill people are violent, the fact that they are taking a lot of days off because they are sick, ah....that they are aggressive and nobody wants to hire them. They are also seen as dangerous, worthless, not reliable not predictable, that it." (Shimon)

"People also think that they are stupid which is the biggest misconception because a lot of people that I met at the day hospital are almost at a genius level." (Elaine)

Senior's described people's reactions to their mental illness as frustrating. Common reactions reported by the respondents were misunderstanding of their condition which resulted in anger and frustration expressed by family members, professionals and friends. The following quotes illustrate the reactions reported by two seniors regarding their illness:

"Well the standard reaction is like Nancy Reagan's; just do it, just get up and act! Stop whining about your problems and get up and do things. I had people just stare at me or get angry at me and I feel like it's hopeless". (Rona)

"The social worker was... angry with me, she showed anger. Her and my kids. They were suggesting that I am stronger than this, maybe you're looking for attention or something. I've got the phrase not from my family but from some one: snap out of it. I couldn't believe that I got that phrase". (Elaine)

When asked about the public's reaction to mental illness (i.e., How do you explain the image of mental illness in the general public?) one of the respondents replied:

"They are afraid that it's contagious. Nobody wants to be around a negative person. They are struggling to get well and people are treating them like they were monsters or something ". (Elaine)

Some of the seniors interviewed however, noticed a positive shift in the way the public relates to mental illness as compared to the past. They also acknowledged that people need to be approached in a certain way, negotiating and reframing terms and labels in order to receive a positive reaction. Consider this quote where one of the respondents, who used to hide her illness, describes the reaction that she is getting from people when she talks about her illness:

"People accept it more than they used to, you know, if you say manic depressive, most people don't know what this bipolar is but if you say "I'm manic depressive" it's just a matter of fact, it's not a big deal, like they've heard of it before". (Bella)

Comparing mental illness to physical illness. Many seniors expressed that making a comparison between mental illness and physical illness was a way to 'normalize' mental illness and improve its image. The respondents felt that a physical illness is more accepted and that mental illness would be better accepted if it would be described in physical terms. This finding concurs somewhat with the literature that reports an ongoing attempt by

psychiatrists to claim that there is no fundamental difference between mental illness and physical illness. Physical illnesses are reported to have a better image and usually receive empathy from the public. This attempt however, is not yet accepted and/or adopted by the general public (Kendell, 2004). Consider the following quotes which illustrate the differences between treatments based on physical illness as opposed to a mental illness:

"If you would be working in a hospital with people with physical issues you wouldn't think less of me. There is something in an article that I read where the person said people have more sympathy to a person that is handicapped. Even aids or cancer". (Rona)

"Mental illness is so hard to grasp because you can't see it or touch it. But if you say that it is brain structure then people will understand that " (Elaine)

For some seniors, comparing their illness to a physical illness served as a way to mitigate stigma as shown in this quote where one of the seniors was asked if he experienced stigma related to mental illness:

"Well...it was in a strange way because it was not in a negative way for say. But what happened to me is that I had people pity me, and that...I am a very proud man and I could never accept that people felt this way because my mental illness. Cause there is nothing wrong, basically, as far as I am concerned. It's like any other illness like diabetes". (Shimon)

Another senior supported this notion and also acknowledged that physical illness is more accepted than a mental illness. He felt that having a mental illness is embarrassing and causes people to pity you:

" Because physical illnesses are accepted by society in general and mental illness is still an embarrassing thing to have. I can understand where it's coming from and a.....if somebody told me that they had a mental illness I would feel very sorry for them. I don't want anybody feeling sorry for me". (George)

As expressed in these accounts, the majority of the respondents preferred to compare mental illness to physical illness as a way to mitigate feelings of shame and embarrassment attached to mental illness and to enhance their feelings of acceptance by society. It is also possible that there is a gendered response—as the two above cases that refer to pity are both from the male respondents. This however, requires further investigation.

Living a secret. Seniors in this study recounted how they would keep their mental illness from others. Five of the seniors (i.e., George, Hilda, Rona, Carole & Ruth) saw their illness as a private matter, which could only be discussed with specific people, mostly family members and professionals. The reluctance to share their mental health condition with friends and neighbors was explained in light of the negative image that mental illness has in the general public and the fear of being judged and discriminated against. This phenomenon is supported by the literature. According to research, people who feel their illness is stigmatizing, may choose to conceal their treatment history from relatives, employers and friends to avoid rejection (Goffman, 1963; Link et al. 1989). This phenomenon was prominent especially in cases where seniors became sick many years ago, when mental illness was not something you talked about. Consider the following explanation:

” Because it is something that is just not talked about. When I got sick as a child this was not something that people talked about. This was in the 1960’s and people did not talk about mental illness. And I carried that through with me for the rest of my life”.
(George)

For others however, the reluctance to reveal their mental illness derived from the fear of discrimination. The following account highlights how one of the respondents felt she had to hide her illness from her supervisor for fear of being fired:

“I was hiding, I was hiding from it. I told everyone that I had a thyroid condition. Because in those days there was a big stigma attached to having manic depression and, you’re crazy and, you know, that was a big terminology in those days. So people didn’t reveal as readily as they do today that there’s something wrong with them. So as far as the school knew, I went to see the doctor...he was looking after my mother, and I said to him ,I’d appreciate it if you wouldn’t tell the school about my illness because I thought that I’d be fired or whatever right away “. (Bella)

This strategy of concealing the illness was also reported by two of the seniors (i.e., Hilda & George) whose hiding their illness resulted in having to live a secret identity. Consider this quote where Hilda, who lives in a senior residence, described how she hides her depression from the other seniors:

“When it comes I want to cry but I smile because I don’t want other people to know exactly. That’s my secret ...that I’m depressed. I don’t want anybody to treat me like a crazy person”. (Hilda)

Another senior expressed the need to hide his illness because of the fear of being seen in a negative way:

“I’m just embarrassed. I can’t think of a reason off hand but I’m just embarrassed about it. It makes me feel like a very weak, sick person. and I don’t want people to see me this way“. (George)

In these cases however, concealing their illness from others, resulted in limited social interactions and increased sense of isolation. The illness was discussed only with professionals or familiar people who knew and accepted the illness.

Communicating the illness. The theme of communicating the illness emerged from all of the interviews. Seniors expressed ambivalent feelings regarding the way they would choose to talk about their illness and the people they would confide in. In light of the negative image associated with mental illness and the fear of being judged, many of the respondents felt that communicating their illness to others was challenging. For some, explaining what they were going through, especially during episodes of depression, proved to be a daunting task. However, the desire to be understood and accepted by family members, professionals and friends, contributed to the attempt to explain and communicate their illness to others despite the difficulty. Consider the following illustrations where the respondents describe their difficulties to communicate their illness to others:

" There is a metaphor that describes how I felt: you feel like you are behind glass and you are watching everybody interact but you can't touch them or communicate with them because you ... don't feel anything". (Elaine)

"It's trying to explain why you can't do something. I remember once asking a cousin of mine to build together a sewing machine. He looked at the directions and he said: see, here is the diagram; this is how you do it. He was very pleased with himself. And it took me a long time to realize that what I really wanted to say is: No, I can't do it myself. Please do it for me. I don't know if he would have understood this because he was a person who never had this kind of dysfunction and I don't know if he ran into people with that kind of dysfunction". (Rona)

Ambivalent feelings were communicated by all of the seniors when speaking of their illness to unfamiliar people. When talking to professionals (i.e. doctors and social

workers) all of the seniors reported an increased sense of comfort. This phenomenon is called by Goffman (1963) talking to the wise, that is, people who know and accept your illness. However, by only speaking with the wise, people are protecting themselves from rejection but, as a result, limit their social environment (Goffman, 1963). For example, when asked if he discusses his illness with other people, one of the respondents replied: *"Depends who it is. If it's a professional I don't have any problems with it. But the average person I don't discuss it with".* (George) Another respondent expressed this concern in our interview, she says:

"I don't tell people that I'm depressed but I feel I could tell you because you are a professional so you probably wouldn't judge me. But I don't know. I still think that you could think less of me."
(Rona)

Communicating the illness to others was seen both as important and challenging. Out of the ten, six respondents (i.e., Bella, Shimon, Miriam, Mindy & Elaine) expressed a need to be open about their illness, but acknowledged the challenges and difficulties that this entailed. Communicating their illness was seen as an important step in their own journey of recovery and acceptance of their illness. In some cases, communicating their illness served as a tool to normalize and mitigate stigma. The following quote highlights why and how Shimon attempts to address misconceptions about mental illness:

"I do it purposely because my nature is to be open and ah..... I want to demystify the stereotypes, in other words...if someone asks me, oh, how are you today? I say great! And then I say that I am just recovering from an episode and then I start explaining what mental illness is all about. So it is an educating process that I go through every single day." (Shimon)

This attempt to educate others is known in the literature as "preventive telling"- hoping to enlighten others and prevent negative attitudes (Link et al., 1989 p.403).

Communicating the illness to others was also seen as way to preserve the senior's mental health. For these respondents, revealing their mental illness provided a sense of relief. Not having to live 'the secret' was reported to be both a challenging and liberating experience—all at the same time. Consider the following quote where one of the respondents describes why she thinks it is important to talk openly about her illness with other people:

"People have a bad habit. I'm talking about stigma. You have to face what you have. Face it right in the face. Eye to eye, like I've done. And then people realize that there is more to the person who is ill or have problems. Talk about your problems. If you don't, it will bottle inside. I guarantee it. You will end up in the hospital. (Mindy)

Other seniors described their personal experiences when faced with the decision to talk openly about their illness. In these cases, the reaction from others was more positive than expected, resulting in a feeling of relief. Consider this account, where one of the seniors who decided to go back to school, describes how she felt when she talked about her illness with her professor for the first time:

"Well, I had to tell one of my professors that I have bipolar because I really have been struggling with the assignments and he was extremely understanding. I was self conscious, and felt like, I didn't want a special treatment. I just wanted him to understand why I couldn't, why I was late with some assignment. He was understanding. He had dyslexia and at the end of the course he told me that four people including me had some sort of disorder in that class." (Elaine)

In another case, coming out and talking about the illness was seen as a relief and as an empowering experience. When asked how she felt after she told her students about her illness, one of the respondents who worked as a teacher replied:

“After that I never hid it. Once it was out in the open I never hid it after that. One of my students, from that class, turned out to be a psychiatrist in New York and I told him it was me who gave him the incentive to do it [laughing]. He was so curious about my illness that he decided to go into that field. Yeah. So... and I had a few psychologists in that class too and they turned out to be psychologists so I tease them whenever I see them”. (Bella)

THEME THREE: SELF IMAGE

The theme of ‘*self image*’ emerged in all ten of the interviews. Self-image was explored in light of the way seniors see themselves and their realities. A person’s self-image could be described as a mental picture of him or herself, and includes objective components as well as items that have been learned either from personal experiences or by internalizing the judgments of others (Link et al., 2001). In the accounts of the ten senior’s, discussions of self- image emerged in relation to identity, health conditions and age. Self-image was explored in the contexts of living with a mental illness, dealing with stigma and age related challenges and demonstrating resilience and strength.

Perceptions on self. The statements about the ways seniors saw themselves reflected their different and unique personalities and life experiences. When asked to describe themselves, seniors used different adjectives such as nice, giving, and creative. In contrast to what might be expected, seniors who were comfortable discussing their mental and physical conditions in other parts of the interview chose not to mention their mental illness. For example, consider these accounts which illustrate the way three of the seniors described themselves. Shimon says,

“Sense of humor, above average intelligence, creative, musical, very generous, give up myself for other people, I’m a good

person...kind... ah... I have a talent of healing in my hands, I'm a healer, you know. That's it, that who I am". (Shimon)

Elaine, responds by saying, *"Creative...I consider myself a very social person but also an introvert"*, while Miriam says, *" neat and tidy and...a clean, neat interesting person"*

Similar to Grenier's (2007) findings in relation to frailty, the above findings suggest that their sense of self was not defined by their mental or physical health conditions. This notion is also supported by theoretical frameworks such as the recovery model, which claims that a person is more than his illness and that people who learn to identify their strengths as well as their limitations are able to find purpose and enjoyment in their life despite the illness (Ragins, 2007; Jacobson & Greenley, 2001).

However, when asked specifically about their self-image as related to their illness (i.e., Does your mental illness play a role in the way you see yourself), five of the seniors expressed their views that their self image is connected to their mental state. Seniors, who felt that they usually have a positive self-image, reported that when they are depressed, their self image and self-esteem were low, suggesting that negative feelings regarding their sense of self could derive from symptomatic states and that these perceptions are dynamic and dependent on the situation. The following quotes illustrate the ways two seniors describe their self-image as related to their mental health condition:

"At the moment I have strong self- esteem, I think it's due to the fact that I am attending university and being constantly stimulated. While I was ill in the down side of b-polar syndrome I had a very low self- esteem and was pretty much emotionally dysfunctional. But now I feel pretty much better". (Elaine)

“Like I have a poor self-image when I’m depressed. But when I’m not depressed, I have a good self-image. So the lack of self-image defiantly comes from the depression”. (Bella)

The role of mental illness. Different approaches were reported regarding the role that mental illness plays in the respondents’ identities. For some, the onset of the illness was seen as a significant event. Being diagnosed in an early age meant that the illness was always there; being diagnosed later in life meant that some seniors had parts of their life history that were not touched by mental illness. As illustrated by the following quote, being diagnosed with anxiety and depression when he was twelve, led this senior to feel that his illness was always there, becoming a big part of his identity. When asked about it (i.e., Do you think that the illness is a big part of who you are?) he replied:

“Definitely. Always has been. Ever since I was a child. I first had symptoms as a young child and I went to a psychiatrist for the first time when I was 12 and in my teens I was hospitalized three times so it was always a part of my life”. (George)

For another senior, who became sick later in life, feelings of depression and anxiety were not as prominent when she was younger but became so as she aged. Here, she describes the role that mental illness plays in her life today as compared to the past:

“There were times in my life that I wasn’t so miserable. But they were a long time ago and gradually, more and more parts of my life are dominated by it”. (Rona)

In one case however, the illness was completely external to the senior’s identity. In this case, separating bipolar disorder from his sense of self was helpful. The following quote illustrates how this senior relates to his mental illness:

“Well... I am not my illness...I am me, and sometimes, the illness affects me. This is a very important distinction. Very very important. A lot of people define themselves with the illness, and I

don't. They shouldn't. Because it is something external, from the outside". (Shimon)

Perceptions on Age. Positive perceptions in late life emerged as playing an important role in the mental and physical health by many of the respondents. Respondents reported "feeling younger", or "not feeling their age", when their mental illness was balanced especially in cases where seniors were recovering from episodes of severe depression or were stable for a long period of time. Positive mental health was also perceived as the ability to keep busy and productive and to live without physical pain. These findings are supported by studies that talk about the successful aging (Rowe & Kahn, 1997). These studies identify three characteristics that could be used to define successful aging: low risk of disease and disease related disability; high mental and physical function, and active engagement in life. They also support the distinction between 'being frail' and 'feeling frail' that older women used to highlight the differences between difficult moments and their overall sense of identity (Grenier, 2006).

Consider this quote where one of the respondents who suffers from manic and depressive episodes, described how she feels about her age:

"I don't feel my age. I don't feel 61, whatever 61's supposed to be, I don't feel 61, I feel younger....when I hit 60 we had a party with my boyfriend and his two sons who just hit 31 on the same day. And we had a nice party and I didn't feel sick. I don't feel my age." (Bella)

The notion of being healthy as connected to feeling young was echoed by another respondent who described her recovery from a depressive episode by using age related terms:

“ I feel the youngest I ever felt because I’ve gotten the same feeling that I had when I was a young child when everything was so incredibly new and now I feel the same way. It’s because of an emotional transformation. As I’ve gotten more well I got a better sense of self.” (Elaine)

Keeping busy and productive were also connected to positive mental health and was seen as a way to feel young as illustrated by the following quotes:

“A lot of woman my age sort off crawl into a shell because they are not looking 20 anymore. To me, being 20 is 20 and being 60 is being 60. I do a lot of work for different organizations, it keeps me looking younger and my mind occupied as well. That’s the main thing.” (Mindy)

The notion of being productive and healthy as correlated with feeling young is however, also critiqued by researchers (Pearlin & Skaff, 1995; Halpern, 2001) who claim that models that promote successful aging imply that seniors who suffer from challenging health conditions “fail” to demonstrate successful aging and do not acknowledge that many seniors demonstrate resilience and strength within their complicated realities.

Perceptions on resilience and despair. Personal perceptions on resilience and despair emerged from all of the interviews: it was apparent that getting older and living with a diagnosed mental illness was not an easy task. However, the ways respondents perceived and expressed their realities could be described on a continuum from that of ‘hope and resilience’ to ‘frustration and despair’. When asked to look back at their life as a way to summarize the interview, some of the seniors expressed feelings of despair that were connected to the life they had. Mental illness was seen as one of the main obstacles to being healthy and productive, getting married and having a family. It is interesting to note that feelings of despair were not connected necessarily with old age but rather to mental

state and depression. Consider this quote where one of the seniors who suffers from depression and lives in a group home describes how he sees his life today:

"I would prefer to be in a hospital. I'm existing. I'm not living. My life is over." (George)

Feelings of despair were also expressed by another woman when she was asked to look back upon her life. In the following quote she described how financial decisions she made during her life are impacting her future and causing her anxiety and uncertainty.

"Looking back on my life is depressing. I don't have any money, I could have bought stocks from the bank but I didn't want to become a capitalist and if someone would have said to me that someday I wouldn't be able to support myself I would have laughed at him and now I can't and I just still can't believe it." (Rona)

In contrast however, seniors who had described their reality as challenging and/or whom had experienced a series of losses such as a loss of a spouse, a loss of independence and loss of physical and mental health, were able to express feelings of acceptance towards their life, suggesting the existence of resilience and strength as expressed in the following examples:

"I don't let it get to me. (The life I had) I have to be strong also, be able to fight it off, not fight it off but...live with it, and...I think I have that strength in me, I still have" (Carole)

"I say whatever will be will be. I want to live. I want to see my grandchildren, I didn't see them for four years and it's hard. So that's why I try to be strong" (Ruth)

"I had small little periods where I gave up on life but then I think: I have lots to live for. " (Mindy)

Many of the seniors concluded that living with a mental illness and age related health conditions is an ongoing and challenging process and acknowledged that although

they may never be “cured” it is possible to lead a meaningful life by enhancing their sense of empowerment over their lives. In the following quotes, two of the respondents concluded their feelings about living with a mental illness:

“It’s a day to day struggle to stay stable. I watch how my mind thinks and changes and if it starts going to these negative thoughts I now have the tools to replace them with other thoughts.” (Elaine)

“I know I will never totally be cured of my panic attacks but I’m able to handle them a lot easier and I’m coping with things.” (Miriam)

The themes which were discussed above represent the major findings of this thesis. These themes will be discussed and analyzed further in the next chapter within the context of the literature regarding mental illness, stigma and age related health conditions.

Chapter Five:

Discussion

The purpose of this thesis was to explore and better understand the different ways that stigma associated with mental illness influenced the self-image of older adults. More specifically, this study aimed to investigate how and to what extent stigma experiences impact the self image of adults over 50 who live with a diagnosed mental illness and are part of the Mental Health Program in a community center for seniors in Montreal. The ten participants interviewed for this thesis varied with regards to their illness (e.g., depression, bipolar, anxiety and schizophrenia) and their age (58- 87). Their differences and commonalities emerged from the interviews and in the course of the analysis, providing the opportunity to illuminate and explore their interpretations to age related issues, stigma experiences and self- image.

Illness

Accounts on becoming and managing their illnesses occupied a central place in the interviews, suggesting that having to deal with mental illness and age related challenges are significant in the lives of these seniors. An important distinction emerged between respondents who dealt primarily with mental illness and respondents who experienced both mental and physical illnesses. Respondents' who dealt mainly with mental illness, discussed in detail feelings of unhappiness and despair that led to the realization of them being ill. Since the respondents got ill during different stages of their lives (i.e. as adolescences, young adults or in their forties and fifties) accounts on becoming ill varied and were dependent on their life stages and circumstances.

Throughout the interviews it became apparent that the context and circumstances, by which each of the respondents became ill, influenced the different ways he or she chose to make meaning of the illness. For each, “making meaning” involved a complicated process of personal interpretations of the ways mental illness is seen by others, coping strategies and validations from professionals and family members. It was also influenced by the symptomatic state of each of the respondents (i.e., being stable or in a midst of depression). Receiving and living with a formal psychiatric diagnosis played a part in the way the respondents perceived their illness.

Researchers debate about the way people who suffer from a mental illness may perceive their diagnosis. Researchers who support the labelling theory (Link et al., 1989; Corrigan & Kleinlein, 2005) believe that since mental illness has a negative stigma attached to it, accepting a diagnosis of mental illness would attach personal relevance to these negative assumptions and stigmas. Furthermore, supporters of this theory believe that having the label ‘mentally ill’ applied to individuals could influence their behaviours (Graf et al., 2001; Link et al., 2001). Others, who support the medical model, argue that since medical origins are responsible for mental illness (Gove, 1975) psychiatric diagnosis provides treatment and relief from troubling symptoms (Gregoire, 1990; Hayward & Bright, 1997). This tension has emerged within the accounts of the respondents. For some, especially seniors who underwent ongoing feelings of despair for long periods of time (i.e., Shimon, Elaine, & Bella) without knowing what was wrong, receiving a diagnosis provided an answer to their otherwise feelings of uncertainty. In these cases, receiving a psychiatric diagnosis provided these seniors with treatment and validation from

professionals, acknowledging that they suffer from a recognizable illness. Living with a psychiatric diagnosis however, is not uncomplicated.

The findings from this study echo the ambivalence reported in the literature and can best be described as multilayered perceptions of acceptance and rejection toward their illness and the labels attached to it. The respondents were able to express the benefits of receiving a diagnosis, "*It (The diagnosis) helped me to understand the illness better. The mechanisms of the cells...that kind of thing.*" (Shimon) and the hardship it entails, "*I can't really accept it (the diagnosis). I know, I read and I heard about it and maybe it is with other people but I can't accept it in me because I am a perfectionist and need to be able to just get up and go.*" (Rona) These statements reveal how different responses toward having a psychiatric diagnosis could be explained as connected to personal values, perceptions of self and circumstances that brought about the illness. The acceptance or rejection of their psychiatric diagnosis also seems to be influenced by the mental and symptomatic state of the respondents and the way they associate their psychiatric diagnosis with stigmatizing reactions from the public. Respondents that were stable in terms of their symptomatic states (i.e., Elaine, Bella, Shimon and Miriam) were able to express feelings of acceptance towards their illness, suggesting that being stable contributed to their sense of control over their lives and enhanced their ability to accept their realities.

Respondents, who suffer from co-morbid health conditions, described a different reality. When asked to describe their health condition, they focused almost entirely on their physical ailments. Only when probed about their mental health issues, did the accounts on their mental illness emerge. This phenomenon was apparent in the cases where the

respondents were older (i.e., Hilda, Carole & Ruth), but also in the case of a younger respondent (i.e., Miriam) who suffers from multiple health and mental conditions. The differences in the significance that mental illness played in the lives of the respondents was especially striking when compared to other accounts expressed by seniors who did not encounter physical ailments. When looking at the literature, there is evidence that older adults may deny mental health symptoms (Sullivan et al., 2004). Seniors tend to be embarrassed to report symptoms or regard them as a natural part of aging (Preville et al., 2004). While this can explain part of the phenomenon, in these accounts, physical pain seemed to overshadow feelings of depression and anxiety, perceiving them as secondary to or a result of physical conditions: " *I think my mental health is o.k. it's just the pain that I am having a lot. It makes me feel anxious sometimes, not depressed but worried, because when I don't feel good I get really fed up with it ...with the pain*" (Carole). These findings are concerning especially in light of studies that show that seniors who live with a mental illness have a high prevalence of co-occurring major medical disorders (Dickey et al., 2002) and that co-morbidity is a key risk factor in maintaining mental health. Overlooking mental health in this way could lead to masking mental illnesses that may leave seniors un- treated (Preville et al., 2004).

Stigma

Stigma attached to mental illness was discussed in all of the interviews, suggesting that all of the respondents were aware of its existence. Acknowledging the broadness of the concept, the respondents were asked about the image that mental illness has in the general public. The responses were unanimous: Mental illness was perceived by the public as a

negative and shameful condition and a person who had mental illness was perceived as: *“dangerous, worthless, not reliable not predictable” (Shimon)*. While acknowledging these negative images however, some of the respondents (i.e., Bella, Mindy, Shimon and Elaine) did not necessarily agree with them and regarded them as misconceptions: *“People also think that they are stupid which is the biggest misconception because a lot of people that I met at the day hospital are almost at a genius level” (Elaine)*. Feelings of frustration and anger emerged from the respondents’ accounts as a result of the way people react to their illness: *“Stop whining about your problems and get up and do things” (Rona)*. Many of the seniors expressed their desire that the public will see mental illnesses in the same light as physical illnesses. Mental illness was compared to physical illness on different levels. One of the seniors (Shimon) compared mental illness to another chronic illness (i.e., diabetes) as a way to demystify mental illness and mitigate stigma. Others (Elaine, Mindy, Bella and George) echoed this notion by referring to mental illness as a chemical imbalance in the brain (See p.51 of this thesis), thus, emphasizing that it is an illness like any other. In these accounts, it seemed that comparing mental illness to physical illness served as a coping strategy of the respondents. By using this comparison, the respondents “normalized” their illness, attempting to enhance both their sense of control over their own situation and the sense of acceptance from others.

The way the respondents chose to deal with stigma varied and could be described on a continuum from hiding the illness to educating the public about it. Many of the seniors felt that they were misunderstood, and unjustly portrayed in a negative light. Seniors who chose to keep their mental illness from others (i.e., George, Hilda, Rona, Carole and Ruth) saw their illness as a private matter and were comfortable speaking about it only with

familiar people and professionals (i.e., family members, doctors and social workers). A number of explanations for this phenomenon which is broadly reported in the literature (Corrigan & Kleinlein, 2005; Wahl, 1999; Goffman, 1963) can be considered.

Making connections between this study and labelling theory, one can see how respondents perspectives sometimes differed from what is currently understood by labelling theory. According to the labeling theory, a person with a mental illness who lives in a society embedded in negative and stigmatizing attitudes can internalize and start to believe the negative assumptions. For example, a person, who believes that others will reject and judge him, will fear social contact and may conceal his/her illness in order to avoid rejection (Link et al., 2001).

In the context of this study, some of the respondents became sick many years ago, when having mental illness was considered taboo and was not talked about (See p.52 of this thesis). Seniors also expressed concerns of being judged by others as soon as the information about their illness was known. This phenomenon can be understood in light of previous experiences that the respondents encountered throughout their lives, creating expectations of rejection which create a vicious circle of withdrawal and rejection even if the rejection does not actually occur (Angell et al., 2005). Within this context, accounts on “living a secret” emerged. Having to live a secret was seen as an ongoing struggle: “*When it comes I want to cry but I smile because I don’t want other people to know exactly. That’s my secret ...that I’m depressed*” (Hilda) which often resulted in an increased sense of isolation, thus enhancing feelings of loneliness and depression.

Participants' efforts to communicate their experiences however, conflict with labelling theory. Being able to talk openly about the illness was discussed by all of the respondents, indicating the ongoing struggle that the respondents underwent to communicate their illness. In some cases (i.e., Elaine, Bella, Shimon) the experience of communicating their illness could be linked to a 'coming out' process brought about by external circumstances (i.e., Telling a professor in order to receive an extension on school work) or as an intentional coping strategy (i.e., volunteering information about the illness in order to prevent rejecting responses as seen in Shimon's case). In all of the examples brought up by the respondents, the experience of 'coming out' was seen both as challenging and liberating. Respondents saw this process as more positive than expected, as empowering and as a way to preserve mental health (See p.56 of this thesis). The struggle to hide or reveal the illness does suggest that the respondents consider their illness stigmatizing and that they anticipated responses of rejection from others. However, in light of these expectations, their ability to speak about their illness openly indicates the existence of strength and resilience.

Self-image

Self-perception emerged in all of the accounts as connected to personal interpretations of life experiences, age related challenges and mental state. In the process of the interviewing, it became apparent that one's concept of self-image is influenced and shaped by many components and therefore can be seen as dynamic and multidimensional. Self-image can be understood as a mental picture of one's self, influenced by objective and subjective components. Personal experiences, other people perceptions and dominant

discourses could all be incorporated within this concept (Link et al., 2001). Within this context, one can see how the challenges related to the participants' mental and physical conditions emerged and influenced their self-image. Respondents, who were suffering from mental and /or physical symptoms were able to describe themselves in a positive way, yet acknowledging how symptomatic states (i.e., depression and pain) influence the way they see themselves.

As previously described, all of the respondents have lived with mental illnesses for many years. Throughout interviews, it was evident that the illness became part of their life. However, it was interesting to see how differences and commonalities emerged in terms of the role that the illness played in their identity. The life stage in which the respondents became ill seemed to be significant in the way the respondents perceived themselves. Seniors who got sick at a relatively early age (i.e., George, Ruth, Mindy) seemed to perceive their mental illness as "always being there" while seniors, who experienced the illness later in life, were either able to relate to periods in their life that were not touched by it and/or related to it as external to their sense of self as in the case of Shimon (See p.59 of this thesis). As health and homecare practices move to life course perspectives, it is possible that the timing of the diagnosis could help practitioners understand how to best respond to older adults with mental health issues.

Theoretical frameworks such as the modified labelling theory highlight how mental illness carries a negative image among the public that can be internalized by people who suffer from a mental illness and thereby, influence their behaviors (Link et al., 1989). Accounts on living a secret and hiding the illness from others could suggest that some of

the respondents interviewed in this study understood their illness as shameful and therefore, in need of concealment. However, positive descriptions on self- perception also emerged from the accounts by many of the seniors (i.e., Shimon, Elaine, Hilda, Bella, Mindy, Ruth, Carole and Miriam) suggesting that their sense of self was not entirely defined by their illness. Similarly to findings by Grenier & Hanley (2007) on the way older woman perceive 'frailty', these finding can be understood as demonstrating resistance to dominant notions on 'mental illness'. This resistance is also supported by theoretical frameworks such as the recovery model (Ragins, 2007; Jacobson et al., 2001) that considers people with mental illness to be more than their illness, and believe that people can identify their strengths, accept their limitations, and find purpose and enjoyment in their life.

This tension between dominant assumptions and personal resistance emerged in particular, with relation to the respondents' perceptions on age. Positive age related perceptions were noted by respondents as intricately connected to mental health. Respondents, who felt that their illness was stable or recovered from depressive episodes, seemed to feel good about their age (See p. 60 of this thesis). The correlation between decline in health and feeling old continued to be apparent within the accounts of older and younger respondents who suffer from multiple health and mental conditions (i.e., Hilda, Carole, Ruth and Miriam). These findings can be understood as related to the acceptance of dominant concepts regarding "successful aging" (Rowe & Kahn, 1997) which include living without diseases and disabilities, having high mental and physical function and maintaining active engagement in life. However, critics of the successful aging model (Pearlin & Skaff, 1995) argue that in order to address the underlying assumptions of

‘failure’ that are embedded within the concept of ‘successful aging’, the heterogeneity and diversity, as well as cultural, social and health conditions must be considered. In this study, one can see that although all of the respondents reported symptoms of mental illness and/or physical conditions, they all generally adopted the dominant discourse regarding successful aging. These findings indicate that powerful images of aging well are embedded in the way society views older people and that the respondents attempted to apply them to their realities.

Summary discussion

The findings of this thesis reflect the personal interpretations of ten older adults that live with a diagnosed, psychiatric illness. Their accounts shed light on their opinions and self-perceptions of age, health conditions and stigma related to mental illness. Despite the relatively small sample, this thesis generated rich and detailed data. The results of this study coincide with previous research that highlights the impact of stigma related to mental illness on the lives of older adults. While the existence of negative stigma towards mental illness was clearly felt by the respondents, their reactions and attitudes towards it varied.

This thesis utilized the modified labelling theory as a theoretical framework to shed light on the reasons that stigma is created, internalized and influences the behaviors of people who live with a mental illness. While the negative reactions towards mental illness were apparent within the respondent’s accounts, the processes of acceptance and adaptation were less clear. While some of the respondents chose to hide their illness from the fear of being judged, others expressed feelings of anger and frustration towards the negative image mental illness has among the public. Their resistance toward accepting the

negative labels portrayed itself in their decisions to talk openly about their illness. It is important to acknowledge the effort and risk that these respondents took when they decided to 'come out'. In a society that is deeply influenced by negative images regarding mental illness, revealing their mental illness exposed the person to the possibility of rejection and increased marginalization. On the other hand, the decision to talk openly about the illness can be seen as empowering, thus contradicting the assumption that a person who suffers from mental illness is a passive recipient of the public's image of him/her. This phenomenon has implications for practice. Practitioners need to be aware and sensitive to older adults' hesitations to reveal their mental health conditions. Creating safe environments where seniors who live with a mental illness could feel comfortable to speak openly about their illness without being judged, can enhance our ability to understand their realities, thus, creating opportunities for the development of appropriate services that promote personal growth among seniors and practitioners alike.

Study findings also highlight how older people resist dominant discourses of stigma attached to mental illness. It was apparent that most of the participants were able to describe themselves in a positive manner, without mentioning their mental or physical illness. Their sense of self did not seem to be defined by their illnesses. This can also explain why stigmatizing experiences did not dominate their self-image. It is important to acknowledge however, that the mental state of the respondents was a significant part of the way in which they interpreted their realities. Throughout the findings, respondents who were stable in terms of their mental state had a positive outlook on their realities while respondents that were in a midst of a depressive episode saw their realities as frustrating and experienced a low self- image.

Self- perception was not only examined within the contexts of living with a mental illness, but also with regards to age and physical impairment. Results highlight how living with a mental illness can become increasingly complicated when physical ailments were added. Within this sample, four of the respondents had co-morbid conditions. While three of the respondents were in their seventies or eighties, one was in her sixties. The commonalities that emerged from their accounts revealed the challenging realities related to physical pain. Notions of chronic, persistent pain were dominant, to the point of overshadowing feelings of depression and anxiety. Positive aging was correlated with dominant perceptions regarding successful aging; the respondents viewed 'aging well' as living without pain, functioning independently, and being productive. Further research is recommended with regards to our understandings of the challenges that older adults afflicted with mental illness and pain encounter within their life stage and on the implications that these challenges raise with regards to adequate services for this population.

Chapter six:

Conclusions

Cautions and limitations

The ways that limitations in the methodology and design of this thesis may have affected the results need to be considered. First, there is a need to acknowledge the nature of the participants interviewed in this study. The ten seniors that were chosen for this thesis were selected from a convenience sample, and do not by any means represent the population of older adults diagnosed with a psychiatric illness. Their mental and symptomatic states differed from one another and could have influenced their perceptions on stigma, age and self-image. Drawing on the small sample size and the wide age range, it would be suggested that a broader sample of seniors with close age ranges would be useful to determine the influence and impact of age and stigma on self-image.

Second, data that was collected in the course of single semi-structured interviews represent personal interpretations that are specific to this group of respondents for the period of time that the data was collected. Conducting follow up interviews could have enhanced the ability to understand the wider scope of the respondents' realities.

Furthermore, it is possible that the findings of this study may have been influenced from the voluntary nature of the participation. Participants that agreed to be interviewed for this thesis may be the ones that felt comfortable to talk about their illness, thus expressing opinions that are not echoed by other older adult who live with a mental illness.

Finally, my dual role as a social worker in the Mental Health Program and as a researcher may have also influenced the obtained results. While my familiarity with the respondents enhanced their level of comfort during the interviews, it may also have produced reactive responses to my presence.

Conclusions:

This thesis attempted to illuminate and better understand the personal interpretations of older adults who live with a mental illness. The life stories that emerged from the interviews revealed a complicated reality. The respondents acknowledged the negative stigma that is attached to mental illness and expressed their opinions regarding the way they are perceived by others. The way the participants in this study chose to deal with stigmatizing reaction varied and dependent on their life experiences, personal values and coping strategies. It was apparent from the findings of this thesis however, that stigma attached to mental illness applies itself not only to younger adults but also to older people. Their struggle to conceal their illness from others or their conscious decision to talk about it reveals the challenges that these seniors have to face on a daily basis.

The findings revealed in this thesis contribute to the growing body of knowledge regarding the unique challenges and needs that older people who suffer from a mental illness encounter. Accounts regarding co- morbid conditions emerged as dominant in the lives of the respondents. Continued research is necessary to expand our existing knowledge regarding the relationship between physical pain and mental illness. This understanding can contribute to the development of specialized services, tailored to the needs of older adults who suffer from mental illnesses and age related challenges. Both practitioners and

researchers need to demonstrate awareness and sensitivity to the existence and impact of stigma related to mental illness on the lives of older adults. Creating safe, nonjudgmental community based services for seniors would enhance their readiness to reveal their symptoms, ensuring appropriate, respectful provision of care.

Social work implications:

The findings from this thesis lend itself to implications for social work practice. In order to ensure appropriate provision of care to this group of people, there is a need to acknowledge the complexity of their mental health needs, especially in light of the additional age related physical challenges that they face. In light of finding that were discussed in this thesis, stigma associated with mental illness needs to be considered as a factor within the process of building and implementing appropriate community based services. Before we, as health professionals, can expect seniors to reveal their mental health symptoms, we must be ready to examine our own biases and stigmas. Personal assumptions regarding the “mentally ill” need to be exposed and examined to ensure supportive, comprehensive and inclusive community based mental health services tailored to the complicated and challenging needs of older adults who live with a mental illness.

References:

- Angell, B., Cooke, A., & Kovac, K. (2005). First person accounts of stigma. In: P.W. Corrigan (Ed). *On the stigma of mental illness. Practical strategies for research and social change.* (pp.69-98). American Psychological Association: Washington Dc.
- Anthony, W., & Blanch, A. (1987). Supported employment for persons who are psychiatrically disabled: An historical and conceptual perspective. *Psychosocial Rehabilitation Journal*, 1(2), 5-23.
- Banton, R. (1985). *Politics and power. The politics of mental health.* London: Macmillan.
- Barches, J., Elliot, G., Berger, P., Barchas, P., & Solomon, F. (1985). The ultimate stigma: Inadequate funding for research on mental illness and addictive disorders. *American Journal of Psychiatry*, 142(7), 838-839.
- Bartels, S. J. (2004). Caring for the whole person: Integrated health care for older adults with severe mental illness and medical co morbidity. *Journal of the American Geriatric Society*, 52, 249-257.
- Bogdan, R.C., & Biklen, S. K. (1982). *Qualitative research for education: An introduction to theory and methods.* Boston: Allyn and Bacon.
- Canadian Mental Health Association. (2008). *Seniors and mental health.* Retrieved May 3, 2008 from www.cmha.ca
- Corrigan, P. W., & Kleinlein, P. (2005). The impact of mental illness stigma. In P.W. Corrigan (Ed). *On the stigma of mental illness. Practical strategies for research and social change.* (pp.11-33). American Psychological Association: Washington DC.
- Crocker, J., & Brenda, M. (1989). Social stigma and self-esteem: The self-protective properties of stigma. *Psychological Review*, 96(4), 608.
- Depla, M., Graaf, R., Van Weeghel, J., & Heeren, T. J. (2005). The role of stigma in the quality of life of older adults with severe mental illness. *International Journal of Geriatric Psychiatry*, 20, 146-153.
- Dickey, B., Normand, S., & Weiss, R. (2002). Medical morbidity, mental illness, and substance use disorders. *Psychiatry Services*, 53, 861-867.
- Eker, D., & Oner, B. (1999). Attitudes towards mental illness among the general public and professionals, social representations and change. In Guimon, J., Fischer, W., & Sartorius, N. (Eds). *The image of madness. The public facing mental illness and psychiatric treatment.* (pp.1-12). Basel, Karger.
- Farina, A., & Felner, R.D. (1973). Employment interviewer reactions to former mental patients. *Journal of Abnormal Psychology*, 82, 268-272.

Fleury, M.J. (2005). Quebec mental health services networks: Models and implementation. *International Journal of Integrated Care*, 5. Retrieved October 11, 2007 from PubMed Central.

Gergen, M.M., & Gergen, K.J. (2000). Qualitative inquiry: Tensions and transformations. In N. Denzin & Y.S Lincoln (Eds). *Handbook of Qualitative Research*. (2nd ed., pp.1025-1046). Thousand Oaks: Sage.

Goffman, E. (1963). *Stigma: Notes on management of spoiled identity*. New York: Simon & Schuster.

Gove, W.R. (1975). *The labelling of deviance: Evaluating a perspective*. New York: Wiley.

Graf, J., Lauber, C., Nordt, C., Ruesch, P., Meyer, P., & Rossler, W. (2004). Perceived stigmatization of mentally ill people and its consequences for the quality of life in a Swiss population. *Journal of Nervous and Mental Disease*, 192(8), 542-547.

Grenier, A., & Hanley, J. (2007). Older women and 'frailty': Aged, gendered and embodied resistance. *Current Sociology*, 55, 211-228.

Grenier, A. (2006). The distinction between being and feeling frail: Exploring emotional experiences in health and social care. *Journal of Social Work Practice*, 20(3), 299-313.

Gregoire, P.A. (1990). The phenomenology of psychiatric hospitalization: The patient's experience and expectations. *Acta Psychiatrica Scandinavica*, 82, 210-212.

Guimon, J. (2001). *Inequity and madness. Psychosocial and human rights issues*. Kluwer Academic/ Pleum Publishers.

Guimon, J., Fischer, W., & Sartorius, N. (1999). *The image of madness. The public facing mental illness and psychiatric treatment*. Basel, Karger.

Hamilton, D.L., & Sherman, J. W. (1994). Stereotypes. In: R.S. Wyer & T.K. Srull (Eds). *Handbook of social cognition: Basic Processes*. (2nd ed. pp.1-68). Hillsdale, NJ: Erlbaum.

Hall, P., Brockington, I.F., Levings, J., & Murphy, C. (1993). A comparison of responses to the mentally ill in two communities. *British Journal of Psychiatry*, 162, 99-108.

Halpern, P.L. (2001). *Older adults and mental health: Issues and opportunities*. Department of Health and Human Services Administration on Aging. U.S.A.

Hammersley, M., & Atkinson, P. (1995). What is ethnography? In M. Hammersley & P. Atkinson (Eds.). *Ethnography principles in practice*. (2nd Edition, pp.205-238). New York: Routledge.

Hayward, P., & Bright, J.A. (1997). Stigma and mental illness: A review and critique. *Journal of Mental Health*, 6, 345-354.

- Hillert, A., Sandmann, J., Ehlig, S.C., Weisbecker, H., Kepplinger, H. M., & Benkert, O. (1999). The general public's cognitive and emotional perception of mental illness: An alternative to attitude-research. In J. Guimon, W. Fischer and N. Sartorius (Eds). *The image of madness, the public facing mental illness and psychiatric treatment*. (pp.56-71). Basel, Karger.
- Jacobson, N., & Greenley, D. (2001). What is recovery? A conceptual model and explication. *Psychiatric Services*, 52, (4), 482-485.
- Karis, J.M & Wandrei, K.E.(Eds).(1996).Ch 1. PIE: A system for describing and classifying problems of social functioning. *Person-in-environment system*. (pp.3-21). NASW Press
- Kendell, R.E. (2004). Why stigma matters. In A.H. Crisp (Ed): *Every family in the land. Understanding prejudice and discrimination against people with mental illness*. (pp.5-7). London, RSM.
- Kirby, J. L., & Keon, J. (2006). Out of the shadows at last- transforming mental illness and addictions services in Canada. Chapter 3: Seniors. *The Standing Senate Committee on Social Affairs, Science and Technology*. Retrieved September 11, 2007 from <http://www.parl.gc.ca>
- Kramer, M., Simonsick, E., Lima, B., & Levav, I. (1992). The epidemiological basis for mental health care in primary health care: a case for action. In: Halpern, P.L. *Older adults and mental health: Issues and opportunities*. (pp.5).New York: Tavistock/ Routledge.
- Lamb, H.R., & Bachrach, L.L. (2001). Some perspectives on deinstitutionalization. *Psychiatric Services*, 52, (8), 1039-1045.
- Lesage, A. (2007). The 2005-2010 Mental health action plan and the mental health of seniors. *Vital Aging*, 13(3), 4-5.
- Link, B.G., & Phelan, J.C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363-885.
- Link, B.G., Struening, E. L., Neese-Todd, S., Asmussen, S., & Phelan, J.C. (2001). The consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatric Services*, 52(12), 1621-1626.
- Link, B.G., Cullen, F.T., Struening, E., & Shrout, E.P. (1989). A modified labelling theory approach to mental disorders: An empirical assessment. *American Sociological Review*, 54,400-423.
- Lofland, J., & Lofland, L. H. (1984). *Analyzing social settings*. Belmont, CA: Wadsworth Publishing Company.
- MacCourt, P. (2004). *Seniors mental health policy lens*. B.C. Psycho- geriatric Association. Retrieved October 10, 2006 from www.seniorsmentalhealth.ca.

Moscovitz, N. & Regenstreif, A. (2007). Editorial. *Vital Aging*, 13(3), 2-3.

Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage Publications.

Pearlin, L.I., & Skaff, M.M. (1995). Stressors and adaptations in late life. In M. Gatz (Ed), *Emerging issues in mental health and aging*. (pp.97-123). Washington , DC: American Psychological Association.

Porter, R. (2004). Is mental illness inevitably stigmatising? (2004). In A.H. Crisp (Ed). *Every Family in the Land. Understanding Prejudice and Discrimination Against People with Mental Illness*. (pp. 3-13). London, RSM.

Preville, M. Cote, G. Boyer, R. & Hebert.R. (2004). Detection of depression and anxiety disorders by home care nurses. *Aging & Mental Health*, 8(5), 400-409.

Punch, M. (1998). Politics and ethics in qualitative research. In N. Denzin & Y.S. Lincoln (Eds.), *The landscape of qualitative research: Theories and issues*. (pp. 156-184). Thousand Oaks: Sage.

Purvis, B., Brandt, R., Rouse,C., Vera,W., & Range,L.M.(1988). Students' attitudes toward hypothetical chronically and acutely mentally and physically ill individuals. *Psychological Reports*, 62, 627-630.

Quadagno, J.S., & Antonio, R.J. (1975). Labelling theory as an over socialized conception of man: The case of mental illness. *Sociology and Social Research*, 60, 33-45.

Ragins, M. (2007). Recovery with severe mental illness: Changing from a medical model to a psychosocial rehabilitation model. *The Village, Integrated Service Agency*. Retrieved January 11, 2008 from <http://www.village-isa.org>.

Rogers, E.S., Chamberlin, J., Elison, M.L., & Crean, T. (1997). The construct validity of empowerment among consumers of mental health services. *Schizophrenia Research*, 38 (1), 77-84.

Rowe, J.W., & Kahn, R.L. (1997). Successful aging. *The Gerontologist*, 37(4), 433-440.

Rubin, A. & Babbie, E. (2005). *Research methods for social work* (5th ed). Belmont, CA: Brooks/ Cole.

Scheff, T. J. (1966). *Being Mentally Ill: A Sociological Theory*. Chicago, Aldine.

Sirey, J.A., Bruce, M.L., Alexopoulos, G.S., Perlick, D.A., Raue, p., Friedman, S. J., & Meyers, B.S. (2001). Perceived stigma as a predictor of treatment discontinuation in young and older outpatients with depression. *American Journal Psychiatry*, 158,479-481.

Sivis, R., McCrae, C.S., & Demir, A. (2005). Availability of mental health care for older adults: A cross-cultural comparison of the United States and Turkey. *Aging & Mental Health*, 9(3), 223-234.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications.

Sullivan, M.P., Kessler, L., La Clair, K., Stolle, P., & Whitney, B. (2004). Defining best practices for specialty geriatric mental health outreach services: Lessons for implementing mental health reform. *The Canadian Journal of Psychiatry*, 49(7), 458- 466.

Szasz, T. (1972). *The myth of mental illness: Foundations of a theory of personal conduct*. London: Granada.

Thornicorff, G., & Bebbington, P. (1989). Deinstitutionalization : From hospital closure to service development. *British Journal of Psychiatry*, 155,739-753.

Turcotte, M., & Schellenberg, G., (2007). *A portrait of seniors in Canada: Introduction*. Retrieved April 3, 2008 from <http://www.statcan.ca>

Wahl, O.F. (1999). Mental health consumers' experience of stigma. *Schizophrenia Bulletin*, 25(3), 467- 478.

Warner, R. (1995). *Alternatives to the hospital for acute psychiatric treatment*. Washington, DC, American Psychiatric Press.

Weinstein, C.M. (1983). Labelling theory and the attitudes of mental patients: A review. *Journal of Health and Social Behaviour*, 24, 70-84.

World Health Organization and World Psychiatric Association. (WHO-WPA). (2002). *Reducing stigma and discrimination against older people with mental disorders*. A Technical Consensus Statement. Geneva, Switzerland. Retrieved November 9, 2007 from www.who.int/media_health/media/en/499.pdf

Yen, C.F., Chen, C.C., Lee, Y., Yen, J.Y., & Ko, C.H. (2005). Self-Stigma and its correlates among outpatients with depressive disorders. *Psychiatric Services*, 56(5), 599-601