7-3-2023 9:30 AM

Exploring The Experiences Of Familial Mental Illness Stigma Among Individuals Living With Mental Illnesses

Joseph Adu,

Supervisor: Oudshoorn, Abram, *The University of Western Ontario*
A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Health and Rehabilitation Sciences

Recommended Citation

Adu, Joseph, "Exploring The Experiences Of Familial Mental Illness Stigma Among Individuals Living With Mental Illnesses" (2023). *Electronic Thesis and Dissertation Repository*. 9358.
https://ir.lib.uwo.ca/etd/9358

Abstract

Familial mental illness stigma is stigma held by family members towards a loved one living with mental illnesses. There are few empirical studies on familial mental illness stigma, especially compared to studies on other, more public forms of stigma. This dissertation follows an interpretive phenomenological methodology with thematic analysis to understand familial mental illness stigma from the perspectives of both family members and persons with mental illnesses, including ways to reduce this stigma. Thirty interviews were conducted, including 15 persons diagnosed with mental illnesses and 15 family members, all within a mid-sized city in Ontario, Canada. From the perspective of those living with a mental illness, the following themes were developed: (1) diagnosis as a 'double-edged sword; (2) potential familial isolation; (3) familial stigma as societal stigma localized; (4) stories of acceptance; and (5) confronting potential familial mental illness stigma. From the perspective of family members, the following themes were developed: (1) layered perspectives of social and familial stigma; (2) family-related stigma; (3) complex interplay of family relationships and mental illness; (4) confronting stigma personally; and (5) envisioning a better future. The analysis of empirical literature on familial mental illness stigma in high-income countries produced additional six interconnected themes: (1) enactment of familial stigma; (2) familial struggles; (3) coping with familial stigma; (4) negative social consequences; (5) psychosocial impacts; and (6) meta-theme: unspoken stigma. Participants noted that familial mental illness stigma is embedded within the broader social stigma towards mental illness, which then is lived out in family relations. Stigma can be enacted in discriminatory ways such as exclusion, relationship breakdown, and alienation from family decision-making. Where familial mental illness stigma exists, it can impede mental health recovery, while supportive environments that actively confront or prevent stigma were of benefit to participants. That is, participants looked beyond the individual level and because familial mental illness stigma is often just a form of broader mental illness stigma, suggested efforts to confront mental illness stigma broadly. Finally, participants observed that insufficient services for those living with mental illnesses exacerbate the problem by impeding adequate treatment of their conditions. Future research should continue to build the evidence-base to prevent stigma at both the individual and societal levels.

Keywords: Familial mental illness stigma, social stigma, associative stigma, persons with mental health problems, family members or close relatives, interpretive phenomenology, qualitative research, in-depth interviews, thematic analysis

Summary for Lay Audience

Stigma involves unfair negative beliefs about a person or group of people. Mental illness stigma is a known challenge, and this includes stigma within families. Familial mental illness stigma is rarely discussed compared to other more public forms of stigma. Unfortunately, when people with mental illnesses experience stigma from their family members, this can get in the way of their mental health and prolong their recovery. This study explored the experiences of familial mental illness stigma from both the perspective of family members and people living with mental illnesses. We interviewed 15 people from each group to understand their experiences of stigma and what we can do about it. Participants' stories indicate that familial mental illness stigma does occur in some families. This can have negative impacts in terms of how individuals might be excluded from the family or lose relationships. On the other hand, many participants also shared positive experiences with their families who helped with their care and helped them feel respected. Overall, all participants felt we need to be doing a better job to reduce mental illness stigma that still exists.

Co-Authorship Statement

This dissertation includes three integrated manuscripts that were developed through collaborative endeavors under the supervision of Dr. Abram Oudshoorn and advisory committee members Dr. Kelly K. Anderson, Dr. Carrie Anne Marshall, and Dr. Heather Stuart. All members of my supervisory committee are co-authors to all three manuscripts and any others that will be published from this thesis. The primary intellectual contributions in all three manuscripts were made by the first author. This included: the design of the study, review of literature, development of the study protocols and ethics application, participant recruitment, data collection, transcription, data cleaning, and coding. The first author also led the data analysis and the writing of the manuscripts. Dr. Oudshoorn supervised the study, offered theoretical underpinnings and methodological advice as well as academic and editorial support in shaping the manuscripts for publication. All members of the advisory committee gave added methodological guidance, feedback on analysis, and reflexive dialogue, as well as intellectual and editorial support in crafting the various manuscripts for publication.

Acknowledgements

My PhD journey has been challenging yet exciting. I could not have completed this journey without support from various quarters. My culture and faith require that I give thanks first to the Almighty God, who gave me strength and wisdom and sustained me through this roller-coaster experience.

To succeed in academia, one needs role models and mentors. Professor Abram Oudshoorn, my primary supervisor, was the pivot around which my journey revolved, providing me not only with academic support but encouragement and love. He was ably assisted by my indefatigable committee members including Professor Kelly K. Anderson, Professor Carrie Anne Marshall, and Professor Heater Stuart, who, together provided academic advice, intellectual, and editorial support throughout the entire process. To these academic authorities, I say thank you.

Special thanks go to my research hub and colleagues Dr. Mark Owusu Fordjour, Dr. Sebastian Gyamfi, Dr. Ebenezer Martin-Yeboah, Dr. Albert Ahenkan, and Mr. Francis Boadi for the unflinching support. Your role in collaborative research, discussing concepts, and frameworks proved invaluable in my academic pursuit. You gave me a platform to share ideas and experiences and supported me to publish various research findings. I say ‘ayekoo’ to all of you.

Again, I would like to express my profound gratitude to all faculty members, staff, and colleagues in the Department of Health and Rehabilitation Sciences at Western University whose thoughts contributed the completion of this thesis. I will forever be indebted to you all.

To Erynn Monette, I am grateful for your kindness and support. Your final comments and edits were very helpful in the completion of this dissertation.

My heartfelt appreciation to my participants for their boldness, kindness, and commitment of sharing their lived experiences of mental illness stigma with me. Your stories were instrumental to the development and completion of this dissertation.

I am grateful to my examination committee — Dr. Magnus Mfoafo-M'Carthy, Dr. Jennifer Irwin, Dr. Richard Booth, and Dr. Tara Mantler — for an insightful, thought-provoking discourse of my project.

Finally, my special thanks go to my dear wife, Ivy, who has always been a pillar without whom this feat would not have been chalked. Ivy encouraged a positive attitude towards my studies and made sure I stayed on track. My three jewels, Princess, Precious, and Justine provided constant support and reassurance. Seeing them work so hard in their academic pursuits was an added fillip to keep working hard. God richly bless you all, for your constant encouragement and motivation.

Contents

List of Tables

List of Figures

List of Appendices

Chapter 1

1.1 Introduction

While mental health and mental illness-related issues have received increasing attention in past decades, particularly during the late 20th and early 21st centuries, these remain a challenge to the developmental agenda of every nation. The impacts of mental disorders on individuals, their families, and society at large have become a global public health concern because of substantial economic and human development implications in nations worldwide (Becker & Kleinman 2013; Mental Health Commission of Canada [MHCC], 2013; World Health Organization [WHO], 2019). Mills (2018) identified mental disorders as an imperative psychological problem in recent times, especially youth-related mental illnesses. Baranne and Falissard (2018) studied the global burden of mental disorders and highlighted youth mental illnesses as one of the leading public health problems of the 21st century. The authors called for the attention of all, including global leaders, to come together to tackle mental health and mental illness concerns to ensure a healthy labour force going forward (Baranne & Falissard, 2018). Adding to these concerns is that mental illnesses are vastly under-reported, with an estimated 50% of mental disorders among children and adolescents remaining undiagnosed and untreated (WHO, 2020).

Living with a mental illness, particularly if untreated, has significant impacts on morbidity and mortality. Research has shown that over 70% of adults worldwide living with mental illnesses are not receiving any treatment from health care professionals because of mental illness-related stigma, poor processes of detection, and barriers to accessing available treatments (Corrigan et al., 2014; Evans-Lacko et al., 2012; Henderson et al., 2013). Statistics from the

National Institute of Mental Health (NIMH) in the United States indicate that about one in five American adults (aged 18 or older) will experience a mental illness, ranging from mild to severe, which was estimated at over 45.5 million Americans in 2017 (NIMH, 2019). The prevalence of mental illness reported in Canada is similar to that in the United States. In Canada, mental illnesses are one of the leading causes of disability, also affecting one in five persons (Centre for Addiction and Mental Health, 2019; Public Health Agency of Canada, 2019). The Canadian Community Health Survey – Mental Health, in 2012, reported that one in three Canadians (about 9.1 million persons), aged 12 and above, will be impacted by a mental illness (Public Health Agency of Canada, 2019). Similarly, research in the United Kingdom has reported that mental health challenges and mental illnesses account for 28% of national disease burden, as compared to heart diseases that constitute about 16% of the disease burden (The Mental Health Foundation, 2016).

Individuals living with mental illnesses face complex vulnerabilities due to the stigma associated with mental illness, which can include social exclusion, discrimination, impoverishment, and shame (NIMH, 2019; WHO, 2010, 2012). Stigma is a social construct that communicates stereotypes that devalue individuals or groups, deeply established in social structures to discredit and prevent some groups of people from full participation in society (Goffman, 1963). Goffman's description of stigma was a theoretical starting point, recognizing a variety of bases on which stigma occurs such as (race, ethnicity, and religion), physical deformities (e.g., deafness and blindness), and blemishes of character (addiction and mental disorders) [Goffman, 1963]. However, it is noted that the terminology used by Goffman represents discriminations of that time, such as labelling certain things "blemishes of character". Mental illness is more than just a personal experience, it is a familial experience, with the majority of regular support provided by immediate family members (Canadian Mental Health Association [CMHA], 2007, 2008, 2018). The high social vulnerability connected with mental illnesses can make life difficult for people with mental health concerns and their families, especially in situations where the family struggles to adequately meet health needs and experience related stigma by association (Ahmedani, 2011; Knaak et al., 2017; Ngui et al., 2010). All of this is compounded by the fact that mental illness stigma (public stigma, self-stigma, associative, and structural stigma) is one of the leading factors contributing to the vulnerability of persons living with mental illnesses because it prevents such individuals from full participation in activities within their communities (CMHA, 2018; Knaak et al., 2015; WHO, 2012, 2019). Given the family's role in supporting people living with mental illnesses by acting as informal carers and through the provision of both practical and emotional support (Brackertz et al., 2018; Family Mental Health Alliance, 2006; Livingston, 2013; Pirkis et al., 2010; Public Health Agency of Canada, 2006), it is worth considering the multi-faceted nature of mental illness stigma, including reflecting on stigma enacted by family members towards those living with mental illnesses.

This dissertation explores experiences of familial mental illness stigma among individuals living with mental illnesses in Ontario, Canada. Familial mental illness stigma occurs when family members or close relatives enact stigma through stereotyping, prejudice, and/or discrimination against their family members with a mental illness. Although the literature on mental illness stigma has grown in Canada (CMHA, 2014; Livingston, 2013; Ratnasingham et al., 2013), notable gaps exist specifically around familial mental illness stigma. The majority of literature on mental illness stigma explores the perspectives of the general public, stigma by and towards mental health professionals, and stigma experienced by family members of those with a mental illness (Corrigan et al., 2014; Evans-Lacko et al., 2012; Koschorke et al., 2017). As family serves the role of the primary support mechanism for those living with mental illnesses in Canada, the experience of mental illness stigma emanating from some family members towards their relatives must be explored. Ultimately, by uncovering experiences of familial mental illness stigma we open the potential for practices and policies to reduce its existence. This study used qualitative methods—specifically interpretive phenomenology and meta-synthesis—to achieve it aims. These approaches are further described in the methods chapter of the study.

1.2 Background and Context

Mental health is a state of well-being in which people recognize the value of their potential and are able to cope with normal stresses of daily life, work productively, and contribute to their community (Galderisi et al., 2015; WHO, 2004). Mental illness, on the other hand, is understood as a broad range of mental health conditions or disorders that affect the emotions, thoughts, and behaviours of individuals (Manderscheid et al., 2010; WHO, 2004) with negative impacts on daily functioning. According to the United States Department of Health and Human Services (DHHS), mental illness includes all mental disorders characterized by alterations in thinking, mood, or behaviour coupled with distress and/or impaired functioning (DHHS, 1999). The American Psychological Association (APA) defines mental illness as a health condition that involves changes in emotion, thinking, or behaviour that are associated with distress and/or problems of functioning in social, work, or family activities (APA, 2018). In the current study, the terms “mental disorders” and “mental illnesses” are used interchangeably to refer to a clinically relevant impairment in mental health that would meet the threshold for diagnosis. Thus, good mental health is closely related to total health—an expression of full physical, mental, and social well-being, and not simply the absence of disease or disability

(WHO, 1948). At this point, it can be concluded that a strong correlation exists between mental health and physical health, hence equal attention must be given to both mental and physical illnesses to ensure healthy populations (Brown et al., 2009; Canadian Institute for Health Information, 2008). Individuals living with severe mental disorders could experience prolonged physical illness, and people living with protracted physical illnesses risk developing mental health disorders, such as depression and anxiety disorders.

The extant literature suggests that the co-existence of mental and physical health concerns tends to reduce the quality of life of individuals, resulting in poorer population health outcomes (CMHA, 2008; Patten, 1999). This finding aligns with the WHO's recent assertion that "there can be no health or sustainable development without mental health" (WHO, 2019, p.1). This recent statement by WHO (2019) follows upon that of WHO (2007) on the link between mental illness and poverty. The WHO stated that the problems connected with mental disorders are grave, with multilayered intersections that relate to poverty (WHO, 2007). Individuals with low socio-economic status are eight times more likely to be diagnosed with severe mental illnesses than those in the high-income brackets (WHO, 2007). Hence, there is a need for concerted efforts across civil society to join forces to address the social and structural causes of mental illnesses and its related stigmas. The optimum time is now "for multiple stakeholders to engage in critical interdisciplinary debates about mental health and development, avoiding the often simplistic take up of one by the other" (Mills, 2018, p.861). In this way, the potential exists to break the reticence of addressing mental illness, which seems to relate to a lack political will, funding, and pragmatic public policies to fight mental illness-related stigma. Evidence-based research can support the collective efforts by multiple stakeholders to devise innovative ways to address the complex social factors that continue to heighten the morbidity of mental illnesses.

For instance, a recent study in mental illness reiterated the need for the establishment of anti-stigma programs in partnership with academic researchers to critically appraise and analyse their activities to create evidence informed public policy and practice (Stuart, 2016). In this way, research can be a catalyst for resource allocation and policy-making needed for systemic change. Resources, herein, denote the availability of effective clinical and social care, including anti-stigma interventions for persons with mental illnesses at all levels of society as envisaged by the Lancet Commission on Global Mental Health and Sustainable Development (Patel et al., 2018; Thornicroft et al., 2022).

The Lancet Commission's agenda for improving global mental illness is centered around the following four pillars: (1) mental health is a universal public good and is pertinent to sustainable development in all nations; (2) mental health disorders or problems exist along a continuum (e.g., mild, time-limited distress to long-term, progressive, and severely disabling conditions); (3) mental health of individuals are unique products of social and environmental influences; and (4) mental health is a basic human right for all persons and requires a rights-based approach to safeguard the well-being of persons living with mental disorders and its related stigma (Patel et al., 2018). Patel and colleagues (2018) further suggested that overcoming traditional barriers to improving global mental health, besides the four pillars, requires innovative health policies and developmental efforts suitable for each country's social environment. That is, the involvement of intersectoral actions within the health sector and navigation of other sectors that constitute the determinants of mental health (e.g., education, workplaces, social welfare, gender empowerment, child and youth services, and criminal justice) are critical to improving mental health while reducing mental illness-related stigma (Patel et al., 2018). This assumes that intersectoral or combined approaches to developing social interventions to reduce and prevent mental illness-related stigma could be successful and are supported by a foundation of resources being equitably distributed, and all sectors are well-synchronized for possible inclusion of all persons. Nonetheless, the reality of mental illness-related stigma in all facets of society continues to hinder the fight against mental illnesses globally, as emphasized by the Lancet Commission on mental illness stigma and discrimination— “it is time to end all forms of stigma and discrimination against people with mental health conditions, for whom there is double jeopardy: the impact of the primary condition and the severe consequences of stigma” (Thornicroft et al., 2022, p. 1). In fact, the most recent report of the Lancet Commission, compiled by over 50 experts worldwide, described mental illness stigma as being worse than the mental health issue or diagnosis (Thornicroft et al., 2022).

It is notable that mental illness-related stigma can originate from a variety of sources (such as educational institutions, landlords, employers, health care providers, and other service providers including the criminal justice system) and thus requires a well-rounded anti-stigma strategy suitable for diverse segments of society to bring about change (Arboleda-Flórez & Stuart 2012; National Academies of Sciences, Engineering & Medicine, 2016; Sartorius, 2010; Szeto & Dobson, 2010). The contextualization of anti-stigma programs is vital to fighting mental illness-related stigma due to the existence of various cultures in our communities, cities, and countries (Sartorius, 2010; Stuart, 2016). Globally, the stigma connected to mental illnesses is different across sociocultural environments, and its related negative implications continue to grow in effect (Kadri & Sartorius, 2005; Sartorius & Schulz, 2005). Cultural acceptability is, therefore, vital in the success of anti-stigma campaigns to reduce mental illness-related stigma (Sartorius, 2010; Stuart & Sartorius, 2022). This finding is upheld by a recent study showing that the use of multiple strategies for mental illness stigma reduction is more effective than a generalist model which fails to acknowledge variations in skillsets, diverse groups, and cultures (Adu et al., 2022; Ungar et al., 2016).

Anti-stigma initiatives or strategies are on the increase, particularly in the developed world (Stuart et al., 2012), and some of these programs are implemented in collaboration with academic institutions to assess and review their effectiveness over time (Stuart, 2016). Examples of some prominent anti-stigma initiatives include the Time to Change program in the United Kingdom, New Zealand's Like Minds Like Mine, Opening Minds in Canada, Bell Let's Talk in Canada, and the See Me campaign in Scotland. The Opening Minds initiative was founded by the MHCC in 2009 to roll out anti-stigma programs to ensure fairness and integration of Canadians living with mental illnesses to participate in all social activities (Szeto et al., 2019). Szeto and colleagues (2019) studied activities undertaken by Opening Minds and reported on a new strategy aimed at reducing mental illness stigma at selected workplaces as well as post-secondary institutions. One of the approaches adopted by Opening Minds is "contact-based education, wherein individuals who have experienced and recovered from mental illnesses present in the workshop and can discuss their experiences of mental illness and stigma" (Szeto et al., 2019, p. 5). The Bell Let's Talk anti-stigma initiative has partnered with several colleges, universities, and non-academic institutions across Canada to advance research in mental illness-related stigma, including a research Chair at Queen's University (Bell Canada, n.d.). The Bell Let's Talk initiative has afforded many Canadians opportunities to openly engage in discourse about mental illnesses and the need to embrace individuals living with mental illnesses at all levels of society.

Additionally, there are several anti-stigma initiatives seeking to reduce mental illness-related stigma in Europe as reported by Beldie and colleagues in 2012. In their review on confronting stigma of mental illness in mid-sized European countries, the researchers helped in supporting 14 nations in the documentation of various anti-stigma activities to make them more accessible. These researchers noted that in spite of this first step, more work still needs to be executed to attain a stigma-free environment in all communities. Most of the programs were generic mental wellness programs; hence, no clear definition of anti-stigma programs was followed (Beldie et al., 2012).

Looking at the complexities of mental illness-related stigma, the fight against this stigma cannot be complete without the involvement of the family, given that familial mental illness stigma is often over-looked. Considering the family is the nucleus of social society (Bledsoe, 1990; Nukunya, 2003), as well as the key role families often play in the lives of persons with mental illnesses and the intricacies of mental illness-related stigma, it will be valuable to shed light on whether and how families enact stigma against their relatives living with mental illnesses.

1.3 Significance of the Study

Stigma towards persons with mental illnesses from within the family system can be devastating for affected individuals due to the central social function of families. The goals of this study are to shed light on experiences of familial mental illness stigma in Ontario, Canada, and thus to fill out the knowledge base about this least-discussed source of stigma. Additionally, the results of this dissertation will contribute to policy-making regarding the creation and enactment of programs to safeguard people with mental illnesses from stigma within their families. In the end, it is my hope that health professionals and policy-makers will not only see mental illness stigma as a problem that exists in broader society, but as one that could also come from within the individual’s immediate family. The voices of those living out this stigma or suffering from it provide understanding as to what can be done about it.

1.4 Problem Statement

The large impacts of mental health challenges on economies around the world illustrate the need for evidence-based approaches to creating healthier contexts. It is clear from the literature that one contributing factor that worsens experiences of mental illness in modern societies is the stigma of mental illness. Stigma (stereotypes, prejudice, and discrimination) associated with mental illnesses has been extensively studied worldwide (Corrigan & Watson, 2002; Knaak et al., 2017; Link & Phelan, 2001; Livingston, 2013). Most of these studies have focused on mental illness stigma originating from the general public or related to accessing care from mental health professionals (Huggett et al., 2018; O’Reilly et al., 2019; Park & Park, 2014; Paul & Nadkarni, 2017). Some research has explored stigma by association or associative stigma in mental illness, including stigma experienced by health professionals and/or by family members (Kulik et al., 2008; Nyblade et al., 2019; O’Brien et al., 2015; Östman & Kjellin, 2002; Phelan et al., 1998; van Der Sanden et al., 2013,2015, 2016). Very little research has explored stigma from family members towards their relatives living with mental illnesses. A comprehensive understanding of mental illness-related stigma is vital due to the perpetual exclusion of individuals living with mental illnesses from full engagement in their families, communities, and society (Livingston, 2013; Mfoafo-M’Carthy, & Sossou, 2017). Until mental illness-related stigma is fully addressed, it will continue to serve as a barrier to care and a factor that increases morbidity and mortality connected to mental illnesses.

To date, some literature acknowledges familial mental illness stigma. It has been noted that individuals living with mental illnesses may be discriminated against by their family members due to their needs, creating the potential for emotional distress (Adu et al., 2020, 2021, 2022; Koschorke et al., 2017; Mascayano et al., 2015). The literature further states that these experiences of discrimination and humiliation may lead people to hide their mental health concerns from their close relatives, thus increasing the likelihood of inadequate treatment (Adu et al., 2021; Koschorke et al., 2017; Larson & Corrigan, 2008; Park & Park, 2014). Studies that have explored the complex role of family members have touched upon life experiences of siblings of individuals diagnosed of schizophrenia and the lived-experience of parents involved in caregiving for young persons experiencing a first episode of psychosis (Aldersey & Whitley, 2015; Barnable et al., 2006; Clarke & Winsor, 2010; Hamilton-Wilson & Conroy, 2012). While these studies have shed light on family experiences of mental illness-related stigma by association, they do not delve into the issue of stigma that emanates from close relatives towards people living with mental illnesses.

Familial mental illness stigma is worth investigating in Canada, given that 11 million (38%) Canadians aged 15 and above have at least one immediate or extended family member living with a mental health disorder (MHCC, 2012; Pearson, 2015; Pearson et al., 2013). Also, the report of a recent population estimates in Canada indicated 24.4% of participants with mental illnesses felt stigmatized while accessing healthcare and most of these individuals were less than 55 years and unemployed (Patten et al., 2016). Another population-based study reported that some Canadians are more likely to stigmatize persons with depression and the odds of employers denying such individuals jobs were high (Stuart et al., 2014). Additionally, about 71% of Canadians felt that their livelihoods were impacted by their relatives’ mental illness while caring for them (MHCC, 2012; Pearson, 2015; Pearson et al., 2013). Additional research is warranted to understand what is happening within these family systems, and if there is a need for interventions to support families in addressing their own stigmatizing perspectives.

1.5 Purpose of the Study

This dissertation seeks to build out knowledge on the least-acknowledged form of mental illness stigma, familial mental illness stigma. It aims to achieve the following objectives:

1. Understand the experiences of individuals living with mental illnesses and their close relatives, in relation to mental illness-related stigma and how this impacts familial relationships.
2. Explore how family members or close relatives and the individuals with a diagnosis of mental illness address potential familial mental illness stigma.

1.6 Research Questions

To achieve the above-mentioned objectives, this dissertation will answer the following research questions:

1. What are the lived experiences of individuals with a diagnosis of mental illness in relation to mental illness stigma, and how does this impact familial relationships?
2. What are the lived experiences of close relatives of individuals with a mental illness diagnosis in relation to mental illness stigma, and how does this impact familial relationships?
3. How do family members or close relatives of individuals with a diagnosis of mental illness prevent or reduce potential familial mental illness stigma?
4. How do individuals diagnosed with a mental illness deal with potential stigma, including familial mental illness stigma?

1.7 Conceptual Perspectives

Many conceptual models have been suggested for the study of mental illness stigma and its related problems in society (Bos et al., 2013; Link & Phelan, 2001; Hatzenbuehler et al., 2013; Stangl et al., 2019). In particular, the model proposed by Fox et al. (2018) is taken up within this dissertation to explain some concepts in mental disorders that connect with familial mental illness stigma. Components in Fox and colleagues' model that are of relevance to this dissertation include: (1) perspective of the stigmatizer [stereotypes, prejudice, discrimination] (2) perspective of the stigmatized [internalized stigma, anticipated stigma, experienced stigma] (3) intersectionality. In brief, the framework not only adds to existing models that explain the processes involved in mental illness stigma, but it also establishes a model to explain terminologies that broadly define the mechanisms of societal stigma of mental illness that include both the stigmatized and the stigmatizer. That is, the model demonstrates the need to think about personal level factors (stigmatized) as well as external factors (stigmatizer) while explaining the roots of public mental illness stigma, considering the hegemony that plays out in separating persons with mental illnesses from other members within the larger society. Intersectionality herein, reflects the perceived stigma as envisaged by both the stigmatizer and the stigmatized. Intersectionality, however, is contingent on some characteristics of the stigmatized (the type of mental illness, treatment engagement or availability, and socio-economic status). Fox et al. (2018) explains that:

> "A key benefit of the framework is that by integrating existing definitions and conceptualizations of mental illnesses stigma through common terminology, we tie together the immense and varied body of mental illness stigma research and delineated

> the types of stigma that are most important to outcomes for people with and without mental illness, regardless of the specific condition under study" (p.351).

From Fox et al. (2018), it is presumed that mental illness is socio-culturally embedded in the public realm with an out-group identity which often results in stigma and further impacts the self-esteem and self-efficacy of individuals with mental illnesses. These consequences seem to connect more with the less privileged in society living with mental illnesses compared to the economic elites and political class. For instance, various studies on stigma have identified its damaging effect on the allocation of life opportunities available to people with mental illnesses, who are often denied equal access to employment opportunities, healthcare, and housing (Corrigan, 2004; Hipes et al., 2016; Rüsch et al., 2005). Fox et al.'s model is useful for advancing the concepts of mental illness stigma, whilst looking at how it is grounded within families in high-income countries. This is because the model directs attention on the stigmatizer and stigmatized and the three components of public and self-stigma (stereotypes, prejudice, and discrimination).

1.8 Overview of Chapters

This dissertation adheres to the integrated-article format as per the School of Graduate and Postdoctoral Studies at Western University. The dissertation is organized in six chapters. Chapter 1 consists of the study background, justification and focus of the study, research questions, and an overview of chapters of the study. Chapter 2 is a published meta-synthesis of qualitative empirical literature on the experiences of familial mental illness stigma in high-income countries. Chapter 3 provides a detailed methodology (phenomenology) of the study, including participant recruitment methods, description of the data collection instruments, and the data analysis strategy. Chapters 4 and 5 are manuscripts that provide the study findings and results. Finally, Chapter 6 presents the conclusions, implications, and recommendations of the dissertation in respect to research, education, policy, and practice. Because of the manuscript format, there is some degree of overlap in Chapters 4 and 5 with the background, methods, and results sections of the dissertation as these are fully, independently publishable manuscripts.

References

Adu, J., & Oudshoorn, A. (2020). The deinstitutionalization of psychiatric hospitals in Ghana: An application of Bronfenbrenner's social-ecological model. *Issues in Mental Health Nursing, 41*(4), 306-314. https://doi.org/10.1080/01612840.2019.1666327

Adu, J., Oudshoorn, A., Anderson, K.A., Marshall, C.A., Stuart, H., & Stanley, M. (2021). Policies and Interventions to Reduce Familial Mental Illness Stigma: A Scoping Review of Empirical Literature. *Issues in Mental Health Nursing Journal*. *42*(12), 1123–1137. https://doi.org/10.1080/01612840.2021.1936710

Adu, J., Oudshoorn, A., Anderson, K., Marshall, C. A., & Stuart, H. (2022). Social contact: Next steps in an effective strategy to mitigate the stigma of mental illness. *Issues in Mental Health Nursing*, *43*(5), 485–488. https://doi.org/10.1080/01612840.2021.1986757

Ahmedani, B. K. (2011). Mental health stigma: Society, individuals, and the profession. *Journal of Social Work Values and Ethics*, *8*(2), 4-1.

Aldersey, H. M., & Whitley, R. (2015). Family influence in recovery from severe mental illness. *Community Mental Health Journal*, *51*(4), 467-476. DOI: 10.1007/s10597-014-9783-y

American Psychiatric Association (2018). *What Is Mental Illness?* Retrieved from https://www.psychiatry.org/patients-families/what-is-mental-illness.

Arboleda-Flo´rez, J., & Stuart, H. (2012). From into science: Fighting the stigmatization of mental illnesses. *Canadian Journal of Psychiatry*, *57*(8), 457–463. https://doi.org/10.1177/070674371205700803

Baranne, M. L., & Falissard, B. (2018). Global burden of mental disorders among children aged 5–14 years. *Child and Adolescent Psychiatry and Mental Health*, *12*(1), 19.

Barnable, A., Gaudine, A., Bennett, L., & Meadus, R. (2006). Having a sibling with schizophrenia: A phenomenological study. *Research and Theory for Nursing Practice*, *20*(3), 247. DOI: 10.1891/rtnp.20.3.247

Becker, A. E., & Kleinman, A. (2013). Mental health and the global agenda. *New England Journal of Medicine*, *369*(1), 66-73. DOI: 10.1056/NEJMra1110827

Beldie, A., Den Boer, J. A., Brain, C., Constant, E., Figueira, M. L., Filipcic, I., Jarema, M., Jelenova, D., & Karamustafalioglu, O. (2012). Fighting stigma of mental illness in midsize European countries. *Social Psychiatry and Psychiatric Epidemiology*, *47*(1), 1-38. DOI 10.1007/s00127-012-0491-z

Bell Canada. Bell Let's Talk. Retrieved from https://letstalk.bell.ca/en/our-initiatives/.

Bledsoe, C. (1990). Transformations in sub-Saharan African marriage and fertility. *Annals of the American Academy of Political and Social Science*, 510: 115-125.

Bos, A. E., Pryor, J. B., Reeder, G. D., & Stutterheim, S. E. (2013). Stigma: Advances in theory and research. *Basic and Applied Social Psychology*, *35*(1), 1-9. https://doi.org/10.1080/01973533.2012.746147

Brackertz, N., Wilkinson, A., & Davison, J. (2018). Housing, homelessness, and mental health: towards systems change. *AHURI Research Paper, Australian Housing and Urban Research Institute Limited, Melbourne*.

Brown, L.C., Svenson, L.W., & Beck. C.A. (2009). Diabetes and Mental Health Disorders in Alberta. *Alberta Diabetes Atlas 2009*. (113-126). Institute of Health Economics. Edmonton, AB

Canadian Institute for Health Information. (2008). A Framework for Health Outcomes Analysis: Diabetes and Depression Case Studies. Ottawa, Canada. Retrieved from https://publications.gc.ca/site/eng/9.691320/publication.html

Canadian Mental Health Association. (2007). Poverty and mental illness. Retrieved from https://ontario.cmha.ca/documents/poverty-and-mental-illness/

Canadian Mental Health Association. (2008). CMHA Ontario Annual Report 2007-2008. Retrieved from www.https://ontario.cmha.ca/wpcontent/uploads/2016/10/cmhaannualreport20072008.pdf.

Canadian Mental Health Association. (2018). Mental health in the balance: Ending the health care disparity in Canada. *Canadian Mental Health Association*. Retrieved from https://cmha.ca/wp-content/uploads/2018/09/CMHA-Parity-Paper-Full-Report-EN.pdf.

Centre for Addiction and Mental Health. (2019). Mental illness and addiction: Facts and statistics. Retrieved from https://www.camh.ca/en/driving-change/the-crisis-is-real/mental-health-statistics.

Clarke, D., & Winsor, J. (2010). Perceptions and needs of parents during a young adult's first psychiatric hospitalization: “we’re all on this little island and we're going to drown real soon”. *Issues in Mental Health Nursing*, *31*(4), 242-247. DOI: 10.3109/01612840903383992

Corrigan, P. W. (2004). How stigma interferes with mental health care. *The American Psychologist. 59*(7), 614-625.

Corrigan, P. W., Mittal, D., Reaves, C. M., Haynes, T. F., Han, X., Morris, S., & Sullivan, G. (2014). Mental health stigma and primary health care decisions. *Psychiatry Research*, *218*(1-2), 35-38. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4363991/

Corrigan, P.W. & Watson, A.C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, Vol.1, 16-20.

Evans-Lacko, S., Brohan, E., Mojtabai, R., & Thornicroft, G. (2012). Association between public views of mental illness and self-stigma among individuals with mental illness in 14 European countries. *Psychological Medicine,* 42(8), 1741-1752. [1]. 10.1017/S0033291711002558

Family Mental Health Alliance. (2006). Caring together: Families as partners in the mental health and addiction system. Canadian Mental Health Association, Ontario.

Fox, A. B., Earnshaw, V. A., Taverna, E. C., & Vogt, D. (2018). Conceptualizing and measuring mental illness stigma: The mental illness stigma framework and critical review of measures. *Stigma and Health, 3*(4), 348. https://dx.doi.org/10.1037%2Fsah0000104

Galderisi, S., Heinz, A., Kastrup, M., Beezhold, J., & Sartorius, N. (2015). Toward a new definition of mental health. *World psychiatry: official journal of the World Psychiatric Association (WPA)*, *14*(2), 231–233. doi:10.1002/wps.20231.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon & Schuster.

Hamilton Wilson, J., & Conroy, S. (2012). *First Episode Psychosis: The Experience of Parent Caregivers* [ProQuest Dissertations Publishing]. http://search.proquest.com/docview/1152020928/

Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a fundamental cause of population health inequalities. *American Journal of Public Health*, *103*(5), 813–821. https://doi.org/10.2105/AJPH.2012.301069

Henderson, C., Evans-Lacko, S., & Thornicroft, G. (2013). Mental illness stigma, help seeking, and public health programs. *American Journal of Public Health*, *103*(5), 777–780. https://doi.org/10.2105/AJPH.2012.301056

Hipes, C., Lucas, J., Phelan, J. C., & White, R. C. (2016). The stigma of mental illness in the labor market. *Social Science Research*, *56*, 16-25. S0049089X15001969 https://doi.org/10.1002/casp.2221

Huggett, C., Birtel, M. D., Awenat, Y. F., Fleming, P., Wilkes, S., Williams, S., & Haddock, G. (2018). A qualitative study: experiences of stigma by people with mental health problems. *Psychology and Psychotherapy: Theory, Research and Practice*, *91*(3), 380-397. DOI: 10.1111/papt.12167

Jacob, K. S., Sharan, P., Mirza, I., Garrido-Cumbrera, M., Seedat, S., Mari, J. J., Sreenivas, V, & Saxena, S. (2007). Mental health systems in countries: where are we now?. *The Lancet*, *370*(9592), 1061-1077.

Kadri, N., & Sartorius, N. (2005). The global fight against the stigma of schizophrenia. *PLoS Medicine*, *2*(7), e136.

Knaak, S., Mantler, E., & Szeto, A. (2017, March). Mental illness-related stigma in healthcare: Barriers to access and care and evidence-based solutions. In *Healthcare management forum* (Vol. 30, No. 2, pp. 111-116). Sage CA: Los Angeles, CA: SAGE Publications.

Knaak, S., Patten, S., & Ungar, T. (2015). Mental illness stigma as a quality-of-care problem. *Lancet Psychiatry*, *2*(10), 863-864. DOI: 10.1016/S2215-0366(15)00382-X

Koschorke, M., Padmavati, R., Kumar, S., Cohen, A., Weiss, H. A., Chatterjee, S., Pereira, J., Naik, S., John, S., Dabholkar, H., & Balaji, M. (2017). Experiences of stigma and discrimination faced by family caregivers of people with schizophrenia in India. *Social Science & Medicine*, *178*, 66-77. http://dx.doi.org/10.1016/j.socscimed.2017.01.061

Kulik, C. T., Bainbridge, H. T., & Cregan, C. (2008). Known by the company we keep: Stigma-by-association effects in the workplace. *Academy of Management Review*, *33*(1), 216-230. https://doi.org/10.5465/amr.2008.27752765

Larson, J. E., & Corrigan, P. (2008). The stigma of families with mental illness. *Academic Psychiatry*, *32*(2), 87-91. http://dx.doi.org/10.1176/appi.ap.32.2.87

Link, B. & Phelan, J. (2001). Conceptualizing stigma. *Annual Review of Sociology* 27:363-385. DOI: https://doi.org/10.1146/annurev.soc.27.1.363

Livingston, J. D. (2013). Mental illness-related structural stigma: The downward spiral of systemic exclusion. Calgary, Alberta: Mental Health Commission of Canada. Retrieved from www.mentalhealthcommission.ca. Accessed August 12, 2020.

Manderscheid, R. W., Ryff, C. D., Freeman, E. J., McKnight-Eily, L. R., Dhingra, S., & Strine, T. W. (2010). Evolving definitions of mental illness and wellness. *Preventing Chronic Disease*, *7*(1), A19.

Mascayano, F., Armijo, J. E., & Yang, L. H. (2015). Addressing stigma relating to mental illness in low-and middle-income countries. *Frontiers in Psychiatry*, *6*, 38.

Mascayano, F., Toso-Salman, J., Ho, Y. C. S., Dev, S., Tapia, T., Thornicroft, G., Cabassa, L.J., Khenti, A., Sapag, J., Bobbili, S.J., & Alvarado, R. (2020). Including culture in programs to reduce stigma toward people with mental disorders in low-and middle-income countries. *Transcultural Psychiatry*, *57*(1), 140-160. https://doi.org/10.1177/1363461519890964

Mental Health Commission of Canada. (2012). Changing Directions, Changing Lives: The Mental Health Strategy for Canada. Calgary: Alberta. Retrieved from http://strategy.mentalhealthcommission.ca/download/

Mental Health Commission of Canada. (2013). Making the case for investing in mental health in Canada. *Ottawa, ON: Mental Health Commission of Canada*. Retrieved from https://www.mentalhealthcommission.ca/sites/default/files/201606/Investing_in_Mental_Health_FINAL_Version_ENG.pdf.

Mental Health Commission of Canada. (2014). Overview of Mental Health Data in Canada: Background, Needs, and Gaps, Calgary, AB. Retrieved from https://www.mentalhealthcommission.ca.

Mfoafo-M'Carthy, M., & Sossou, M. A. (2017). Stigma, discrimination, and social exclusion of the mentally ill: The case of Ghana. *Journal of Human Rights and Social Work, 2*(4), 128-133.

Mills, C. (2018). From 'invisible problem 'to global priority: The inclusion of mental health in the sustainable development goals. *Development and Change*, *49*(3), 843-866.

National Academies of Sciences, Engineering, and Medicine. (2016). *Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change*. Washington, DC: The National Academies Press. https://doi.org/10.17226/23442.

National Institute of Mental Health. (2019). Mental Health Information. Retrieved from https://www.nih.gov/about-nih/what-we-do/nih-almanac/national-institute-mental-health-nimh.

Ngui, E. M., Khasakhala, L., Ndetei, D., & Roberts, L. W. (2010). Mental disorders, health inequalities and ethics: A global perspective. *International Review of Psychiatry (Abingdon, England)*, *22*(3), 235–244. https://doi.org/10.3109/09540261.2010.485273

Nukunya, G. K. (2003). *Tradition and change in Ghana: introduction to sociology*. Second edition. Accra: Ghana Universities Press.

Nyblade, L., Stockton, M. A., Giger, K., Bond, V., Ekstrand, M. L., Mc Lean, R., ... & Turan, J. (2019). Stigma in health facilities: why it matters and how we can change it. *BMC Medicine*, *17*(1), 25. DOI: https://doi.org/10.1186/s12916-019-1256-2

O’Brien, A., Ashby, G. A., White, S., & Crame, J. (2015). What do general psychiatrists do? A question posed to medical students and the general population. *Journal of Mental Health*, *24*(3), 126-128. DOI: 10.3109/09638237.2014.971149

O’Reilly, C. L., Paul, D., McCahon, R., Shankar, S., Rosen, A., & Ramzy, T. (2019). Stigma and discrimination in individuals with severe and persistent mental illness in an assertive community treatment team: Perceptions of families and healthcare professionals. *International Journal of Social Psychiatry*, *65*(7-8), 570-579. DOI: 10.1177/0020764019867358

Östman, M., & Kjellin, L. (2002). Stigma by association: psychological factors in relatives of people with mental illness. *The British Journal of Psychiatry*, *181*(6), 494-498.

Park, S., & Park, K. S. (2014). Family stigma: A concept analysis. *Asian Nursing Research*, *8*(3),165-171. https://doi.org/10.1016/j.anr.2014.02.006

Patel, V., Saxena, S., Lund, C., Thornicroft, G., Baingana, F., Bolton, P., Chisholm, D., Collins, P.Y., Cooper, J.L., Eaton, J., & Herrman, H. (2018). The Lancet Commission on global mental health and sustainable development. *The Lancet*, *392*(10157), 1553-1598. https://doi.org/10.1016/S0140-6736(18)31612-X

Patten, S. B. (1999). Long-term medical conditions and major depression in the Canadian population. *The Canadian Journal of Psychiatry*, *44*(2), 151-157.

Patten, S. B., Williams, J. V., Lavorato, D. H., Bulloch, A. G., Charbonneau, M., Gautam, M., Moss, P., Abbey, S., & Stuart, H. (2016). Perceived stigma among recipients of mental health care in the general Canadian population. *The Canadian Journal of Psychiatry*, *61*(8), 480-488.

Paul, S., & Nadkarni, V. V. (2017). A qualitative study on family acceptance, stigma and discrimination of persons with schizophrenia in an Indian metropolis. *International Social Work*, *60*(1), 84-99. https://doi.org/10.1177%2F0020872814547436

Pearson, C. (2015). *The impact of mental health problems on family members*. Statistics Canada. Retrieved from https://www150.statcan.gc.ca/n1/pub/82-624-x/2015001/article/14214-eng.pdf .

Pearson, C., Janz, T., & Ali, J. (2013). Mental and substance use disorders in Canada. Health at a glance. Statistics Canada Catalogue no. 82-624-X. http://www.statcan.gc.ca/pub/82-624-x/2013001/article/11855- eng.htm

Phelan, J. C., Bromet, E. J., & Link, B. G. (1998). Psychiatric illness and family stigma. *Schizophrenia Bulletin*, *24*(1),115-126. https://doi.org/10.1093/oxfordjournals.schbul.a033304

Pirkis, J., Burgess, P., Hardy, J., Harris, M., Slade, T., & Johnston, A. (2010). Who cares? A profile of people who care for relatives with a mental disorder. *Australian & New Zealand Journal of Psychiatry*, *44*(10), 929-937.

Public Health Agency of Canada. (2006). The human face of mental health and mental illness in Canada 2006. Retrieved from https://www.phac-aspc.gc.ca/publicat/human-humain06/pdf/human_face_e.pdf. Accessed on June 27, 2020.

Public Health Agency of Canada. (2019). Data blog: Mental illness in Canada. Retrieved from https://health-infobase.canada.ca/datalab/mental-illness-blog.html.

Ratnasingham, S., Cairney, J., Manson, H., Rehm, J., Lin, E., & Kurdyak, P. (2013). The burden of mental illness and addiction in Ontario. *The Canadian Journal of Psychiatry*, *58*(8), 529-537.

Rüsch, N., Angermeyer, M. C., & Corrigan, P. W. (2005). Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma. *European psychiatry*, *20*(8), 529-539. Doi:10.1016/j.eurpsy.2005.04.004

Sartorius, N. (2010). Short-lived campaigns are not enough. *Nature*, *468*(7321), 163-165. https://doi.org/10.1038/468163a

Sartorius, N., & Schulz, H. (2005). Reducing the stigma of mental illness: A report from a global association. New York: Cambridge University Press

Schulze, B., & Angermeyer, M. C. (2003). Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives, and mental health professionals. *Social Science & Medicine*, *56*(2), 299–312. DOI: 10.1016/s0277-9536(02)00028-x

Stangl, A. L., Earnshaw, V. A., Logie, C. H., Van Brakel, W., C. Simbayi, L., Barré, I., & Dovidio, J. F. (2019). The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Medicine*, *17*, 1-13. https://doi.org/10.1186/s12916-019-1271-3

Stuart H. (2016). Reducing the stigma of mental illness. *Global mental health (Cambridge, England)*, *3*, e17. https://doi.org/10.1017/gmh.2016.11

Stuart H, Arboleda-Flórez J, Sartorius N (2012). *Paradigms Lost: Fighting Stigma and the Lessons Learned*. Oxford University Press: Oxford.

Stuart, H., & Sartorius, N. (2022). *Paradigms lost, paradigms found: lessons learned in the fight against stigma to mental illness.* New York, NY: Oxford University Press

Stuart, H., Arboleda-Florez, J., & Sartorius, N. (2011). *Paradigms lost: fighting stigma and the lessons learned*. Oxford University Press.

Stuart, H., Patten, S. B., Koller, M., Modgill, G., & Liinamaa, T. (2014). Stigma in Canada: results from a rapid response survey. *The Canadian Journal of Psychiatry*, *59*(1_suppl), 27-33.

Szeto, A. C., & Dobson, K. S. (2010). Reducing the stigma of mental disorders at work: a review of current workplace anti-stigma intervention programs. *Applied and Preventive Psychology*, *14*(1-4), 41-56. https://doi.org/10.1016/j.appsy.2011.11.002

Szeto, A., Dobson, K. S., Luong, D., Krupa, T., & Kirsh, B. (2019). Workplace Anti-stigma Programs at the Mental Health Commission of Canada: Part 1. Processes and Projects. *The Canadian Journal of Psychiatry*, *64*(1_suppl), 5S-12S.

The Mental Health Foundation. (2016). Fundamental Facts about mental health 2016 [online]. Available from: https://www.mentalhealth.org.uk/publications/fundamental-facts-about-mental-health-2016 .

Thornicroft, G., Sunkel, C., Aliev, A. A., Baker, S., Brohan, E., El Chammay, R., ... & Winkler, P. (2022). The Lancet Commission on ending stigma and discrimination in mental health. *The Lancet*, *400*(10361), 1438-1480.

Ungar, T., Knaak, S., & Szeto, A. C. (2016). Theoretical and practical considerations for combating mental illness stigma in health care. *Community Mental Health Journal*, *52*(3), 262-271. DOI 10.1007/s10597-015-9910-4

United States Department of Health and Human Services. (1999). Mental health: a report of the Surgeon General. Retrieved from http://www.surgeongeneral.gov/library/mentalhealth/home.html

van der Sanden, R. L. M., Bos, A. E. R., Stutterheim, S. E., Pryor, J. B., & Kok, G. (2013). Experiences of stigma by association among family members of people with mental illness. *Rehabilitation Psychology, 58*(1), 73–80. https://doi.org/10.1037/a0031752

van Der Sanden, R. L., Bos, A. E., Stutterheim, S. E., Pryor, J. B., & Kok, G. (2015). Stigma by association among family members of people with a mental illness: A qualitative analysis. *Journal of Community & Applied Social Psychology*, *25*(5), 400-417.

van der Sanden, R. L., Pryor, J. B., Stutterheim, S. E., Kok, G., & Bos, A. E. (2016). Stigma by association and family burden among family members of people with mental illness: the mediating role of coping. *Social Psychiatry and Psychiatric Epidemiology*, *51*(9), 1233-1245. https://doi.org/10.1007/s00127-016-1256-x

World Health Organisation (2010). Mental health and development: Targeting people with mental health conditions as a vulnerable group. WHO Press, Geneva. Retrieved from https://www.mhinnovation.net/resources/who-mental-health-and-development-targeting-people-mental-health-conditions-vulnerable

World Health Organization. (1948). WHO definition of health. In *Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference*.

World Health Organization. (2004). Promoting mental health: Concepts, emerging evidence, practice: Summary report. Retrieved from https://www.who.int/mental_health/evidence/en/promoting_mhh.pdf .

World Health Organization. (2007). Breaking the vicious cycle between mental ill-health and poverty. *Geneva: Mental health core to development information sheet*.

World Health Organization. (2007). Breaking the vicious cycle between mental ill-health and poverty. *Geneva: Mental health core to development information sheet*. Retrieved from https://www.who.int/mental_health/policy/development/1_Breakingviciouscycle_Infosheet.pdf.

World Health Organization. (2008). *The global burden of disease: 2004 update*. World Health Organization. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/43942/9789241563710_eng.pdf .

World Health Organization. (2008). *The global burden of disease: 2004 update*. World Health Organization. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/43942/9789241563710_eng.pdf .

World Health Organization. (2012). Risks to mental health: An overview of vulnerabilities and risk factors. *Geneva: WHO*. Retrieved from https://www.who.int/mental_health/mhgap/risks_to_mental_health_EN_27_08_12.pdf.

World Health Organization. (2019). The WHO Special Initiative for Mental Health (2019-2023): universal Health Coverage for Mental Health. Available from: https://apps.who.int/iris/handle/10665/310981.

World Health Organization. (2020). Adolescent mental health. Retrieved from https://www.who.int/news-room/fact-sheets/detail/adolescent-mental-health.

Chapter 2 – Meta-Synthesis

This chapter puts forward a critical overview of existing literature on mental illness stigma with a specific emphasis on familial mental illness stigma. A qualitative meta-synthesis of empirical literature was conducted on experiences of familial mental illness stigma among individuals living with mental illnesses in high-income countries to contextualize the extent of the problem. The fundamental aim of this chapter is to take a rigorous analysis of the extant literature with a focus on familial mental illness stigma in high-income countries to pinpoint existing gaps. This chapter is published as:

Experiences of Familial Stigma among Individuals Living with Mental Illnesses: A Meta-Synthesis of Qualitative Literature from High-Income Countries

Adu, J., Oudshoorn, A., Anderson, K., Marshall, C. A., & Stuart, H. (2022). Experiences of Familial Stigma among Individuals Living with Mental Illnesses: A Meta-Synthesis of Qualitative Literature from High-Income Countries. *Journal of Psychiatric and Mental Health Nursing*. https://doi.org/10.1111/jpm.12869

Abstract

Introduction: Familial mental illness stigma is a pervasive issue but very subtle in high-income countries. Familial mental illness stigma implies persons living with mental illnesses are discriminated against by their family members or close relatives.

Aim/Question: This meta-synthesis explored the experiences of familial stigma among individuals living with mental illnesses in high-income countries, focusing on empirical literature, to understand the breadth of current literature and ways to reduce this form of stigma.

Method: We conducted a meta-synthesis through a structured search of qualitative data from six electronic databases (Sociological Abstract, CINAHL, Medline, PsycINFO, Google Scholar, and Embase). Inclusion criteria comprised: empirical primary research, primary technique for data collection is qualitative, studies published in a peer-reviewed journal in the English language between 2000 to 2020, studies reported on experiences of familial mental illness stigma, and studies conducted in high-income countries. The exclusion criteria were: all grey literature, studies not written in English and non peer-reviewed, studies not focused on familial mental illness stigma, quantitative peer-reviewed articles on the related concept, and peer-reviewed articles on the related topic before the year 2000.

Results: The study identified only 28 peer-reviewed articles on the topic within two decades. Concealment of familial stigma was found to be detrimental due to the potential for alienation within one's home environment. Disclosure and social contact within the family system were considered as critical interventions to provide some safety-nets for individuals with mental illnesses.

Discussion and implications for practice: The paucity of studies over the review period highlights the need for further attention to support optimal environments for persons living with mental illnesses. Families' understanding of the difficulties of mental illness stigma is vital to supporting the development of policies and interventions towards the avoidance of social exclusion within societies. Families should make concerted efforts to reduce stigma, and this includes within the family system. Education and training approaches around mental illness-related stigma should involve individuals with lived experience and their families, as well as service providers and the general public.

Key words: familial stigma, associative stigma, mental illness, discrimination, psychiatric disorders

Accessible Summary

What is known on the subject?

- Mental illness stigma has been long acknowledged as a social problem that continues to persist and contribute to social exclusion of affected persons globally.
- Researchers have explored mental illness stigma in the general public and among health professionals, with little focus on stigma from family members and close relatives of persons with mental illnesses.

What the paper adds to existing knowledge?

- This study appears to be the first meta-synthesis on familial mental illness stigma in high-income countries.
- Family members or close relatives of persons with mental illnesses may be perpetrators of stigma. That is, the family may enact stigma of mental illness against their relative to 'save face' or by avoiding or narrowing their social contacts.
- Familial stigma is harmful due to the likely disaffection it brings within one's home environment. Familial mental stigma from the existing literature seems to be a by-product of public stigma and stigma by association

Implications for practice?

- Further research is necessary to look at the existence of familial mental illness stigma as well as available policies to reduce its impact on affected individuals in high-income countries.
- Researchers in high-income countries should endeavour to examine the relationship between familial, public, and associative stigma to establish baseline metrics to inform future anti-stigma programs seeking to reduce familial mental illness stigma.

2.1 Background

Mental illnesses are one of the leading contributors to the global burden of disease, accounting for 7.4% of all illnesses, which makes these an important public health concern (Becker & Kleinman 2013; Mollica et al., 2004; Whiteford et al., 2013). The rise in mental illnesses is seen as a priority issue due to its significant contribution to years lived with disability (YLDs) worldwide (Mollica et al., 2004; Rehm & Shield, 2019; WHO, 2014). YLDs are "years of healthy life lost due to time spent in a less than-optimal functional health status because of a specific health condition" (Martel & Steensma, 2012, p.4). The primary causes of YLDs are mental and substance-use disorders ─ it is estimated that mental and substance-use disorders constitute over 25% of global YLDs (Mollica et al., 2004; Whiteford et al., 2013). Similarly, but at an even higher rate, Vigo et al. (2016) argued that mental and substance-use disorders represent approximately one-third of global YLDs. Likewise, Rehm and Shield (2019) raised concern on the increase in mental illnesses "(i.e., accounting for 7% of all global burden of disease as measured in disability adjusted life years (DALYs) and 19% of all years lived with disability)", which is driven in part by stigma, absence of treatment, and paucity of research (p. 1). Stigma herein implies a process whereby labelling, stereotyping, separation, status loss, and discrimination co-occur in the context of power (Link & Phelan, 2006). Higher proportions of people affected by these conditions live in high- and upper-middle-income countries (National Institute of Mental Health, 2019; Public Health Agency of Canada, 2019; Rehm & Shield, 2019). For instance, data from Canada shows that one in five persons live with a mental illness, with over 6.7 million of the population experiencing mental illnesses since 2011 (Mental Health Commission of Canada, 2016). The situation is concerning and thus calls for multi-disciplinary approaches to confront the occurrences of mental illnesses and to reduce the impact of any related stigma on affected persons and their families.

Mental illness stigma is a form of stigma connected with psychiatric disorders, which is ingrained in cultures and functions within all levels of society, with the potential to devalue persons with mental illnesses in the eyes of others and further deprive them of full participation in society (Henderson & Gronholm, 2018; Link et al., 2004; Stuart, 2017). Mental illness-related stigma can result in undue stress on persons with mental illnesses and their families, knowing that most people with mental illnesses maintain close relationships with family members for social support (Canadian Mental Health Association [CMHA], 2007, 2018; Chadda, 2014). The pivotal roles played by close relatives in the care of persons with major mental illnesses have increased globally since the advent of the deinstitutionalization (Talley et al., 2014), which has led to a rise in community-based care hospitalization (Mental Health Commission of Canada, 2009; Talley et al., 2014).

In the context of both social and caregiving pressures, it is noted that family members themselves at times will stigmatize their relatives with mental illnesses. The literature on family members as perpetrators of stigma is notably limited, compared to other forms of mental illness stigma (Aldersey & Whitley, 2015; Barnable et al., 2006; Clarke & Winsor, 2010). Studies in this area have concentrated on social stigma experienced by people with mental illness, their family members, and impacts of associative stigma on family members (Allerby et al., 2015; Catthoor et al., 2015; Corrigan & Miller, 2004; Krupchanka et al., 2016; van Der Sanden et al., 2015). Associative stigma has been described as the process by which a person is stigmatized by virtue of an association or close relationship with another stigmatized individual (Gyamfi, 2016; Östman & Kjellin, 2002). For example, Allerby et al. (2015), in their study on stigma and burden among relatives of persons with schizophrenia, concluded that mental illness stigma negatively affects the quality of life of both individuals with mental illnesses and their family. Again, Catthoor et al. (2015) assessed the presence and severity of associative stigma among family members of persons with psychosis and reported an increased prevalence of associative stigma, with many family members experiencing symptoms of depression which eventually weakened relationships. That said, Corrigan and Miller (2004) reviewed the impact of mental illness stigma on family members and revealed that relatives of persons with mental illnesses are often accused of triggering their children’s mental illnesses whilst their wives are censured for not ensuring that their husbands with mental illnesses follow treatment plans. Krupchanka and colleagues (2016) studied experiences of stigma in the private lives of relatives of people diagnosed with schizophrenia and identified anticipated stigma, separation of families, feelings of guilt, fear, and anticipatory anxiety as reasons for non-disclosure of their ailment to avoid other family members. In the same vein, van Der Sanden et al. (2015) investigated stigma by association among family members of people with mental illnesses and found that family members were stigmatized by community members, mental health professionals, and civil servants, with close relatives suffering high levels of associative stigma than extended family members. These studies from high income countries point to a link between associative and familial stigma with respect to mental illnesses within the family system. The results indicate that family members endure high levels of stigma and its associated negative outcomes relative to negative public descriptions of mental illness, structural discrimination against mental illness, stigma encountered in everyday life, psychological distress, and coping with stigma.

This meta-synthesis, therefore, seeks to explore the existing literature on familial mental illness stigma among individuals with mental illnesses in high-income countries, with a focus on peer-reviewed papers, to understand the breadth of current literature and to provide guidance to a primary study. High income countries were selected as this synthesis was to provide guidance for mental health stigma research in a primary study, and the goal was to include healthy systems with a degree of similarity sufficient to be comparable. In particular, the focus is on what is known about the human experience of this form of stigma and therefore the review is limited to qualitative literature. Qualitative approaches to research offer a thick description and rich insights into persons' experiences of a given phenomenon (mental illness stigma) from the viewpoints of the individuals living with the identified problem. Furthermore, qualitative strategies are particularly applicable when dealing with sensitive social issues Charmaz (2000) and Denzin (2008), such as experiences of mental illnesses stigma from the perspectives of persons and close relatives living with the problem. Familial mental illness stigma is a form of stigma experienced by persons from within the family or close relatives due to their mental health status (Adu et al., 2021).

2.3 Methods

This meta-synthesis aims to examine the experiences of familial stigma among persons living with mental illnesses to appreciate the nature and extent of what is known about how family members may stigmatize their relatives, and what can be done to reduce it. A meta-synthesis is a form of review involving an interpretive integration of qualitative findings involving consistent accounts of a phenomenon that offers insightful analysis of the reviewed data (Sandelowski & Barroso, 2007). A review of the qualitative literature on familial mental illness stigma is provided to address the following questions: What are the experiences of stigma among persons with mental illnesses from their family members? What forms of stigma are experienced by persons with mental illnesses from their family members?

This study employed a methodological framework established by Arksey and O'Malley (2005), consisting of five steps: (1) identifying the research question; (2) identifying relevant studies; (3) selecting appropriate studies; (4) charting the data/data extraction; and (5) collating, summarizing, and reporting the results. The review method is effective in defining the current scope of peer-reviewed studies and to ascertain knowledge gaps, given the comprehensive nature of the research question that underpins the study. The review is guided by a broader research question and a quality assessment of all included studies. This current meta-synthesis adheres to the reporting principles outlined in PRISMA and COREQ [Consolidated criteria for reporting qualitative research for systematic reviews and meta-syntheses] (Tong et al., 2007). Our meta-synthesis also took into consideration indications of Tong et al. (2012) in the 'enhancing transparency in reporting the synthesis of qualitative research' (ENTREQ) statement. The ENTREQ statement comprises of 21 items categorized into five main domains: introduction, methods and methodology, literature search and selection, appraisal, and synthesis of findings.

In addition, the research team subjected all included articles in this study to quality assessment using the Eight "Big-Tent" Criteria for Excellent Qualitative Research, comprising (a) worthy topic, (b) rich rigor, (c) sincerity, (d) credibility, (e) resonance, (f) significant contribution, (g) ethics, and (h) meaningful coherence (Tracy, 2010). Worthy topic implies how applicable, timely, and significant the selected article is to our study. Rich rigor talks about the theoretical construct and scientific approaches to data collection and analysis processes of included studies. Sincerity denotes the researcher's positionality and self-reflexivity to reduce biases, and ensures transparency in the methods employed. Credibility herein describes the trustworthiness or confidence of the study findings with respect to triangulation, thick description of data, and multivocality. Ethics and meaningful coherence reflect on whether the researcher followed due processes to obtain ethical clearance prior to data collection and if the study attained it intended purposes, respectively.

2.3.1 Search strategy

A search was conducted using the following databases: Sociological Abstract, CINAHL, Medline, PsycINFO, Google Scholar, and Embase from 2000-2020 to know the depths of literature on the topic within the immediate past two decades. Search terms employed included a combination of the following: family, famil*, husband*, wife*, mother*, sibling*, sister or sister-in-law, father*, father-in-law, uncle*, paternal uncle or maternal uncle, aunt maternal aunt/paternal /brother /brother-in law, grandfather/grandmother/ grandchild*, and family relation*. Additional terms considered in the retrieval of articles were: stigma*, social stigma, discrimination*, shame*, disgust, as well as mental disease, mental illness, mental disorder*, mental illness stigma, psychiatric disorder*, familial stigma, and associative stigma. We combined the search terms with Boolean “OR/AND” to ensure more focused and productive results on familial mental illness stigma. See figure 1 below (Medline search strategy) for details of our search strategy.

Search terms/ parameters
1 exp Family/ or family*.mp. or exp Family Relations/ or exp Nuclear Family/
2 exp Humans/ or exp Family/ or famil*.mp.
3 exp Humans/ or exp Spouses/ or exp Marriage/ or husband*.mp.
4 exp Spouse Abuse/ or Female/ or exp Marriage/ or wife*.mp. or Male/ or exp Spouses/
5 Mother-Child Relations/ or mother*.mp.
6 exp Adult/ or exp Male/ or exp Sibling Relations/ or exp Bipolar Disorder/ or exp Female/ or exp Child/ or exp Siblings/ or sibling*.mp. or exp Adolescent/
7 sister*.mp. or exp Female/
8 sister-in-law.mp. or exp Female/ or exp Adult/
9 exp Mothers/ or father*.mp. or exp Fathers/ or exp Female/ or exp Adolescent/ or exp Male/ or exp Adult/
10 exp Male/ or exp Adult/ or exp Adolescent/ or uncle*.mp. or exp Female/ or exp Family/
11 exp Adolescent/ or exp Family/ or exp Female/ or exp Adult/ or aunt*.mp. or exp Male/
12 maternal*.mp.
13 exp Male/ or exp Adult/ or exp Family/ or "paternal uncle*".mp. or exp Female/
14 exp Siblings/ or exp Male/ or brother*.mp.
15 exp Marriage/ or brother-in-law.mp. or exp Family Relations/
16 exp Grandparents/ or grandfather*.mp. or exp Family/
17 exp Family/ or exp Mothers/ or grandmother*.mp. or exp Grandparents/
18 exp Family/ or exp Child/ or exp Female/ or exp Male/ or grandchild*.mp.
19 exp Family/ or exp Adult/ or exp Male/ or exp Child/ or exp Adolescent/ or exp Female/ or "family relation*".mp. or exp Family Relations/
20 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
21 exp Mental Disorders/ or exp Adult/ or exp Social Stigma/ or exp Stereotyping/ or stigma*.mp. or exp Female/ or exp Male/
22 exp Adult/ or "social stigma".mp. or exp Social Stigma/ or exp Attitude to Health/
23 exp Social Discrimination/lj [Legislation & Jurisprudence]
24 discrimination*.mp.
25 exp Shame/ or shame*.mp. or exp Guilt/
26 exp Social Stigma/ or disgrace*.mp. or exp Stereotyping/ or exp Mental Disorders/
27 Fear/ or exp Emotions/ or exp Disgust/ or disgust*.mp.
28 exp Mental Disorders/ or exp Stereotyping/ or exp Social Stigma/ or "associative stigma".mp.
29 exp Social Stigma/ or "courtesy stigma".mp. or exp Stereotyping/
30 exp Stereotyping/ or "stigma by association".mp. or exp Depression/ or exp Social Stigma/
31 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30
32 exp Depression/ or exp Mental Disorders/ or mental disease*.mp. or exp Schizophrenia/
33 exp Schizophrenia/ or exp Mental Disorders/ or mental illness*.mp.
34 exp Depression/ or exp Mental Disorders/ or exp Depressive Disorder, Major/ or mental disorder*.mp. or exp anxiety disorders/
35 exp Mental Disorders/ or exp Stereotyping/ or exp Prejudice/ or "mental illness stigma".mp. or exp Social Stigma/
36 "psychiatric disorder".mp. or exp Mental Disorders/
37 exp Social Stigma/ or exp Mental Disorders/ or exp Stereotyping/ or "familial mental illness stigma".mp.
38 exp Stereotyping/ or exp Social Stigma/ or exp Mental Disorders/ or "mental illness stigma from family members".mp.
39 32 or 33 or 34 or 35 or 36 or 37 or 38
40 20 and 31 and 39
41 limit 40 to (abstracts and English language and full text and humans and yr="2000 - 2020" and "young adult and adult

Figure 1. Sample Search Strategy – Medline

2.3.2 Inclusion and exclusion criteria

Articles were screened at the title and abstract stage, and articles remaining at the full-text review stage were read in full. Studies were included if they were: (1) empirical primary research; (2) primary technique for data collection is qualitative; (3) the study was published in a peer-reviewed journal in English between 2000 to 2020; (4) reported on experiences of familial mental illness stigma; and (5) study was conducted in any high-income country. High-income countries are nations with gross national income (GNI) per capita of $12,056 or more which is estimated by adding gross domestic product to determine incomes from overseas residents, then deducting all income earned by non-residents (World Population Review, 2021). Mental illnesses or disorders herein are consistent with the DSM-5 and comprise: Schizophrenia, Mood disorders (Depression – major and minor, Bipolar disorders – Bipolar I (mania), Bipolar II (mixture of major depression and hypomania), Anxiety disorders (Panic disorders, Phobias, and Generalized anxiety disorders) (see America Psychiatric Association, 2018, 2022). Studies were excluded if they were: 1) grey literature; 2) not written in English; 3) not focused on familial mental illness stigma, quantitative peer-reviewed articles on the related concept, and peer-reviewed articles on the related topic before the year 2000. The inclusion and exclusion criteria outlined enabled us to critically examine the literature within the confines of the study and to identify any current research gaps. The search results were saved in .ris files and imported into Covidence^{TM} (Veritas Health Innovation, 2016), a review software designed for organizing abstracts, removing duplicates, and data extraction.

2.3.3 Data extraction

Three researchers screened the titles and abstracts of all initial selected studies.
All identified conflicts during the screening process were resolved through team consensus, which involved discussion of each article with a conflict among all researchers who participated in the screening exercise.

Full-text articles of retrieved data were examined for inclusion by the research team. The team extracted relevant information from each included study using a Microsoft Word processor which was inclusive of all extracted citations under the following headings: author and year of publication, study location, objectives, study design/method, study population and sample, and key findings. The data gathered for the review were initially summarized in the form of a table. See Table 1 (Characteristics of included studies) for details. We then did a content analysis of all 28 included studies which involved first immersion in the data through reviewing the extracted data, assigning of preliminary codes, reviewing, and discussing the codes as a research team, and proposing and refining themes, organizing the articles via these themes and looking for gaps or duplications (Braun & Clarke, 2006; Miles et al., 2013).

2.4 Results

The initial literature search yielded 16,031 studies with 6,836 duplicates from the six databases, resulting in 9,195 unique studies. Nine thousand, one hundred and ninety-five (9,195) titles and abstracts were screened, in accordance with the inclusion and exclusion criteria. Title and abstract screening as well as full-text review were completed to determine the exact number of articles that met the study eligibility. Eight thousand, eight-hundred and eighty-four (8,884) studies were excluded from the review at the end of the title and abstract review due to the following reasons: wrong study locations and topics, wrong study design, and the study being out of scope of the current review. Two hundred and eighty-five (285) studies out of the 311 were further excluded at full-text review because they did not meet the inclusion criteria. See the Flow chart diagram for details. Ultimately, 26 studies met the inclusion criteria from the primary search. We added two articles that aligned with the study objective that were found from the reference lists of included studies but were not identified in the initial search. In total, 28 peer-review articles were included in the review. Articles removed at the full-text stage and reasons for exclusion are detailed in Figure 2 below.

FIGURE 2 HERE

2.4.1 General characteristics of included studies

The overall characteristics of studies included in this meta-synthesis are described in Table 2 below. All 28 peer-reviewed articles were published between 2001 and 2020, with 78.6% (22/28) published between 2011 and 2020. Only two studies included in the analysis were published between 2001 and 2005 and the last four studies were published between 2006 and 2010.

Table 2. Table displaying country of origin for all included studies (n = 28)

Year of publication	**Country of study**	**n (%)**
2001	UK	1 (3.57)
2003	Canada	1 (3.57)
2008	USA	1 (3.57)
2009	Taiwan, USA	2 (7.14)
2010	USA	1 (3.57)
2011	Australia, Taiwan	2 (7.14)
2012	USA, Canada	2 (7.14)
2013	Canada (2), USA (3), Israel	6 (21.43)
2014	UK, Puerto Rico	2 (7.14)
2015	Finland, Netherlands	2 (7.14)
2016	UK	1 (3.57)
2017	Greece, USA	2 (7.14)
2018	Czech Republic, USA (2)	3 (10.71)
2020	Sweden, USA	2 (7.14)
TOTAL		**28 (100)**

Table 1: Characteristics of all included studies

Author (s) & year of publication	**Country of study**	**Study population & sample size**	**Aims of the study**	**Research methodology & design**	**Key findings related to familial mental stigma**
Alexander, 2001	UK	Patients with a diagnosis of depression; sample size is 18 men	To find out whether a group of men with a diagnosis of depression had confidants; to establish who their confidants were; and to explore their reasons for not confiding in potential confidants.	Exploratory descriptive study	Concealment of thoughts and feelings to avoid worrying others. For example, one man was temporarily living apart from his wife and family in a group home because of the pressure to be 'normal' when with the family─ insecurity and lack of trust within the relationship not even my wife. Fear of abandonment and perceived or actual rejection.
Bonnington & Rose, 2014	United Kingdom (UK)	People diagnosed with BD or BPD; sample size is 29	This study explores experiences of stigma and discrimination amongst people diagnosed with bipolar disorder (BD) or borderline personality disorder (BPD)	Qualitative study/In-depth interviews and mini focus groups	Persons with mental illnesses (PWMI) marginalized from family and friendship relations as well as social roles and privileges. Families are motivated to normalise versus accept a loved one's illness to invite public stigma. Powerlessness and marginalisation were intertwined, "it was like being in a prison because my first husband and my dad they wouldn't let me out of the house/out of their sight and I was virtually locked up in my bedroom." Loss of status, "everyone [in the family] thinks they can tell me and my daughter what to do and I don't find it helpful."
Chen et al. 2013	USA	Chinese psychiatric patients (immigrants); sample size is 53	This study focused on mental illness disclosure in Chinese-immigrant communities in New York City	Qualitative/ in-depth interviews	PWMI reported personal and familial concerns of losing face and its negative social consequences. PWMI felt ashamed of having mental illness. Family members consider having a member with mental illness, specially one having the need for hospitalization to be shameful. Families strongly discourage PWMI to disclose the illness. Families restricted information sharing to those within the circle of confidence. Worried that disclosure could cause the family to be threatened or affect family members' future work or marriage.

Author (s) & year of publication	Country of study	Study population & sample size	Aims of the study	Research methodology & design	Key findings related to familial mental stigma
Choi & Kimbell, 2008	USA	Care managers (1 RN and 7 bachelor's-level social workers) and 1 MSW intern; 8 staff members (site managers, program specialists, & activity coordinators) from 4 senior centers; 2 sessions with a total of 14 family care- givers of older adults on Meals on Wheels (MOW) program clients, each with 7 participants with sample size of 131	To examine family caregivers' experiences of depression in their homebound loved ones and barriers to their loved ones seeking depression treatment; to collect suggestions from both social service providers and family caregivers about interventions for depression that can be integrated into existing aging service settings or implemented in older adults' homes.	Qualitative method and focus groups interview	Loss of independence, family conflicts, and a lack of social support from family other members. For example, caregivers had to either take their parent into their home or move in with their parent when the parent's health deteriorated resulting in increased sense of loss and grief. The grief is the result of isolation or loneliness and feelings of resentment, which in turn, complicate their depression.
Darmi et al., 2017	Greece	Parents of children with psychotic disorders. Sample size is 16, made up of 14 mothers and two fathers	Explore the parents' lived experience of caring for a child with psychosis	Hermeneutic phenomenology/ in-depth interviews	Exposure to marital problems, violent scenes, and spousal neglect, extreme distress over failed love relationships, refused to acknowledge that their son or daughter was mentally ill. Parents tended to normalize or deny the psychotic manifestations and delayed seeking psychiatric help. Parents liken their relationship with their loved one to a frightening 'stranger.
Elkington et al., 2013	USA	Youth and adolescent with mental illness. Sample size is 24.	Role of mental illness-related stigma on romantic or sexual relationships and sexual behavior among youth with mental illness — youths' experiences of stigma, internalization of these experiences, and the behavior associated with managing stigma within romantic and sexual relationships.	Hermeneutic phenomenology /in-depth interviews Qualitative/ in-depth interviews	Direct experiences of rejection by partners following a change in their relationships after revealing their diagnosis to their partner. Stigma within relationships, undeserving of romantic or sexual relationships. Fear of rejection and abandonment because of having a mental illness transformed itself into sexually passive behavior for a few youths. Participant described trying to get his girlfriend pregnant to maintain the relationship, despite not wanting to be a father.
Elliott et al., 2018	USA	Veterans of the recent Iraq and Afghanistan wars living in New York City with PTSD. Sample size is 50.	Examination of PTSD narratives— as voiced in qualitative interviews and focus groups with 50 veterans of the recent Iraq and Afghanistan wars living in New York City— attends to the processes through which veterans conceive and navigate PTSD symptoms and diagnoses.	Qualitative design/in-depth and focus group interviews	Family issues and dating were raised in the context of discussions about PTSD. PTSD diagnosis comprises serious vulnerability in attempting to secure joint custody of his child after a divorce — "I just put the claim in and I was scared to do it at first, because of my son. I don't want him taken away. A veteran explained how he had "hardly seen his family since separation." Another veteran recounted his recent

Author (s) & year of publication	Country of study	Study population & sample size	Aims of the study	Research methodology & design	Key findings related to familial mental stigma
					experience of a divorce and his struggle with the controversial stereotype of Black and alcoholic.
Franz et al., 2010	USA	African American family members directly involved in treatment initiation for a relative with first-episode psychosis. Sample size is 12.	Study explored the effects of stigma, as perceived by family members, on duration of untreated psychosis.	Qualitative/ in-depth interviews	Fear of an official label make relatives adopted at least four coping behaviours: external attribution, excusing, secrecy, and denial. Felt discomfort admitting that relatives suffered from a mental illness but at ease attributing their behaviours to external factors. Delay treatment to ensure secrecy and to avoid social stigma.
Frieh, 2020	USA	Women with serious mental illness. Sample size is 55.	Investigating how women hospitalised with SMI, especially those who have histories of sexual abuse and trauma, experience sexuality and perceive men and masculinity	Qualitative design/in-depth interviews	Women struggling with intimacy due to effects of trauma blamed themselves for not being able to deal with their problems. Women saw themselves as inadequate partners whose mental health problems, histories of abuse, and difficulty feeling comfortable with physical intimacy made them undesirable or broken. Woman expressed a fear that potential partners would leave her if they knew she had a mental illness ─ fear of being totally open and honest about her struggling. Experiences of stigma prevented women from pursuing relationships because they believe ‘people don’t want people with mental illnesses. Another woman asked, ‘who wants to have sex with a woman who has mental problems, sick, and ugly?
Hinton et al., 2017	USA	Stakeholders recruited, including 15 depressed older (i.e., age ≥ 60) men, 12 family members, and 10 clinic staff. Sample size is 37.	The study aimed to describe challenges in engaging family members in older men’s depression treatment and potential strategies to overcome those challenges.	Qualitative/ in-depth interviews	Strained relationships might make family involvement difficult. Referring to his wife, one man said: “It scares me sometimes because we’ll get on it about something like that right there, and she turns everything around that it’s my fault.” Marital relationships were frayed that partners were not willing to help.
Huang et al., 2009	Taiwan	Carers who live with someone with long-term schizophrenia, within the cultural context of Taiwan Sample size is 10.	The purpose of this study was to explore the experiences of carers who live with someone with long-term schizophrenia, within the cultural context of Taiwan.	Descriptive phenomenological approach & face-to-face interviews	Conflicts between client and family often happen when the family feel the client PWMI is ‘useless; "His brothers argue with him, sometimes fight with each other because he does not have a job and sits at home and gets looked after. They think he is a lazy, useless man". "My husband argues with me and he couldn’t accept my son just sitting or sleeping all day“. Feeling of shame and embarrassment are two of the major causes of family conflicts, especially for siblings of the client. Husband never brings friends

Author (s) & year of publication	**Country of study**	**Study population & sample size**	**Aims of the study**	**Research methodology & design**	**Key findings related to familial mental stigma**
					home as he doesn't want to let others know that his son has schizophrenia. Before my husband died, he rejected my son. I feel sad about my family life as I have a schizophrenic son.
Karnieli-Miller et al., 2013	USA	Family members of relatives' living with mental illness. Sample size is 14.	Exploring family members' experiences and efforts to cope with mental illness stigma in social encounters.	Qualitative design/focus group interviews	Family members choose to conceal their relative's illness due to potential negative consequences of disclosure and the "lesson learned" to conceal. Disclosure can be beneficial by helping to elicit support: "…my family members are supportive… they know…". Selective disclosure to avoid undue stigma and discrimination from some close relatives and loved ones. Parents struggled to determine whether it was their choice to disclose versus their relative's choice. Other family members also expressed concern that their relative's decision to disclose could be harmful. One mother said, "my daughter is ready to tell everybody, she wants to be an advocate, and I hold her [back], because I'm afraid for her, about what people would say.
Ketokivi, 2015	Finland	Finnish parents of mentally ill grown children (N = 8) and adults themselves suffering from mental health issues (N = 9). Sample size is 17.	This article examines how belonging in Finnish families is negotiated in the presence of mental illness.	Qualitative design /in-depth interviews	Discussed her illness with me quite easily until her husband, a retired judge, walked by. She whispered that he does not want these issues talked about. Mental health issues come with secrecy, shame, and stigma. Silence around depression was experienced by Sanna, who suffered from postnatal depression. Tuija became depressed and was hospitalised and her children were temporarily placed in foster care, and this led to complete estrangement from her family of origin because she was considered "unfit to be a mother". Sanna was able to talk about her depression to her parents even though she was not fully embraced. Reijo had a mental breakdown and fell into serious depression and his parents and siblings distanced themselves.
Koro-Ljungberg & Bussing, 2009	USA	Parents of children with ADHD. Sample size 30.	Investigating how parents of adolescents with attention deficit hyperactivity disorder (ADHD) manage courtesy stigma in their lives.	Qualitative/ face group interviews	Denial of ADHD by Val's husband could be explained by his courtesy stigma management and refusal to own a stigmatizing label that identifies his son. Her daughter with ADHD did not care about her appearance, whereas her other daughter was very particular about her looks. Her older sister was aggravated about her sister's behavior and the social

Author (s) & year of publication	**Country of study**	**Study population & sample size**	**Aims of the study**	**Research methodology & design**	**Key findings related to familial mental stigma**
					stigma it created for the family. Extra time and care given to the teenager with ADHD increase conflicts and disputes over attention due to limited resources and time available for other family members. Mother of a teen with ADHD who was continuously challenged by her daughter reported how she "called the COPS on her" because "she can be so overwhelming at times" and interactions with police officers "make her think."
Krupchanka et al., 2018	Czech Republic	Relatives of patients diagnosed with schizophrenia. Sample size is 25.	The study aimed to inform an anti-stigma campaign undertaken in the framework of the national mental health reform in the Czech Republic.	Qualitative/ in-depth interviews	Fear of the PWMI in the family. Believe in the incapability of persons with Schizophrenia (PLS). Endorsement of stereotypes within the family. Hopelessness and helplessness and worry about an unclear future ─ "I will not be here forever", and regrets about lost opportunities of "normal life". Within the family there were examples of prejudice toward PLS ─ a perception of schizophrenia as contagious. Some family members (a) presented fear of dangerousness of PLS, (b) believed in unreliability and incapability of PLS, or (c) distanced themselves from the PLS. Schizophrenia is an infectious disease, because I would not employ a problematic person, to have problems, when I can employ a normal person instead.
Ladd, 2018	USA	Women given a clinical diagnosis of a BD in the first year postpartum. Sample size is 15	The study addressed the problem of the lack of knowledge regarding the stigma of a diagnosis of bipolar disorder (BD) in the first year	Qualitative/ in-depth interviews	Women reported their partners as either not understanding the diagnosis, avoiding them, or suggesting women had control over the disorder. Women stated BD as something they can fix themselves ─ "he wouldn't be in the same room as I was. He thought it was something that I could just fix." My husband now does not understand or agree with the diagnosis. My spouse struggled with "separating the symptoms of depression from me making a personal choice to act or feel a certain way." Women described stigma from their parents in the form of expressions of concern regarding the safety of their medication or regarding the risk of stigma from other parents. "My parents were the driving force with how I handled talking about my illness because they encouraged me to not reveal, to not be open about it." My mother doesn't believe in

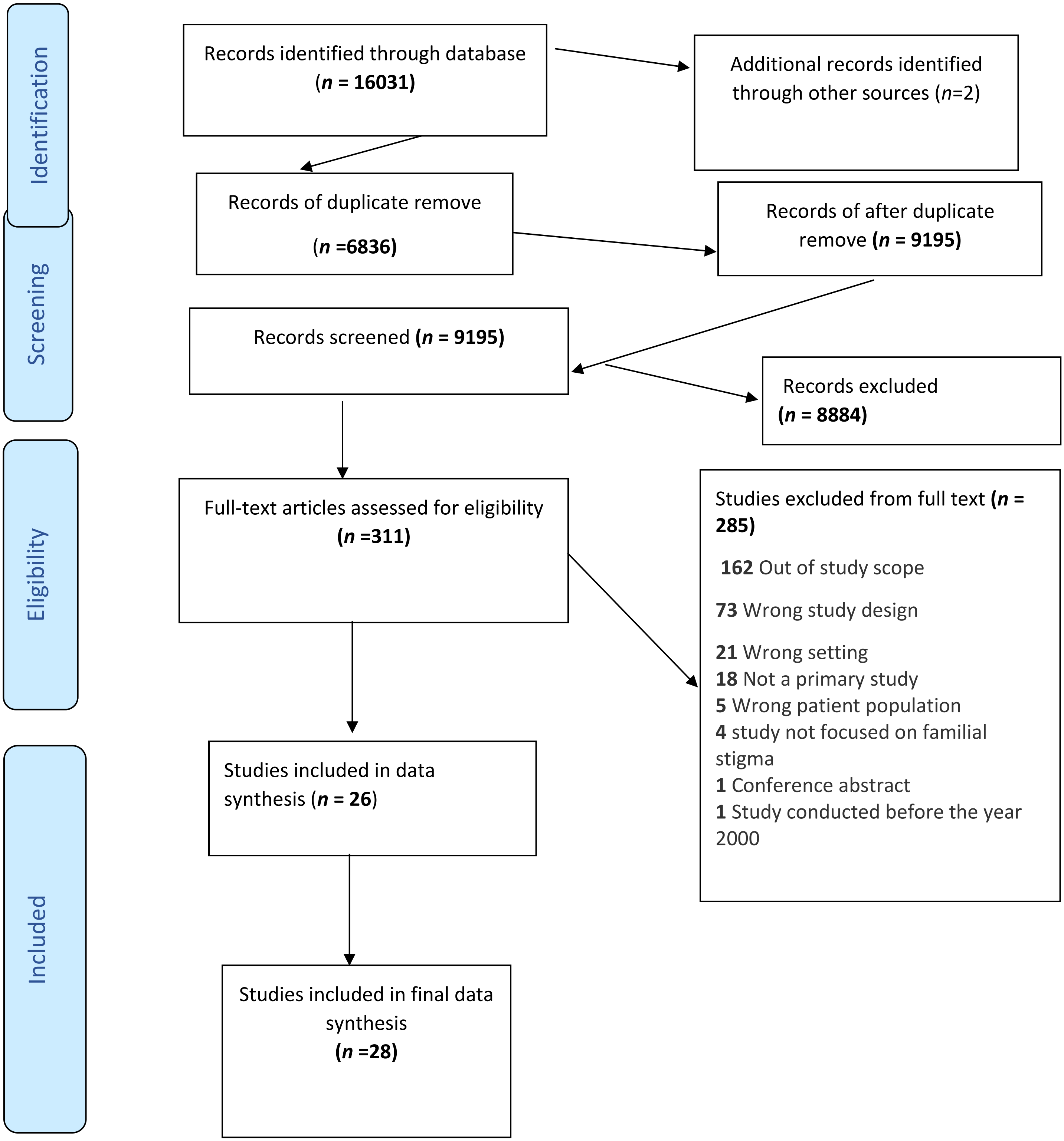
Author (s) & year of publication	Country of study	Study population & sample size	Aims of the study	Research methodology & design	Key findings related to familial mental stigma
					psychiatric care. I got a lot of crap from her about that. “I mean, they don't believe in mental illness, even my dad's a doctor, but he's actually a surgeon.”
McCann et al., 2011	Australia	Caregivers of young adults who had experienced a first-episode of psychosis. Sample size is 20	This study explored how caregivers of young adults who had experienced a first episode of psychosis coped with stigma while maintaining their caregiving role	Qualitative/ In-depth interviews	Concerned about fears and experiences of stigma from others ─friends/ neighbors deterred carers from being open about their situation and the young person’s illness and have contact with others. Denial and blame from others ─respondents’ accounts indicated that stigma was evident in families’ lack of understanding and support for the caregiver’s situation. Denial that a family member had psychosis and blame caregivers for something going “wrong” with the young person. Secretive styles of coping with stigma to avoid loss of status.
Onwumere et al., 2016	UK	Caring for a relative with delusional beliefs. Sample size is five.	The study sought to investigate carer experiences of supporting a relative with delusional beliefs, which involve family members.	Qualitative and in-depth interviews	Ongoing fear linked to episodes of aggression. Acts of aggression involving the use of weapons such as knives. Concealment and secrecy such as withholding information to protect members of the family. Carers minimize the potential for stigma towards the patient and themselves. A carer stated "we don’t say everything; we don’t say everything to anybody other than ourselves, other than the two of us [partner]. We filter out a lot of it, but his brother and wife are quite supportive, and we’ve got two other friends who are very supportive". Carer reports of loss about their relationship with the patient and of the person they once were close ─a sense of life being unfair.
Rivera ─Segarra et al., 2014	Puerto Rico	People Living with Borderline Personality Disorder (BPD). Sample size is eight	Exploring how people living with BPD experience stigmatization	Qualitative/ in-depth interviews	Feeling in the family was like a dirty underwear washed in the house and stays in the house. Family considered the diagnosis as something secret and dirty that no one else besides them should know — “I remember my father telling me I was hysterical and my mother telling me I was a clown and hearing those words made me feel like I wasn’t normal”. The last thing my partner said after knowing about the diagnosis was “he couldn’t marry me because of the problem I had, my condition, he couldn’t marry someone like that”. Another participant narrates the verbal and emotional abuse she received by her boyfriend because of her BPD diagnosis.

Author (s) & year of publication	Country of study	Study population & sample size	Aims of the study	Research methodology & design	Key findings related to familial mental stigma
Seeman, 2013	Canada	Observation and documentation of clinical notes over a ten-year period in an outpatient clinic for women with schizophrenia. Illustrative examples were selected from approximately 200 entries dealing with sibling relationships.	The paper identifies gaps in knowledge about siblings and caregiving in schizophrenia, and to suggest further research directions.	Qualitative/ observation& documentation	Sibling involvement encouraged but remained relatively absent. Most siblings stepped up to the plate and took on the responsibilities of caregiving. Other siblings continued to distance themselves from the patient even after both parents became frail or died. Negative life events, such as long-term illness, especially schizophrenia, make reciprocal engagement impossible. Affection, companionship, and intimacy that characterize many sibling bonds went missing in schizophrenia ─ i.e., A, the sister of a severely ill patient changed her name and kept her contact particulars out of the telephone book so that her sister after she developed schizophrenia to cut contact her. Another patient abandoned by siblings with whom she had once been very close (shared an apartment for a long time with) due to severe schizophrenia.
Sinding et al., 2013	Canada	Social workers at a multisite acute and tertiary care centre in Ontario, Canada. Sample size is 11	The study aimed to better understand the processes of care for people living with serious mental illness who are diagnosed with cancer, from the perspectives of social workers.	Qualitative/in-depth interviews	Patient with long-term mental illnesses is often suicidal and needs hospitalization many times. Her children and husband relationship with her was “quite strained” due to her persistent mental illness. Her family’s attitude completely turned around when diagnosed with Cancer. The woman’s children had thought for many years that their mother would die, but —in contrast to what would have happened if she had completed suicide. The woman told the social worker that dying from cancer would be “better for her husband” than dying from suicide ─ cancer absolved her of responsibility for dying. Nobody wants to tell other people of a relative mental illness but cancer diagnosis.
Tryssenaar et al., 2003	Canada	Participants ranged in age from 37 to 64 and had a variety of diagnoses. Sample size is 19.	The study describes consumers’ perspectives and complex factors involved as persons with serious mental illness grow older in the community.	Qualitative/in-depth interviews	Participants had challenging circumstances and trouble developing or maintaining relationships. Physical, sexual, emotional, and verbal abuse were consistently identified by the female participants as part of their family environment. Mom would take money from men and they could go in the basement with me and do anything they wanted; I was so ashamed. I find that stigma is a big deal. I do not feel comfortable.

Author (s) & year of publication	**Country of study**	**Study population & sample size**	**Aims of the study**	**Research methodology & design**	**Key findings related to familial mental stigma**
van der Sanden et al., 2015	Netherlands	Immediate family members of people with mental illnesses. Sample size is 23	Exploring experiences of stigma by association (SBA) among immediate family members of PWMI while paying particular attention to the characteristics of familial relationship, co-residence, and gender to better understand how experiences of SBA affect immediate family members of PWMI to identify adequate tailored support/ education for family members.	Qualitative /in-depth interviews	Some participants indicated a reduction of contact with family members, friends, and acquaintances, and avoid some forms of social engagement to avoid having to talk or not talk about their family member with mental illness. Participants dodge social events avoid confrontation with stigmatising reactions by others. Siblings conceal their relationships with PWMI to avoid negative reactions and the potential loss of friendships and even (potential) romantic relationships. I never talked about her". "I moved in with my boyfriend sooner because of my sister’s mental illness”.
Weiss et al., 2013	Israel	Ultra-Orthodox Jewish female caregivers and their mentally ill family members. The sample size is 50.	This study employs qualitative methods to identify culturally related aspects within verbal interactions taking place between ultra-Orthodox Jewish female caregivers and their mentally ill family members	Qualitative/in-depth interviews	No one in the family knows about the illness, just me and my husband. A family member coping with mental illness poses a threat to other siblings in the family for whom parents are looking to arrange good marriages. Maintaining secrecy takes dominance because stigma and labeling of mental illness has the possibility of harming matchmaking prospects. Conflict between the cultural norms and a son’s ability to comprehend more complex situation in light of his illness ─"you and dad don’t take steps to marry me off like you did for my siblings.
Yang et al., 2012	Taiwan	Long-term hospitalized patients diagnosed with schizophrenia were interviewed. Sample size is 22.	The study explored how hospitalization and the diagnosis of schizophrenia have an impact on Taiwanese patients’ spiritual life	Qualitative/in-depth interviews	Patient lost her marriage after hospitalization due to mental illness and was separated from the family. All the above are Ming or fate Ming arranges our lives. Participants felt isolated, abandoned, and distanced from their families. They were no longer welcome to return to their families again. The participants usually received a heartless reception from their family. I still feel hurt; why did my father abandon me here? "I hate my father and my brother. It is unfair, I am their family. Families …, the stigma of mental illness does not bring honour to them and their families within the society.
Y-Garcia et al., 2012	USA	Persons with history or knowledge of Depression. Sample size is 116	The study sought to develop & evaluate office-based interventions to encourage patients to disclose depressive symptoms, allowing the	Qualitative/ focus group interviews	Participants labeled by family members because of their depression symptoms. Labeling could be hurtful ─ my family calls me very serious. ‘You’re always so serious. When “I had my first serious episode of

Author (s) & year of publication	Country of study	Study population & sample size	Aims of the study	Research methodology & design	Key findings related to familial mental stigma
			patient and the clinical team to make informed collaborative decisions about appropriate treatment		depression my family said I'm getting lazy ─I internalized a lot of shame." "We were never allowed to express our feelings and if, and if we did, as a male, we were called a 'sissy or weak. Other participants described how fear of labeling may inhibit future discussion.
Piuva & Brodin, 2020	Sweden	Mothers in Sweden who care for their adult children suffering from severe mental illness. Sample size is 15	This study explores experiences of mothers in Sweden who care for their adult children suffering from severe mental illness.	Qualitative/In-depth interviews	Siblings of ill children were neglected and, in many cases, conflicts between the parents emerged. Separation and breaking-up of the original family. The breaking-up of the family both included separation from the father of the child and from grandparents or one or several of the siblings. Relatives have responded with negative reactions to their children's illnesses. The family networks around their children diminished considerably since their illness generating conflicts between the mothers and other relatives. Isolation was in some cases related to self-imposed feelings of shame for their children's behaviours ─ one mother argued that if her daughter had behaved a little bit more 'normal' during her adolescence, maybe the mother and her husband would have invited people for dinner. Daughter usually behaved in a strange way hence withdrew from social interactions.
Suto et al., 2012	Canada	Individuals living with bipolar disorder (3 groups) and family members (2 groups) during an annual bipolar disorder community engagement event. Sample size is 44	The study contributes to the stigma and bipolar disorder literature focused on understanding structural, social, and self-stigma experiences from the perspectives of individuals living with bipolar disorder and their family members.	Qualitative-Community-based participatory and focus group interviews	Stigma was within family relationships where acceptance is expected. One mother whose child has bipolar disorder said: "I've always said to family, 'You know what? If my child had leukaemia, you would all be bringing me lasagna. But now he has bipolar disorder, you are not showing up.' So for me that's where the stigma is present for us". Adults with bipolar disorder were excluded from family party invitations and their relationships with siblings were negatively affected. People were withdrawing from me and kind of cutting me out of their life.

Figure 2 Flow Diagram of study selection process based on PRISMA



2.4.2 Synthesis

Overall, our review highlights a limited number of primary qualitative studies on familial mental illness stigma with respect to high-income countries, given the fact that only 28 peer-reviewed articles were identified on the topic between 2000 and 2020. Majority of the studies were conducted in the United States (11 studies), followed by Canada, UK, and Taiwan ─ with 4, 3, and 2 studies, respectively. Single studies were found in the following countries: Sweden, Australia, Puerto Rico, Israel, Finland, Czech Republic, Netherlands, and Greece.

Content analysis of the 28 included studies produced six interconnected themes, with several sub-themes. The following section explores the themes proposed from the identified studies.

2.4.3 Enactment of Familial Stigma

Nineteen studies (67.85%) reported on discriminatory treatment engaged in by family members of persons with mental illnesses, which often results in withdrawal of social support. Enactment of familial stigma as a theme incorporated 2 sub-themes: abandonment and verbal and emotional abuse.

Abandonment. Abandonment of persons living with mental illnesses by family members was identified in 11 studies (Alexander, 2001; Bonnington & Rose, 2014; Darmi et al., 2017; Frieh, 2020; Ketokivi, 2015; Krupchanka et al., 2018; Piuva & Brodin, 2020; Seeman, 2013; Suto et al., 2012; Yang et al., 2012; Y-Garcia et al., 2012). For instance, Ketokivi (2015) acknowledged that parents and siblings of persons with mental illnesses dissociated themselves from their relative due to the illness. Also, Krupchanka et al. (2018) found that siblings of people living with schizophrenia distanced themselves because they perceived the condition as an infectious disease. Other studies pointed to mental illness-related stigma as a hindrance to maintaining relationships among relatives and loved ones (Frieh, 2020; Piuva & Brodin, 2020; Seeman, 2013; Yang et al., 2012). The frustrations associated with abandonment at the family level due to mental illness compelled a participant in Yang et al.'s (2011) to state the following: "I still feel hurt; why did my father abandon me here? Sometimes I hate my father and my brother. It is unfair, I am their family. They sent me away from home. I am angry and lonely" (p.5). By implication, the family is enacting stigma of mental illness against their relative while 'saving face' of the larger family by avoiding or narrowing their social contacts.

Verbal and emotional abuse. Ten studies identified and described various forms of abuse such as verbal insults, belittling, and being made to feel "other" against persons with mental illnesses (Alexander, 2001; Chen et al., 2013; Frieh, 2020; Huang et al., 2009; Koro-Ljungberg & Bussing, 2009; Piuva & Brodin, 2020; Rivera-Segarra et al., 2014; Tryssenaar et al., 2003; van Der Sanden et al., 2015; Weiss et al., 2013). Findings in 3 studies indicated that women experienced emotional abuse in their relationships due to a diagnosis of a mental illness or mental illness symptoms (Rivera-Segarra et al., 2014; Tryssenaar et al., 2003; Weiss et al., 2013). For instance, in van Der Sanden et al. (2015) a participant recounts being left by her sister with whom she had previously co-housed due to her mental illness. Similarly, Tryssenaar and colleagues (2003) reported that persistent sexual, emotional, and verbal abuse were mentioned by an individual with a mental illness as a problem within the household:

> "my mom would take money from men and they could go in the basement with me and do anything they wanted . . ., whatever they felt like doing. My dad would watch . . ., I'm dealing with that now. And he just shoved me or hit me and go on and on, just rave like a maniac, and he'd keep this up for 2 or 3 hours" (p.7).

2.4.4 Familial Struggles

Familial struggles appear to be connected with mental illnesses because families have diverse viewpoints on mental health problems, many of which create conflict within family environments. Familial struggles in this review include 2 sub-themes: denial of mental illness and reducing social contact by family members. Ten articles (35.71%) [Alexander, 2001; Bonnington & Rose, 2014; Chen et al., 2013; Darmi et al., 2017; Franz et al., 2010; Krupchanka et al., 2018; Ladd, 2018; Suto et al., 2012; van Der Sanden et al., 2015; Y-Garcia et al., 2012] cited various instances to illustrate the existence of familial stigma, with some family members attributing symptoms of mental illnesses to personal flaws while others reduced social contacts with affected individuals.

Denial. Denial in this study happened in the form of close relatives ignoring or downplaying their loved ones' illnesses to save face and avoid associated public stigma (Bonnington & Rose, 2014; Chen et al., 2013). Three authors noted that the pressure from family members for persons with mental illnesses to hide their symptoms often resulted in families living apart (Alexander, 2001), delays in seeking psychiatric assessments and treatment (Darmi et al., 2017; Franz et al., 2010), and secrecy to avoid social stigma (Franz et al., 2010).

Reducing social contacts. Findings also included family members of persons with mental illnesses reducing their social contacts to "save face" from potential stigma. Two authors made the following observations: close-family members avoided the risk of being observed with someone showing symptoms of a mental illness by circumventing all social activities (van Der Sanden et al., 2015; Suto et al., 2012). These attitudes and behaviours point to the potential negative outcomes of stigma, including family members not accepting or supporting their relatives in times when they are needed the most.

2.4.5 Coping with Familial Stigma

Concealment and selective disclosure were employed by family members as well as persons with mental illnesses as forms of coping with familial stigma. Thirteen (46.42%) out of the 28 studies spoke about concealment and selective disclosure.

Concealment is a known approach employed to reduce the impact of mental illness stigma on persons with mental illnesses and their immediate families. However, concealment does not contribute to positive long-term outcomes and often has unintended negative consequences on both affected persons as well as their families (Adu et al., 2021, 2022; Public Health Agency of Canada, 2006; van der Sanden et al., 2016). Family members of persons with mental illnesses ensured concealment through restriction of information on their relative's condition (Bonnington & Rose, 2014; Chen et al., 2013; Karnieli-Miller et al., 2013; McCann et al., 2011; Onwumer e et al., 2016), disallowing their relative from taking medications, and encouraging them not to reveal or be open about their condition (Koro-Ljungberg & Bussing, 2009; Ladd, 2018). Other studies noted that concealing one's mental illness in the family becomes self-perpetuating as it can indeed lead to reduced experiences of stigmatization (Karnieli-Miller et al., 2013; Piuva & Brodin, 2020; Weiss et al., 2013). In terms of parent-child relationships, some parents prevented their children post-diagnosis from spending time with friends as a form of concealment (van Der Sanden et al., 2015). Family members were of the conviction that secrecy would protect them and their loved ones from the negative reactions of others: "you really don't want anyone to know because no one wants to be looked at in a different way, as 'abnormal'. You know, something's wrong with that person. Sometimes it's just overwhelming, dealing with them differently" (Franz et al., 2010, p. 6).

Selective disclosure. Participants in some studies sought to minimize familial stigma by controlling or limiting disclosures (Chen et al., 2013; Karnieli-Miller et al., 2013; Onwumer e et al., 2016). Selective disclosure herein implies a means to both elicit support while reducing risk by restricting information sharing within their circle of care. Selective disclosure includes the stress of managing who within the family circle knows what information. For instance, in Ketokivi (2015), there is a story of an individual who discussed:

> “her son’s mental illness quite easily until her husband, a retired judge, walked by and she then whispered that he does not want these issues talked about. We kept the conversation lighter while he was there and then went back to the topic” (p.5).

This selective disclosure was reinforced through instances when the spread of knowledge about one’s condition without their control indeed led to experiences of stigma (Chen et al., 2013).

2.4.6 Cloud Hanging Over Oneself

A cloud hanging over an individual with mental illnesses, with respect to familial stigma, reflects the general feeling of distrust or helplessness stemming from the immediate family. The fear of potential stigma within the family environment may put a lot of strain on affected individuals, which could aggravate their conditions and prolong recovery. Fourteen studies (50%) [Alexander, 2001; Bonnington & Rose, 2014; Choi & Kimbell, 2008; Elkington et al., 2013; Elliott et al., 2018; Frieh, 2020; Huang et al., 2009; Ketokivi, 2015; Krupchanka et al., 2018; Ladd, 2018; McCann et al., 2011; Suto et al., 2012; van Der Sanden et al., 2015; Weiss et al., 2013] examined familial stigma and highlighted concerns people have regarding how their family will respond to them. These concerns were often grounded in prior experiences, such as how affected persons felt not listened to or understood or othered by family members

(Alexander, 2001), loss of status within the family due to their illness (Choi & Kimbell, 2008; van Der Sanden et al., 2015), how relatives saw persons with mental illnesses as lazy, desperate, or unfit for general society (Huang et al., 2009; Ketokivi, 2015; Krupchanka et al., 2018), and perpetuated powerlessness and marginalization (Bonnington & Rose, 2014). Additional noted exclusions included being left out from group activities (Suto et al., 2012), fear of reduced romantic contacts (van Der Sanden et al., 2015), fear of rejection and permanent separation (Elkington et al., 2013; Elliott et al., 2018; Frieh, 2020).

2.4.7 Negative Social Consequences

With respect to negative social consequences, this review pointed to stigma as a strain on intimate relationships or causes of relationship breakdown. A total of 17 studies (60.71%) [Alexander, 2001; Chen et al., 2013; Choi & Kimbell, 2008; Elkington et al., 2013; Elliott et al., 2018; Frieh, 2020; Hinton et al., 2017; Karnieli-Miller et al., 2013; Ketokivi, 2015; McCann et al., 2011; Piuva & Brodin, 2020; Seeman, 2013; Sinding et al., 2013; Suto et al., 2012; van Der Sanden et al., 2015; Weiss et al., 2013; Y-Garcia et al., 2012] outlined various relational challenges that confronted persons with mental illnesses due to the lack of support and stigma from their family members. In many of the 17 articles, there was a mention of insecurity, lack of trust within relationships, loss of status within the family, exclusion from family and community social events (Alexander, 2001; Chen et al., 2013; van Der Sanden et al., 2015), and lack of social support from the family in regard to relationship potential (Choi & Kimbell, 2008). Others included family stigma towards current relationships such as being perceived as undeserving of romantic or sexual relationships (Elkington et al., 2013) and actual breakdown of intimate relationships (Elliott et al., 2018).

Frieh (2020) identified that experiences of stigma prevented women from pursuing romantic relationships because they believed ‘people do not want persons with mental illness’ while Ketokivi (2015) reported on estrangement through divorce of a woman from her family after a hospital admission due to a mental illness and ultimately loss of custodial care of her children. Within the concept of isolation and harmful relationships that occurred in families due to stigma of mental illnesses, four studies described a range of emotional experiences related to familial stigma. These included hurtful labeling, self-imposed feelings of shame, and expression(s) of fear that led to isolation (Piuva & Brodin, 2020; Y-Garcia et al., 2012), negative relationships with siblings (Suto et al., 2012), and the belief that one’s mental illness would make other members of the family less likely to find a good marriage due to associative stigma (Weiss et al., 2013). Again, several authors in this review found expression of fear within the environment of persons living with mental illnesses (Alexander, 2001; Elkington et al., 2013; Elliott et al., 2018; Frieh, 2020; McCann et al., 2011; Suto et al., 2012; van Der Sanden et al., 2015; Weiss et al., 2013). Fear of being rejected and abandoned by close relatives and romantic partners led to people keeping their symptoms to themselves and pretending all was well. Keeping a mental illness secret to avoid familial stigma became an approach for people to remain connected with their loved ones. In Frieh’s (2020) study, a participant mentioned that potential partners would leave her if they knew she had a mental illness: “fear of being totally open and honest about some of the things I have struggled with for fear of rejection” (p.9), which suggests internalized feelings of enacted stigma by loved ones.

2.4.8 Psychosocial Impacts

Psychosocial impacts associated with mental illness stigma relate to reduced quality of life for both affected individuals and their close family members, which also have the tendency to increase social distance between persons and their relatives (Iseselo et al., 2016). Psychosocial impacts are categorized herein with 4 sub-themes; feeling of shame and embarrassment, identified as dangerous and fearful, family conflict, and spousal neglect. In all, 20 studies (71.43%) spoke to the psychosocial impacts theme.

Feeling of shame and embarrassment. With reference to feelings of shame and embarrassment,12 studies described various emotions that both affected persons and their families (Alexander, 2001; Chen et al., 2013; Frieh, 2020; Huang et al., 2009; Koro-Ljungberg & Bussing, 2009; Ladd, 2018; Piuva & Brodin, 2020; Rivera-Segarra et al., 2014; Tryssenaar et al., 2003; van Der Sanden et al., 2015; Y-Garcia et al., 2012; Weiss et al., 2013). Family members saw hospitalization of relatives due to episodes of mental illnesses as shameful and causing the family to lose face (Alexander, 2001; Chen et al., 2013; Huang et al., 2009). Family conflicts, particularly for siblings of persons with mental illness (Huang et al., 2009; Koro-Ljungberg & Bussing, 2009), and name calling or being labeled by family members (Rivera-Segarra et al., 2014; Y-Garcia et al., 2012) were also identified. Other authors noted the shame that comes with being stigmatized by family members (Ladd, 2018; Tryssenaar et al., 2003) and other familial consequences such as harm to the family reputation (Weiss et al., 2013). For instance, in one study a sibling left home to stay with the boyfriend because of their sister's mental illness (van Der Sanden et al., 2015). In Frieh (2020), it was reported that some women who encountered stigma from intimate partners blamed themselves for being the cause of their predicament.

Dangerous. In terms of family members identifying their relatives living with mental illnesses as dangerous, six authors (Koro-Ljungberg & Bussing, 2009; Krupchanka et al., 2018; McCann et al., 2011; Onwumer e et al., 2016; Piuva & Brodin, 2020; Sinding et al., 2013) spoke on different issues that served as stressors to affected individuals at the family level. Koro-

Ljungberg and Bussing (2009) recounted how the mother of a teenager continuously called the police anytime she was overwhelmed or scared by her daughter's behaviour (having denied already that her daughter was suffering from a mental illness). Relatives perceived risk related to potential harms associated with behaviours they attributed to mental illness such as the potential for use of weapons (Krupchanka et al., 2018; McCann et al., 2011; Onwumer e et al., 2016). Relatives perceived those with mental illnesses as unpredictable and with unknown future behaviours (Piuva & Brodin, 2020; Sinding et al., 2013).

Family conflict. Some authors in this review saw family conflict as a root issue with familial stigma where family members of persons with mental illnesses attribute behaviours to personal failings rather than the illness. Nine studies (Choi & Kimbell, 2008; (Darmi et al., 2017; Franz et al., 2010; Hinton et al., 2017; Huang et al., 2009; Koro-Ljungberg & Bussing, 2009; Piuva & Brodin, 2020; van Der Sanden et al., 2015; Weiss et al., 2013) included discussions around family conflict in relation to familial mental illness stigma. Two studies found relationship struggles as blamed on illness in the family (Choi & Kimbell, 2008; Darmi et al., 2017) and further situations include conflict as children without an illness feel they are neglected due to a sibling's mental illness (Piuva & Brodin, 2020). Another study found that conflict between client and family occurred when it was perceived that a family member with a mental illness was 'useless' (Huang et al., 2009). Two studies noted how continuous relationship strain limited supportive care (Hinton et al., 2017) and with one scenario highlighting that a severe crisis was required before the family would offer support, including the threat of incarceration (Franz et al., 2010).

Spousal neglect. This took the form of a strain on intimate partner relationships and was discussed in nine articles (Alexander, 2001; Darmi et al., 2017; Elkington et al., 2013; Hinton et al., 2017; Huang et al., 2009; Ladd, 2018; Rivera-Segarra et al., 2014; Sinding et al., 2013; Yang et al., 2012). A common thread identified by the majority of these studies was that spousal neglect started soon after partners of affected persons became aware of a diagnosis (Alexander, 2001; Darmi et al., 2017; Elkington et al., 2013; Hinton et al., 2017; Huang et al., 2009; Ladd, 2018; Yang et al., 2012). For example, in Yang et al. (2012) it was revealed that a participant got divorced and separated from her family after a hospital admission. In another study a participant explained the ramifications of disclosing a diagnosis of a mental illness: "the last thing he said to me was that he couldn't marry me because of the problem I had, my condition, he couldn't marry someone like that…, because what kind of family we would have?" (Rivera-Segarra et al., 2014, p. 12). Openness about one's mental illness to a partner appears to come with a risk of separation or relationship strain. For instance, it was identified that some partners were unwilling to assist with mental health care (Hinton et al., 2017) or became aloof once a diagnosis is disclosed (Ladd, 2018).

2.4.9 Meta-theme: Unspoken Stigma

Meta-themes are ideas obtained through a methodical co-merging of two or more themes (Armborst, 2017). 'Unspoken stigma' as a theme acknowledges familial stigma as hidden, harmful, taboo, often cultural, and hard for both family members and those living with mental illnesses to acknowledge. Fifteen studies (53.57%) [Alexander, 2001; Bonnington & Rose, 2014; Elkington et al., 2013; Franz et al., 2010; Frieh, 2020; Hinton et al., 2017; Huang et al., 2009; Karnieli-Miller et al., 2013; Ladd, 2018; Piuva & Brodin, 2020; Rivera ─Segarra et al., 2014; Sinding et al., 2013; Suto et al., 2012; Tryssenaar et al., 2003; Yang et al., 2012] spoke to familial stigma as the most hidden and taboo form of stigma found within some families, which has the tendency to impact negatively on both persons with mental illnesses and their close relatives. While least acknowledged, this form of stigma can be deeply harmful including the loss of intimate relationships (Alexander, 2001; Bonnington & Rose, 2014), anticipated loss of one’s most important relationships (Elkington et al., 2013), and a driving force for social alienation (Franz et al., 2010; Frieh, 2020; Huang et al., 2009; Rivera ─Segarra et al., 2014). Whereas most research and interventions related to mental illness stigma focus on social stigma within the general public, our review details the key, unspoken concern faced by individuals from within their own families, “I got a lot of crap from my parents about mental illness” (Ladd, 2018, p. 2093). One participant noted that their health concerns were perceived as the “family’s dirty underwear” (Rivera ─Segarra et al., 2014, p. 9), their health needs were somehow too deeply personal and too shameful to be spoken of. Again, in Y-Garcia et al. (2012), a participant mentioned that: “we were never allowed to express our feelings and if, and if we did, as a male, we were called a ‘sissy.’ I remember being called ‘sissy’ all the time” (p.3). Ultimately, where much has now been said and written about mental illness stigma, one that originates from within the family network still primarily remains unconsidered, unacknowledged, and unspoken. The stigmatizing and marginalizing words are spoken to those living with mental illnesses, but the existence of such a stigma is rarely acknowledged.

Table 3. **Themes and Sub-Themes Represented by Included Studies**

Theme	Sub-Themes	Studies Included
Enactment of familial stigma (n=21)	Abandonment (n=11) Verbal and emotional abuse (n=10)	Alexander, 2001; Bonnington & Rose, 2014; Chen et al., 2013; Darmi et al., 2017; Elkington et al., 2013; Elliott et al., 2018; Frieh, 2020; Huang et al., 2009; Ketokivi, 2015; Koro-Ljungberg & Bussing, 2009; Krupchanka et al., 2018; McCann et al., 2011; Piuva & Brodin, 2020; Seeman, 2013; Suto et al., 2012; Rivera-Segarra et al., 2014; Tryssenaar et al., 2003; van Der Sanden et al., 2015; Weiss et al., 2013; Yang et al., 2012; Y-Garcia et al., 2012
Familial struggles (n=10)	Denial (n=6) Reducing social contacts (n=4)	Alexander, 2001; Bonnington & Rose, 2014; Chen et al., 2013; Darmi et al., 2017; Franz et al., 2010; Krupchanka et al., 2018; Ladd, 2018; Suto et al., 2012; van Der Sanden et al., 2015; Y-Garcia et al., 2012
Coping with familial stigma (n=13)	Concealment (n=12) Selective disclosure (n=5)	Bonnington & Rose, 2014; Chen et al., 2013; Franz et al., 2010; Karnieli-Miller et al., 2013; Ketokivi, 2015; Koro-Ljungberg & Bussing, 2009; Ladd, 2018; McCann et al., 2011; Onwumer e et al., 2016; Piuva & Brodin, 2020; Seeman, 2013; van Der Sanden et al., 2015; Weiss et al., 2013
Cloud hanging over oneself (n=14)		Alexander, 2001; Bonnington & Rose, 2014; Choi & Kimbell, 2008; Elkington et al., 2013; Elliott et al., 2018; Frieh, 2020; Huang et al., 2009; Ketokivi, 2015; Krupchanka et al., 2018; Ladd, 2018; McCann et al., 2011; Suto et al., 2012; van Der Sanden et al., 2015; Weiss et al., 2013
Negative Social Consequences (n=17)		Alexander, 2001; Chen et al., 2013; Choi & Kimbell, 2008; Elkington et al., 2013; Elliott et al., 2018; Frieh, 2020; Hinton et al., 2017; Karnieli-Miller et al., 2013; Ketokivi, 2015;

Theme	**Sub-Themes**	**Studies Included**
		McCann et al., 2011; Piuva & Brodin, 2020; Seeman, 2013; Sinding et al., 2013; Suto et al., 2012; van Der Sanden et al., 2015; Weiss et al., 2013; Y-Garcia et al., 2012
Psychosocial impacts (n=20)	Feeling of shame and embarrassment (n=12) Dangerous (n=6) Family conflict (n=9)	Alexander, 2001; Chen et al., 2013; Choi & Kimbell, 2008; Darmi et al., 2017; Franz et al., 2010; Frieh, 2020; Huang et al., 2009; Hinton et al., 2017; Koro-Ljungberg & Bussing, 2009; Krupchanka et al., 2018; Ladd, 2018; McCann et al., 2011; Onwumer e et al., 2016; Piuva & Brodin, 2020; Rivera-Segarra et al., 2014; Sinding et al., 2013; Tryssenaar et al., 2003; van Der Sanden et al., 2015; Weiss et al., 2013; Y-Garcia et al., 2012
Meta-theme: Unspoken Stigma (n=17)		Alexander, 2001; Bonnington & Rose, 2014; Elkington et al., 2013; Franz et al., 2010; Frieh, 2020; Hinton et al., 2017; Huang et al., 2009; Karnieli-Miller et al., 2013; Ladd, 2018; Piuva & Brodin, 2020; Rivera ─Segarra et al., 2014; Sinding et al., 2013; Suto et al., 2012; Tryssenaar et al., 2003; Weiss et al., 2013; Yang et al., 2012; Y-Garcia et al., 2012

2.5 Discussion

While stigma within society is a known social problem connected with mental illnesses, little attention has been given to familial mental illness stigma over the years due to its subtle nature within the family system. Findings from this review highlight various types of familial stigma and related challenges confronting persons with mental illnesses. These insights contribute to existing knowledge while also highlighting that a minute fraction of the research on mental illness stigma addresses this particular form in high income countries.

The most visible familial mental illness stigma in high-income countries included verbal and emotional abuse (Chen et al., 2013; Frieh, 2020; Huang et al., 2009; Piuva & Brodin, 2020), which has the potential to worsen illness and make the home environment one that impedes care and recovery. There is a knock-on effect as some of these abuses could also lead to persons with mental illnesses developing self-stigma, which tends to negatively affect their self-esteem and self-efficacy as well as decreasing one's sense of empowerment. This is supported by the finding that self-empowerment is tied with positive family supports (Corrigan & Rao, 2012; Umberson &Karas Montez, 2010). Unfortunately, the lack of support within family systems or households furthers the already threatened social contacts as individuals navigate perceived and real stigma beyond the home (Forsman et al., 2011; Min et al., 2013). Conversely, positive relationships with caring and supportive family members create a platform for increased social support, which emboldens one's sense of self-worth (Corrigan et al., 2013).

Some elements of familial stigma are rooted in misconceptions of mental illnesses, including family systems in high-income countries. This includes family members ascribing their loved ones' behavioural challenges to personal flaws rather than symptoms of mental illnesses and therefore failing to support them in seeking appropriate care. It is conceivable, therefore, that continued growth of general acknowledgement and understanding of mental illnesses should reduce to some degree familial stigma (Huang et al., 2009). This seemingly speaks to the role of health professionals in ensuring that the whole family system is included in long-term care and recovery approaches while being tactful in the entire process.

Moments of disclosure of diagnoses are particularly vulnerable times (Corrigan & Rao, 2012; Rüsch et al., 2017; Üçok et al., 201). This is a vital point as the evidence steers the importance of disclosure as a step towards normalizing experiences of mental illness within the broader social system (Evans-Lacko et al., 2012). Unfortunately, fears related to disclosure often actualized when family members cut-off social engagements after a diagnosis is disclosed (McCann et al., 2011; van Der Sanden et al., 2015; Weiss et al., 2013). As well, cultural differences play important roles in deepening uncertainties related to disclosure of mental illnesses within families for fear of associative stigma emanating from social stigma. This assertion is in congruence with the views of Ahmed et al. (2020) and Mirza et al. (2019) that mental illnesses and it associated stigma are yet culturally mediated. Supportive interventions that are culturally sensitive, are therefore, required to sustain families through the experience of a recent diagnosis.

Beyond reduction in social support, another lived effect of familial mental illness stigma is the decreased access to professional care in high-income countries (Public Health Agency of Canada, 2006; van der Sanden et al., 2016). If families impose denial upon those living with an illness they can also impede directly or indirectly access to professional services (Adu et al., 2022; Corrigan et al., 2010; McCann et al., 2011; Umberson & Karas Montez, 2010). These barriers could be reduced if family members understand the causes, diagnoses, and prognoses as well as the damage that stigma brings to affected individuals. Public education to correct the misconceptions around mental illnesses continues to be a key to reducing the long-standing social stigma that often starts with familial stigma. That said, as public education has been a focus for many years, there is decreasing return on investment from such campaigns (Adu et al., 2022; Cook et al., 2014; Heijnders &Van Der Meij, 2006).

More recent research looks to transformative versus didactic education models to achieve reductions in stigma (Adu et al., 2021, 2022; Corrigan et al., 2012, 2013; Evans-Lacko et al., 2012). For instance, stakeholder’s engagement in mental health care and mental illness policies has brought about a decrease in prejudice and unjust treatment toward persons with mental illnesses and their families (Corbière et al., 2012; Corrigan, 2003; Dunne et al., 2018). Social contact-based education approaches in particular offer an ideal practice where both public stigma and stigma by association are targeted to reduce familial mental illness stigma. The use of this approach is capable of reducing the related stigma that results in abandonment, verbal and emotional abuse, denial, social distancing, concealment, selective disclosure, and feeling of shame and embarrassment associated with mental illnesses as outlined in this study. Family members complete understanding of their relatives’ mental illnesses have been linked to the provision of emotional support —capable of lowering psychological distress among individuals living with mental illnesses (Adu et al., 2021, 2022; Umberson & Karas Montez, 2010). In addition, both education and social contact have been highlighted as effective against public stigma of mental illness (Corrigan et al., 2012; Thornicroft et al., 2016). Presumably, the effective use of public education and social contact will also help to reduce family conflicts and spousal neglect revealed in our review.

2.6 Conclusion

Various forms of familial mental illness stigma that are seldom talked about in literature and the media, specifically in high-income countries were revealed in this current study. The concealed nature of familial stigma is particularly pernicious due to alienation within one's home environment. Disclosure of mental illnesses and social contact within the family system are very critical to provide some safety-nets for individuals with mental illnesses at the family level. Family members' understandings of the complex interplay of mental illness stigma are essential to support a healthy recovery environment among persons with mental illnesses in high-income countries. The development of policies and interventions towards solutions to avoid social exclusion while encouraging all-inclusiveness in our societies is a next step for practice.

2.7 Limitations of the review

We limited our study to only qualitative peer-reviewed articles in high-income countries, excluding all qualitative studies from low-and middle-income countries as well as quantitative peer-reviewed articles from both developed and developing nations. It is possible that quantitative data on familial mental illness stigma would add to conclusions regarding best interventions for reducing this stigma.

2.8 Implications for practice and research

Further research is necessary to look at the existence of familial mental illness stigma as well as available policies to reduce its impact on affected individuals in high-income countries.

Establishing social contacts within the family system is vital in reducing familial stigma. This calls for the involvement of persons with mental illnesses and their families as well as the public in anti-stigma programs necessary to reduce familial mental illness stigma.

Researchers in high-income countries should endeavour to examine the relationship between familial, public, and associative stigma to establish a baseline to inform future anti-stigma programs seeking to reduce familial mental illness stigma.

Researchers in high-income countries should look at the relationship between cross-culture and the existence of familial mental illness stigma since culture can negatively influence the social life of persons with mental illnesses.

References

Adu, J., Oudshoorn, A., Anderson, K., Marshall, C. A., Stuart, H., & Stanley, M. (2021). Policies and interventions to reduce familial mental illness stigma: A scoping review of empirical literature. *Issues in Mental Health Nursing*, *42*(12), 1123-1137. https://doi.org/10.1080/01612840.2021.1936710

Adu, J., Oudshoorn, A., Anderson, K., Marshall, C. A., & Stuart, H. (2022). Social contact: Next steps in an effective strategy to mitigate the stigma of mental illness. *Issues in Mental Health Nursing*, *43*(5), 485-488. https://doi.org/10.1080/01612840.2021.1986757

Adu, J., & Oudshoorn, A. (2022). Social Contact: A human approach to mental illness stigma. retrieved from https://bppblog.com/2022/07/21/social-contact-a-human-approach-to-mental-illness-stigma/

Ahmed, S., Birtel, M. D., Pyle, M., & Morrison, A. P. (2020). Stigma towards psychosis: Cross-cultural differences in prejudice, stereotypes, and discrimination in White British and South Asians. *Journal of Community & Applied Social Psychology*, *30*(2), 199-213. https://doi.org/10.1002/casp.2437

Aldersey, H. M., & Whitley, R. (2015). Family influence in recovery from severe mental illness. *Community Mental Health Journal*, *51*(4), 467-476. DOI: 10.1007/s10597-014-9783-y

Alexander, J. (2001). Depressed men: an exploratory study of close relationships. *Journal of Psychiatric and Mental Health Nursing*, *8*(1), 67-75. https://doi.org/10.1111/j.1365-2850.2001.00354.x

Allerby, K., Sameby, B., Brain, C., Joas, E., Quinlan, P., Sjöström, N., Burns, T., & Waern, M. (2015). Stigma and burden among relatives of persons with schizophrenia: results from the Swedish COAST study. *Psychiatric Services*, *66*(10), 1020-1026. Doi: https://doi.org/10.1176/appi.ps.201400405

American Psychiatric Association (2018). *Diagnostic and Statistical Manual of Mental Disorders,* Fifth Edition. Retrieved from https://www.hakjisa.co.kr/common_file/bbs_DSM-5_Update_October2018_NewMaster.pdf

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.). https://doi.org/10.1176/appi.books.9780890425787

Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. International journal of social research methodology, 8(1), 19-32. https://doi.org/10.1080/1364557032000119616

Armborst, A. (2017). Thematic Proximity in Content Analysis. *SAGE Open*. https://doi.org/10.1177/2158244017707797

Barlow, F. K., Paolini, S., Pedersen, A., Hornsey, M. J., Radke, H. R. M., Harwood, J., Rubin, M., Sibley, C. G. (2012). The contact caveat: Negative contact predicts increased prejudice more than positive contact predicts reduced prejudice. *Personality and Social Psychology Bulletin. 38* (12): 1629-1643. doi:10.1177/0146167212457953

Barnable, A., Gaudine, A., Bennett, L., & Meadus, R. (2006). Having a sibling with schizophrenia: A phenomenological study. *Research and Theory for Nursing Practice*, *20*(3), 247. DOI: 10.1891/rtnp.20.3.247

Becker, A. E., & Kleinman, A. (2013). Mental health and the global agenda. *New England Journal of Medicine*, *369*(1), 66-73. DOI: 10.1056/NEJMra1110827

Bonnington, O., & Rose, D. (2014). Exploring stigmatisation among people diagnosed with either bipolar disorder or borderline personality disorder: A critical realist analysis. *Social Science & Medicine*, 123, 7-17. https://doi.org/10.1016/j.socscimed.2014.10.048

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi. org/10.1191/1478088706qp063oa

Bril-Barniv, S., Moran, G. S., Naaman, A., Roe, D., & Karnieli-Miller, O. (2017). A qualitative study examining experiences and dilemmas in concealment and disclosure of people living with serious mental illness. *Qualitative Health Research*, *27*(4), 573-583. https://doi.org/10.1177/1049732316673581

Canadian Mental Health Association. (2007). Poverty and mental illness. Retrieved from https://ontario.cmha.ca/documents/poverty-and-mental-illness/.

Canadian Mental Health Association. (2018). Mental health in the balance: Ending the health care disparity in Canada. *Canadian Mental Health Association*. Retrieved from https://cmha.ca/wp-content/uploads/2018/09/CMHA-Parity-Paper-Full-Report-EN.pdf.

Catthoor, K., Schrijvers, D., Hutsebaut, J., Feenstra, D., Persoons, P., De Hert, M., Peuskens, J., & Sabbe, B. (2015). Associative stigma in family members of psychotic patients in Flanders: An exploratory study. *World Journal of Psychiatry*, *5*(1), 118. http://dx.doi.org/10.5498/wjp.v5.i1.118

Chadda R. K. (2014). Caring for the family caregivers of persons with mental illness. *Indian journal of psychiatry*, *56*(3), 221–227. https://doi.org/10.4103/0019-5545.140616

Charmaz, K. (2000). *Grounded Theory: Objectivist and Constructivist Methods. Handbook of Qualitative Research*. In: NK Denzin and YS Lincoln. Thousand Oaks, CA, Sage Publications, pp. 509–535.

Chen, F. P., Lai, G. Y. C., & Yang, L. (2013). Mental illness disclosure in Chinese immigrant communities. *Journal of Counseling Psychology*, *60*(3), 379. https://psycnet.apa.org/doi/10.1037/a0032620

Choi, N. G., & Kimbell, K. (2008). Depression care need among low-income older adults: views from aging service providers and family caregivers. *Clinical Gerontologist*, *32*(1), 60-76. https://doi.org/10.1080/07317110802474742

Clarke, D., & Winsor, J. (2010). Perceptions and needs of parents during a young adult's first psychiatric hospitalization: "we're all on this little island and we're going to drown real soon". *Issues in Mental Health Nursing*, *31*(4), 242-247. DOI: 10.3109/01612840903383992

Cook, J. E., Purdie-Vaughns, V., Meyer, I. H., & Busch, J. T. (2014). Intervening within and across levels: A multilevel approach to stigma and public health. *Social Science & Medicine*, *103*, 101-109.

Corbière, M., Samson, E., Villotti, P., & Pelletier, J. F. (2012). Strategies to fight stigma toward people with mental disorders: Perspectives from different stakeholders. *The Scientific World Journal*, 1–10. https://doi.org/10.1100/2012/516358

Corrigan, P. (2003). Beat the stigma: Come out of the closet. *Psychiatric Services*, *54*(10), 1313–1313. https://doi.org/10.1176/appi.ps.54.10.1313

Corrigan, P. W., & Miller, F. E. (2004). Shame, blame, and contamination: A review of the impact of mental illness stigma on family members. *Journal of Mental Health*, *13*(6), 537-548. https://psycnet.apa.org/doi/10.1080/09638230400017004

Corrigan, P. W., & Rao, D. (2012). On the self-stigma of mental illness: Stages, disclosure, and strategies for change. *The Canadian Journal of Psychiatry*, *57*(8), 464–469. https://doi.org/10.1177/070674371205700804

Corrigan, P. W., Kosyluk, K. A., & Rüsch, N. (2013). Reducing self-stigma by coming out proud. *American Journal of Public Health*, *103*(5), 794-800. https://dx.doi.org/10.2105%2FAJPH.2012.301037

Corrigan, P. W., Morris, S., Larson, J., Rafacz, J., Wassel, A., Michaels, P., Wilkniss, S., Batia, K., & Rüsch, N. (2010). Self-stigma and coming out about one's mental illness. *Journal of Community Psychology*, *38*(3), 259–275. https://doi.org/10.1002/jcop.20363

Darmi, E., Bellali, T., Papazoglou, I., Karamitri, I., & Papadatou, D. (2017). Caring for an intimate stranger: parenting a child with psychosis. *Journal of Psychiatric and Mental Health Nursing*, *24*(4), 194-202. https://doi.org/10.1111/jpm.12367

Davis, L., Fulginiti, A., Kriegel, L., & Brekke, J. S. (2012). Deinstitutionalization? Where have all the people gone? *Current Psychiatry Reports*, *14*(3), 259-269. https://doi.org/10.1007/s11920-012-0271-1

Demyttenaere, K., Bruffaerts, R., Posada-Villa, J., Gasquet, I., Kovess, V., Lepine, J. P., Angermeyer, M.C., Bernert, S., De Girolamo, G., Morosini, P., & Polidori, G. (2004). Prevalence, severity, and unmet need for treatment of mental disorders in the World Health Organization World Mental Health Surveys. *Jama*, *291*(21), 2581-2590. https://doi.org/10.1001/jama.291.21.2581

Denzin, N. K. (2008). The new paradigm dialogs and qualitative inquiry. *International Journal of Qualitative Studies in Education*, *21*(4), 315-325. https://doi.org/10.1080/09518390802136995

Drake, R. E., Binagwaho, A., Martell, H. C., & Mulley, A. G. (2014). Mental healthcare in low- and middle-income countries. *BMJ*, 349 doi: https://doi.org/10.1136/bmj.g7086

Dunne, S., MacGabhann, L., Amering, M., & McGowan, P. (2018). “Making people aware and taking the stigma away”: Alleviating stigma and discrimination through trialogue. *Irish Journal of Applied Social Studies*, *18*(1), 5. https://doi.org/10.21427/D7CQ7H

Elkington, K. S., Hackler, D., Walsh, T. A., Latack, J. A., McKinnon, K., Borges, C., Wright, E. R., & Wainberg, M. L. (2013). Perceived mental illness stigma, intimate relationships and sexual risk behavior in youth with mental illness. *Journal of Adolescent Research*, *28*(3), 378–404. https://doi.org/ 10.1177/0743558412467686

Elliott, L., Bennett, A. S., Szott, K., & Golub, A. (2018). Competing constructivisms: the negotiation of PTSD and related stigma among post-9/11 veterans in New York City. *Culture, Medicine, and Psychiatry*, *42*(4), 778-799. https://doi.org/10.1007/s11013-018-9586-7

Evans-Lacko, S., London, J., Japhet, S., Rüsch, N., Flach, C., Corker, E., Henderson, C., & Thornicroft, G. (2012). Mass social contact interventions and their effect on mental health related stigma and intended discrimination. *BMC Public Health*, *12*(1), 489. https://doi.org/10.1186/1471-2458-12-489

Forsman, A. K., Nordmyr, J., & Wahlbeck, K. (2011). Psychosocial interventions for the promotion of mental health and the prevention of depression among older adults. *Health Promotion International*, *26*(suppl_1), i85-i107. https://doi.org/10.1093/heapro/dar074

Franz, L., Carter, T., Leiner, A. S., Bergner, E., Thompson, N. J., & Compton, M. T. (2010). Stigma and treatment delay in first-episode psychosis: a grounded theory study. *Early Intervention in Psychiatry*, *4*(1), 47-56. https://doi.org/10.1111/j.1751-7893.2009.00155.x

Frieh, E. C. (2020). Stigma, trauma and sexuality: the experiences of women hospitalised with serious mental illness. *Sociology of Health & Illness*, *42*(3), 526-543. https://doi.org/10.1111/1467-9566.13034

Gyamfi, S. K. (2016). *Comprehensive psychiatry for nurses.* Accra: Beap Publications.

Hamilton Wilson, J., & Conroy, S. (2012). *First Episode Psychosis: The Experience of Parent Caregivers* [ProQuest Dissertations Publishing]. http://search.proquest.com/docview/1152020928/

Heijnders, M., & Van Der Meij, S. (2006). The fight against stigma: an overview of stigma-reduction strategies and interventions. *Psychology, Health & Medicine*, *11*(3), 353-363.

Henderson, C., & Gronholm, P. C. (2018). Mental health related stigma as a 'wicked problem': the need to address stigma and consider the consequences. *International Journal of Environmental Research and Public Health*, *15*(6), 1158. https://dx.doi.org/10.3390%2Fijerph15061158

Hinton, L., Sciolla, A. F., Unützer, J., Elizarraras, E., Kravitz, R. L., & Apesoa-Varano, E. C. (2017). Family-centered depression treatment for older men in primary care: a qualitative study of stakeholder perspectives. *BMC Family Practice*, *18*(1), 1-9. https://doi.org/10.1186/s12875-017-0659-4

Huang, X. Y., Hung, B. J., Sun, F. K., Lin, J. D., & Chen, C. C. (2009). The experiences of carers in Taiwanese culture who have long-term schizophrenia in their families: a phenomenological study. *Journal of Psychiatric and Mental Health Nursing*, *16*(10), 874-883. https://doi.org/10.1111/j.1365-2850.2009.01468.x

Iseselo, M. K., Kajula, L., & Yahya-Malima, K. I. (2016). The psychosocial problems of families caring for relatives with mental illnesses and their coping strategies: a qualitative urban based study in Dar es Salaam, Tanzania. *BMC Psychiatry*, *16*(1), 1-12. https://doi.org/10.1186/s12888-016-0857-y

Karnieli-Miller, O., Perlick, D. A., Nelson, A., Mattias, K., Corrigan, P., & Roe, D. (2013). Family members' of persons living with a serious mental illness: Experiences and efforts to cope with stigma. *Journal of Mental Health*, *22*(3), 254-262. https://doi.org/10.3109/09638237.2013.779368

Ketokivi, K. (2015). Mental illness, stigma and belonging in family relationships. *Families, Relationships and Societies*, *4*(3), 349-363. https://doi.org/10.1332/204674314X14151979019318

Koro-Ljungberg, M., & Bussing, R. (2009). The management of courtesy stigma in the lives of families with teenagers with ADHD. *Journal of Family Issues*, 30(9), 1175-1200. https://doi.org/10.1177%2F0192513X09333707

Krupchanka, D., Chrtková, D., Vítková, M., Munzel, D., Čihařová, M., Růžičková, T., Winkler, P., Janoušková, M., Albanese, E., & Sartorius, N. (2018). Experience of stigma and discrimination in families of persons with schizophrenia in the Czech Republic. *Social Science & Medicine*, 212, 129-135. https://doi.org/10.1016/j.socscimed.2018.07.015

Krupchanka, D., Kruk, N., Murray, J., Davey, S., Bezborodovs, N., Winkler, P., Bukelskis, L., & Sartorius, N. (2016). Experience of stigma in private life of relatives of people diagnosed with schizophrenia in the Republic of Belarus. *Social Psychiatry and Psychiatric Epidemiology*, *51*(5), 757-765. https://doi.org/10.1007/s00127-016-1190-y

Ladd, W. (2018). " Born Out of Fear": A Grounded Theory Study of the Stigma of Bipolar Disorder for New Mothers. *Qualitative Report*, *23*(9), 2081-2104.

Link, B. & Phelan, J. (2006). Stigma and its public health implications. Lancet 367 (9509):528-529. DOI: 10.1016/S0140-6736(06)68184-1

Link, B. G., Yang, L. H., Phelan, J. C., & Collins, P. Y. (2004). Measuring mental illness stigma. *Schizophrenia Bulletin*, *30*(3), 511-541. https://doi.org/10.1093/oxfordjournals.schbul.a007098

Martel, S. & Steensma, C. (2012). Disability-Adjusted Life Years: An Indicator to Measure Burden of Disease in Québec, Synthesis, Institut National De Santé Publique Du Québec.p70.

McCann, T. V., Lubman, D. I., & Clark, E. (2011). Responding to stigma: first-time caregivers of young people with first-episode psychosis. *Psychiatric Services*, *62*(5), 548-550. https://ps.psychiatryonline.org/doi/full/10.1176/ps.62.5.pss6205_0548

Mental Health Commission of Canada. (2009). Toward Recovery & Well-Being. A Framework for a Mental Health Strategy for Canada. Retrieved from https://www.mentalhealthcommission.ca/sites/default/files/FNIM_Toward_Recovery_and_Well_Being_ENG_0_1.pdf .

Mental Health Commission of Canada. (2016). Advancing the Mental Health Strategy for Canada: A Framework for Action (2017–2022). Retrieved from https://www.mentalhealthcommission.ca/sites/default/files/2016-08/advancing_the_mental_health_strategy_for_canada_a_framework_for_action.pdf.

Miles, M. B., Huberman, A. M., & Saldaña, J. (2013). *Qualitative data analysis: A methods sourcebook* (3rd ed.). SAGE Publications.

Min, J. A., Lee, C. U., & Lee, C. (2013). Mental health promotion and illness prevention: a challenge for psychiatrists. *Psychiatry Investigation*, *10*(4), 307. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3902147/#

Mirza, A., Birtel, M. D., Pyle, M., & Morrison, A. P. (2019). Cultural differences in psychosis: The role of causal beliefs and stigma in White British and South Asians. *Journal of Cross-Cultural Psychology*, *50*(3), 441-459. https://doi.org/10.1177%2F0022022118820168

Mollica, R. F., Cardozo, B. L., Osofsky, H. J., Raphael, B., Ager, A., & Salama, P. (2004). Mental health in complex emergencies. *The Lancet*, *364*(9450), 2058-2067.

Morgan, A. J., Reavley, N. J., Jorm, A. F., & Beatson, R. (2017). Discrimination and support from friends and family members experienced by people with mental health problems: Findings from an Australian national survey. *Social Psychiatry and Psychiatric Epidemiology*, *52*(11), 1395–1403. https://doi.org/10.1007/s00127-017-1391-z

Munn, Z., Peters, M. D., Stern, C., Tufanaru, C., McArthur, A., & Aromataris, E. (2018). Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC medical Research Methodology*, *18*(1), 143. https://doi.org/10.1186/s12874-018-0611-x

National Institute of Mental Health. (2019). Mental Health Information. Retrieved from https://www.nih.gov/about-nih/what-we-do/nih-almanac/national-institute-mental-health-nimh.

Onwumere, J., Learmonth, S., & Kuipers, E. (2016). Caring for a relative with delusional beliefs: A qualitative exploration. *Journal of Psychiatric and Mental Health Nursing*, *23*(3-4), 145-155. https://doi.org/10.1111/jpm.12291

Östman, M., & Kjellin, L. (2002). Stigma by association: psychological factors in relatives of people with mental illness. *The British Journal of Psychiatry*, *181*(6), 494-498.

Piuva, K., & Brodin, H. (2020). Just like any other family? Everyday life experiences of mothers of adults with severe mental illness in Sweden. *Community Mental Health Journal, 56*(6), 1023-1032. https://doi.org/10.1007/s10597-020-00549-z

Public Health Agency of Canada. (2006). The human face of mental health and mental illness in Canada 2006. Retrieved from https://www.phac-aspc.gc.ca/publicat/human-humain06/pdf/human_face_e.pdf. Accessed on February 27, 2021.

Public Health Agency of Canada. (2019). Data blog: Mental illness in Canada. Retrieved from https://health-infobase.canada.ca/datalab/mental-illness-blog.html. Accessed February 28, 2021. Randomised trial. *The British Journal of Psychiatry*, *212*(1), 34-41. DOI: 10.1192/bjp.2017.12

Rehm, J., & Shield, K. D. (2019). Global Burden of Disease and the Impact of Mental and Addictive Disorders. *Current Psychiatry Reports*, *21*(2), 10.

Rivera-Segarra, E., Rivera, G., López-Soto, R., Crespo-Ramos, G., & Marqués-Reyes, D. (2014). Stigmatization Experiences among People Living with Borderline Personality Disorder in Puerto Rico. *Qualitative Report, 19*(15).

Rüsch, N., Rose, C., Holzhausen, F., Mulfinger, N., Krumm, S., Corrigan, P. W., Willmund, G. D., & Zimmermann, P. (2017). Attitudes towards disclosing a mental illness among German soldiers and their comrades. *Psychiatry Research*, 258, 200–206. https://doi.org/10.1016/j.psychres.2017.08.028

Sandelowski, M., & Barroso, J. (2007). Handbook for synthesizing qualitative research. Springer Publishing Company Inc.

Sashidharan, S. P., White, R., Mezzina, R., Jansen, S., & Gishoma, D. (2016). Global mental health in high-income countries. *The British Journal of Psychiatry*, *209*(1), 3-5. http://eprints.gla.ac.uk/117765/

Seeman, M. V. (2013). Spotlight on sibling involvement in schizophrenia treatment. *Psychiatry: Interpersonal and Biological Processes*, *76*(4), 311-322. https://doi.org/10.1521/psyc.2013.76.4.311

Shen, G. C., & Snowden, L. R. (2014). Institutionalization of deinstitutionalization: a cross-national analysis of mental health system reform. *International Journal of Mental Health Systems*, *8*(1), 1-23. http://www.ijmhs.com/content/8/1/47

Sinding, C., Watt, L., Miller, P., Silliker, J., Lawson, L., Kislinsky, C., Stanzlik-Elliot, C.L., O'Neill, J., Pereira, J., & McGillicuddy, P. (2013). Stigmas and silos: Social Workers' accounts of care for people with serious mental illness and cancer. *Social Work in Mental Health, 11*(3), 288-309. https://doi.org/10.1080/15332985.2012.758075

Stuart, H. (2017). Stigma: Mark of shame or complex social process? In S. Hamid-Balma. Visions, Recovery: stigma and inclusion (pp. 5-7). BC Partners for Mental Health and Addictions Information and funded by BC Mental Health and Substance Use Services, an agency of the Provincial Health Services Authority. Retrieved from http://www.heretohelp.bc.ca/.

Stuart, H. (2016). Reducing the stigma of mental illness. *Global mental health (Cambridge, England), 3,* e17. https://doi.org/10.1017/gmh.2016.11

Suto, M., Lapsley, S. E., Livingston, J., Hole, R., Hinshaw, S., Michalak, E., & Hale, S. (2012). Stigma shrinks my bubble: a qualitative study of understandings and experiences of stigma and bipolar disorder. *Stigma Research and Action, 2* (2), 85–92.

Talley, R. C., Fricchione, G. L., & Druss, B. G. (2014). Introduction: Caregiving to Promote Mental Health and Prevent Mental Illness. In *The Challenges of Mental Health Caregiving* (pp. 1-12). Springer, New York, NY.

The Mental Health Foundation. (2016). Fundamental Facts about mental health 2016 [online]. Available from: https://www.mentalhealth.org.uk/publications/fundamental-facts-about-mental-health-2016.

Thornicroft, G., Mehta, N., Clement, S., Evans-Lacko, S., Doherty, M., Rose, D., Koschorke, M., Shidhaye, R., O'Reilly, C., & Henderson, C. (2016). Evidence for effective interventions to reduce mental-health-related stigma and discrimination. *The Lancet*, 387(10023), 1123–1132. https://doi.org/10.1016/S0140-6736(15)00298-6

Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*, 12(1), 181. https://doi.org/10.1186/1471-2288-12-181

Tong, A., Sainsbury, P., Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19* (6)349–357, https://doi.org/10.1093/intqhc/mzm042

Torrey, E. F., Entsminger, K., Geller, J., Stanley, J., & Jaffe, D. J. (2008). The Shortage of Public Hospital Beds for Mentally Ill Persons: A Report of the Treatment Advocacy Center. Treatment Advocacy Center, Arlington.

Tracy, S. J. (2010). Qualitative Quality: Eight "Big-Tent" Criteria for Excellent Qualitative Research. *Qualitative Inquiry, 16*(10), 837-851 https://doi.org/10.1177/1077800410383121

Tryssenaar, J., Chui, A., & Finch, L. (2009). Growing older: The lived experience of older persons with serious mental illness. *Canadian Journal of Community Mental Health*, *22*(1), 21-36. https://doi.org/10.7870/cjcmh-2003-0002

Üçok, A., Serbest, S., & Kandemir, P. E. (2011). Remission after first-episode schizophrenia: Results of a long-term follow-up. *Psychiatry Research*, *189*(1), 33–37. https://doi.org/10.1016/j.psychres.2010.11.013

Umberson, D., & Karas Montez, J., (2010). Social relationships and health: A flashpoint for health policy. *Journal of Health and Social Behavior*,*51*(1_suppl), S54–S66. https://doi.org/10.1177/0022146510383501

van Der Sanden, R. L., Bos, A. E., Stutterheim, S. E., Pryor, J. B., & Kok, G. (2015). Stigma by association among family members of people with a mental illness: A qualitative analysis. *Journal of Community & Applied Social Psychology*, *25*(5), 400-417. https://doi.org/10.1002/casp.2221.

van Der Sanden, R. L., Pryor, J. B., Stutterheim, S. E., Kok, G., & Bos, A. E. (2016). Stigma by association and family burden among family members of people with mental illness: The mediating role of coping. *Social Psychiatry and Psychiatric Epidemiology*, *51*(9), 1233–1245. https://doi.org/10.1007/s00127-016-1256-x

Veritas Health Innovation. (2016). Covidence systematic review software. Melbourne, Australia: Veritas Health Innovation. Retrieved from www.covidence.org.

Vigo, D., Thornicroft, G., & Atun, R. (2016). Estimating the true global burden of mental illness. *The Lancet Psychiatry*, *3*(2), 171-178.

Weiss, P., Shor, R., & Hadas-Lidor, N. (2013). Cultural aspects within caregiver interactions of ultra-Orthodox Jewish women and their family members with mental illness. *American Journal of Orthopsychiatry*, *83*(4), 520. https://psycnet.apa.org/doi/10.1111/ajop.12045

Whiteford, H. A., Degenhardt, L., Rehm, J., Baxter, A. J., Ferrari, A. J., Erskine, H. E., Charlson, F.J., Norman, R.E., Flaxman, A.D., Johns, N., & Burstein, R. (2013). Global burden of disease attributable to mental and substance use disorders: findings from the Global Burden of Disease Study 2010. *The Lancet*, *382*(9904), 1575-1586.

World Health Organization. (2014). Mental health: a state of well-being. 2013. *Report of the WHO Department of Mental Health*.

World Population Review. (2021). High Income Countries 2021. Retrieved from https://worldpopulationreview.com/country-rankings/high-income-countries.

Y- Garcia, E. F., Duberstein, P., Paterniti, D. A., Cipri, C. S., Kravitz, R. L., & Epstein, R. M. (2012). Feeling labeled, judged, lectured, and rejected by family and friends over depression: Cautionary results for primary care clinicians from a multi-centered, qualitative study. *BMC Family Practice, 13*(1), 1-9. https://doi.org/10.1186/1471-2296-13-64

Yang, C. T., Narayanasamy, A., & Chang, S. L. (2012). Transcultural spirituality: The spiritual journey of hospitalized patients with schizophrenia in Taiwan. *Journal of Advanced Nursing*, *68*(2), 358-367. https://doi.org/10.1111/j.1365-2648.2011.05747.x

Yin, M., Li, Z., & Zhou, C. (2020). Experience of stigma among family members of people with severe mental illness: A qualitative systematic review. *International Journal of Mental Health Nursing*, *29*(2), 141-160. https://doi.org/10.1111/inm.12668

Chapter 3

3.1 Methods

The main purpose of this study is to understand the experiences of familial mental illness stigma among individuals living with a diagnosis of mental illness and ways family members reduce or prevent potential familial mental illness stigma. Understanding the lived experiences of mental illness stigma from the perspectives of affected persons with family members with stigmatizing beliefs is crucial considering the potentially negative attitudes of some relatives as both directly harmful and as barriers to healthcare and other social support services (Koschorke et al., 2017; Livingston, 2013; Mascayano et al., 2015). The study, therefore, seeks to answer the following research questions: (1) What are the lived experiences of individuals living with a diagnosis of mental illness in relation to mental illness stigma, and how does this impact familial relationships?; (2) What are the lived experiences of family members or close relatives of individuals with a diagnosis of mental illness in relation to mental illness stigma, and how does this impact familial relationships?; (3) How do family members or close relatives of individuals with a diagnosis of mental illness prevent or reduce potential familial mental illness stigma?; and (4) How do individuals diagnosed with a mental illness deal with potential stigma, including familial mental illness stigma?

Given the overall objectives of the study and research questions, an interpretive (hermeneutic) phenomenology, as expounded by Martin Heidegger (1962), was used for this inquiry. This design was chosen because interpretive phenomenology fosters an appreciation and insight into the meaning of experiences as people interact with others and with their milieu (Lopez & Willis, 2004). This is congruent with Fox et al.’s (2018) model of understanding stigma from the stigmatizer, the stigmatized, and intersectionality. The methodology is outlined in the subsequent sections, starting broadly with phenomenology, followed by distinguishing interpretive phenomenology as well as the various qualitative methods used for the data collection.

Phenomenology is a philosophical standpoint built on careful descriptions and analyses of human experience (Brinkmann & Kvale, 2015). Likewise, Sokolowski (2000) defines phenomenology as the study of individuals' lived experiences and of the ways things unfold to us in and out of those experiences. Phenomenology is considered both philosophy and a method of enquiry (Creswell, 1998; Lopez & Willis, 2004; van Manen, 2002; van Manen et al., 2016), and in the current study is used as a methodology per Gallagher (Gallagher, 2012). Phenomenological research employs inter-subjective approaches to explore individuals' experiences relative to their everyday encounters (Morse, 1991; Moustakas, 1994; Creswell, 2003). Phenomenology as a method of inquiry has been used to describe and interpret lived experiences of individuals or groups (Beck, 1994; Chase, 2005; Morse, 1991; Penner & McClement, 2008). In addition, Mostert (2002) described phenomenology as a methodology that demonstrates multiplicity of experiences existing in the world that people live in, how they can be identified or described, and how we use language to help share and understand these experiences. Van Manen described phenomenology as a fundamental approach to systematically study lived experience or the world in which we live (van Manen, 1997).

Broadly, phenomenology was first developed by a German philosopher and mathematician, Edmund Husserl, who was one of the prominent philosophers of the 20th century (Dowling, 2007). Hursserl's philosophical underpinnings remain an essential factor in how we understand the creation of subjective but shared knowledge. Husserlian phenomenology helped define how human knowing is taken as a form of evidence (Tassone, 2017) by pursuing a form of objectivity of the experience being investigated. Husserl coined what is termed the "descriptive approach" to phenomenological inquiry (Benoist, 2003; Neubauer et al., 2019; Reiners, 2012). For Husserl, it was important for investigators to explain the essence of lived experiences of the phenomenon under study by suspending their premises and presumptions about the incident, striving to only capture the perspective of the participant (Gill, 2020; Husserl, 2002, 2012), releasing oneself from one's own preconceptions and hearing the experiences of others is what Husserl called 'phenomenological reduction'.

Phenomenological reduction is a technique that allows investigators to suspend their preconceived knowledge on the phenomenon under consideration with a focus of arriving at the essence of experience described by participants (Brinkmann & Kvale, 2015; Gearing, 2004). That is, phenomenological reduction compels researchers to suspend their judgement ('epoche') while trying to understand (or arrive at 'verstehen') the phenomenon under study through participants' perspectives. Bracketing is described as "an attempt to place the common-sense and scientific foreknowledge about the phenomena with parentheses in order to arrive at an unprejudiced description of the essence of the phenomenon" (Brinkmann & Kvale, 2015, p. 31). Husserl's preliminary approaches have led to many subsequent philosophers and theorists (Heidegger, Kierkegaard, Sarte, and Merleau-Ponty) contesting his assertion that experience and the world in which it exists are inseparable. The most prominent critic of Husserl's objectivist and descriptive assumptions was Martin Heidegger, a former student of Edmund Husserl. Whereas Husserl was Jewish and persecuted in the 1930s for his identity, Heidegger was a member of the Nazi Party and published several anti-semitic statements. While his contribution to phenomenology is notable, it is also important to acknowledge the highly problematic aspects of his work.

With regard to Heidegger's approach to phenomenology, consciousness is not taken as distinct or separable from the world but is a record of human experience, both observed but also integrated with our own knowing. That is, as humans we cannot isolate ourselves from the occurrences of the world but integrate them to shape our analysis of knowledge. In this way, our understanding and interpretation of the world is contingent on our lived experiences, which is inclusive of our social, cultural, and political life (Heidegger, 1962; Polkinghorne, 1983). Martin Heidegger, therefore, advanced phenomenology as an investigation that is interpretative in nature, which allows us to approach our experiences of the world we live in in relation to other peoples' lived experiences, as opposed to Husserl's more objectivist approach (Heidegger, 1962).

In shifting from a perceived objective, descriptive approach to understanding human experience, Heidegger proposed a more intersubjective approach now termed 'interpretive phenomenology'. Interpretive phenomenology is now deeply connected with hermeneutics, or how we interpret communications, texts, or even pre-understandings. Hermeneutics has been explained as a process and method capable of revealing concealed human experiences and relations, as well as delving deeper into a given phenomenon than mere description of core concepts and essences to look for actual meanings rooted in normal life practices (Lopez & Willis, 2004; Spielgelberg, 1976). Therefore, there is overlap between what is termed interpretive phenomenology and hermeneutic phenomenology, and herein the term "interpretive phenomenology" is used. The focal point of interpretive research is on what human beings experience rather than what they consciously identify with, which is often connected to sociocultural and political settings (Lopez & Willis, 2004). This is an important aspect for understanding experiences of stigma which cannot be separated from socio-cultural contexts.

Heidegger (1962) and later Koch (1995) underscored that it is impractical to eliminate background knowledge from the mind that often directs investigators to consider a topic worthy of studying. For instance, an investigator's knowledge of the extant literature is what drives the conceptualization or formulation of new research into a new phenomenon of interest, and the investigator's past knowledge or experience is essential to the successful completion of the project (Lopez & Willis, 2004). The limited number of primary studies sharing the lived experiences of familiar mental illness stigma is what motivated this project. This implies that individual experiences and expertise are valuable and effective in conducting phenomenological investigations (Flood, 2010; Geanellos, 2000). In fact, the role of the researcher's base knowledge in phenomenological inquiry was highlighted by van Manen when he discussed the importance of anecdote in attaining the objectives of a study (van Manen, 1997).

Benner (1994) explicates the assumptions of interpretive phenomenology as:

> (a) human beings are social dialogical beings; (b) understanding is always before us, in the shared background practices of the human community, within societies and cultures, in the languages, in our skills and activities, and in our intersubjective and common meanings; (c) we are always ready in a hermeneutic circle of understanding; (d) interpretation presupposes a shared understanding between the researcher and the participants; (e) interpretation involves the interpreter and the interpreted in a dialogical relationship (p. 71).

These views connect understanding with interpretation through communication. This is because as humans, our understanding of a given phenomenon today could differ in the coming days since fresh experiences, perceptions, or thoughts may bring out new possibilities of understanding. Therefore, to ensure credibility in hermeneutic phenomenology research, the researcher needs to clearly lay out their position in the work. Interpretive phenomenology is established in the practice where researchers and participants come to the investigation with existing knowledge shaped by their respective backgrounds; and in the process of interaction and interpretation they produce knowledge based on their understanding of the phenomenon under study (Wojnar & Swanson, 2007).

Interpretive phenomenology as a research methodology is suitable for describing and interpreting the lived experiences of familial mental illness stigma with persons living with mental illnesses. This study adopts van Manen's (1997) six practical interactive approaches for interpretive phenomenological inquiry to understand the phenomenon of familial mental illness stigma. The approaches consist of: (1) orientating oneself to the phenomenon of interest and explicating assumptions and pre-understandings; (2) investigating experiences as lived through conversational interviews rather than as we personally conceptualize it; (3) reflecting upon and conducting thematic analysis which characterizes the phenomenon and interpretations through conversations; (4) describing the phenomenon through the art of writing and re-writing (rethinking, reflecting, and recognizing) which aims at creating in-depth writing; (5) maintaining a strong and oriented relation to the fundamental question about the phenomenon, and (6) balancing the research context by considering parts and wholes (van Manen, 1997, p. 30). In keeping with van Manen's (1997) practical interactive approaches, this dissertation puts forward a vivid interpretation of the lived experiences of persons living with familial mental illness stigma in the context of their everyday lives, and contributes to the understanding of stigma.

3.2 Positionality

Positionality has been described as the researcher's stance in relation to others (participants), which is not permanent but rather can shift throughout the process of the study (Maher & Tetreault, 2001; Merriam et al., 2001; Narayan, 1993). According to Narayan (1993), "the loci along which we are aligned with or set apart from those whom we study are multiple and in flux, and factors such as education, gender, sexual orientation, class, race, or sheer duration of contacts may at different times outweigh the cultural identity we associate with insider or outsider status" (p. 671–672). Again, Maher & Tetreault (2001) described the concept of positionality as ways that characterize what people identify with, which are not fixed but situated within networks of relationships and can be analyzed and changed over time. To be explicit about one's positionality suggests an appreciation of where we stand regarding power, beliefs, and passions (Takacs, 2002). Positionality also references the researcher's world view and stance espoused during an investigation within a sociopolitical context (Savin-Baden & Major, 2013), which has the power to determine the direction and outcome of the study (Holmes, 2020).

Personally, I identify with the interpretivist approach of exploring social phenomena. Within this position, the investigator is considered part of the study, and a researcher's prior knowledge has an influence on the research duties, purpose, methods, and therefore the results (Ponterotto, 2005). It is also argued that the investigator's declaration of their world view of experience or expertise is essential in shaping the study, as it can influence every aspect of the inquiry from research questions to conclusion (Crotty, 1998). In conducting this research, I was guided by Crotty's assertion of positionality knowing that the study was undertaken from a viewpoint that openly values the experiences of all participants in understanding the meaning of familial mental illness stigma to co-construct knowledge through the study. I identified myself as an outsider from the start of this study with respect to the research settings, community service organizations, and culture of participants. I am a sub-Saharan African of Ghanaian lineage and thus identify myself as a black and racialized immigrant with a developing knowledge of the Canadian mental health system. I have not experienced any mental illness with its related stigma in my life. However, from my time in Ghana both as a nurse, health administrator, and private citizen, I have seen many people in mental health crises experience various abuses, in part due to mental illness stigma.

As an immigrant pursuing higher education in North America, I had the opportunity to work with children and youth who had been separated from their parents due to persistent abuse. Being a trainee researcher at the time, I was struck by the vulnerabilities of these youth and limited supports for significant mental health needs. I was also made very aware of the complexities of family relations and both the positive and negative roles that family members play related to each other's mental well-being. This dissertation was, therefore, borne from my experiences in supporting these vulnerable children and youth. Simultaneously, I continue to be driven by concern for the high degree of mental illness stigma that exists in my home country of Ghana where families frequently shun family members with mental health problems. My goal is to gain an in-depth knowledge of mental illness and its related stigma in Canada and understand how to best contribute to the promotion of a stigma-free environment for continual improvements in the integration of people with mental illnesses into the community. As an outsider investigator, my ontological and epistemological assumptions were crucial in designing the study. Ontology has been described as the nature of the world which is socially created through discourse and experience (Higgs & Trede, 2009). Ontology is concerned with the type of world we are exploring or studying, as well as the nature of existence and the structure of truth or reality (Crotty, 2003), which also represents our belief systems and how we perceive the universe. Epistemology, on the other hand, is a branch of philosophy that studies the nature of knowing as well as our thoughts about its scope, validity, and reliability of claims to knowledge (Hofer, 2004; Willig, 2001). That said, Crotty sees epistemology as the acquisition of knowledge and explicating how we know what we know (Crotty, 2003).

As a Ghanaian with strong moral principles and respect for culture, I always function by the rule that research denotes a shared space, shaped by both the investigator and participants (England, 1994), and my aim of pursuing the authentic voices of my participants. Therefore, I believe in the idea that the characteristics of both the researcher and participants can conceivably affect the outcome of the study which calls for equal respect with regards to their positionalities or belief systems. While I consider myself as an outsider in the research context, I am well-educated and immersed in research activities which potentially can influence the nature of responses from participants. To understand how any preconceptions came through in the research process, I continually engaged in self-scrutiny, also known as reflexivity, to remind myself of the relationship between me (the researcher) and participants and the need to respect each other’s contributions to the process. This is because the relationship between me and participants within this dissertation is transactional. To safeguard this transactional relationship, I employed the process of self-reflexivity and shared reflexively with my supervisor and supervisory committee who are familiar with the research context, as well as the social systems that deal directly with persons living with mental illnesses. As a non-Canadian who has limited working knowledge of social systems, especially the perspectives of clinical practices that manage mental illnesses, I come into this study with the belief that familial mental illness stigma exists and is under-recognized, at times unspoken. Hence, identifying and accepting my biases was not a singular event but recurred throughout the study and the writing of the thesis. Through this process, I was better placed to learn from the participants of the study (i.e., individuals living with mental illnesses and their families) through their narratives and remained truthful in the acquisition of knowledge to understand the phenomenon of familial mental illness stigma. The outcome of this research is, therefore, contingent on my interactions with participants of the study in a research process to understand their viewpoints, insights, and personal conceptualizations of familial mental illness stigma. Mental illness stigma is considered universal, however, it wasn't until I had immersed myself in the literature and conducted in-depth interviews with participants that I saw how familial mental illness stigma remains widely present in a high-income country like Canada.

The multiple and diverse experiences narrated by participants represent complex views, and the phenomenology approach aims for balance in presenting this uniqueness as well as the commonalities (Creswell et al., 2003). Data collection was achieved through the process of interaction, with the intention of relying on participants' views of a phenomenon under inquiry, driven by the questions from the investigator. Hence, the interpretivist epistemology postulates that participants and investigators interact in the research setting with their views, intuitions, and knowledge and come out of the research process having been influenced to a new knowledge by the experience of that interaction. The current study is based on an interpretivist standpoint and is determined by the interaction of the researcher and participants to produce an empirical insight into the existence and nature of familial mental illness stigma in Canada.

3.3 Research Ethics

Ethics approval for the study was obtained from the Research Ethics Board of Western University, London, Canada, to conform with sound ethical principles involving research using human subjects. As a graduate student, I continually updated my knowledge on the Western University Ethics regulations and the Tri-Council Policy Statement (2014) on ethical conduct for investigations using humans. Although I have participated in seminars on both the Western University ethics guidelines and the Tri-Council Policy Statement on research involving humans, I continued to engage with the materials, for example through the ethics submission process, to ensure I was current in my knowledge during and after the data collection.

Informed consent was obtained from all participants prior to data collection. Particularly, all interviewees were given written consent forms to sign after discussing the purposes of the study and potential harms that could arise during the interviews. The signed consent forms were returned to the researcher before the start of the interviews. Also, permission to audio-record the discussions during interviews was sought from each participant. If participants declined audio-recording during interviews, they were still able to participate in the study, as the researcher took notes throughout the conversation to capture their views. Participants were informed that participation was voluntary and therefore, they were free to decide not to participate at any time they wished to do so without any penalty.

Confidentiality and anonymity of participants was maintained by the researcher and his team. This was done by asking all who might assist with data management to sign a confidentiality agreement to protect the views of respondents, and no participant’s name was included in any transcript from the study for the sake of confidentiality. Participants’ names were, therefore, replaced by pseudonyms and unique identification numbers to conceal their identity. To ensure data security, all information gathered for this study was kept in a secured, locked room at Western University. All files that pertain to data were secured using passwords that are known to only the investigator and supervisor. Hard copy records were protected in cabinets within the locked room and to be shredded at the end of the period specified by the university ethics board.

One of the goals of this research was to seek the welfare of persons living with mental illnesses, hence the principles of beneficence that strive for the avoidance of harm of participants and increase of potential benefits were followed. The primary aim of the principle of beneficence is not just to avoid or reduce harm, but also to maximize the benefits participants accrue from the research (Varkey, 2020). Dealing with vulnerable populations within my research project, I made provisions for any potential psychological activation or distress that may occur during the research interviews with persons living with mental illnesses and their family members. Because the in-depth interviews were done in community service centers, we ensured our knowledge of the resources available at these sites for those with support needs. Participants were reminded of potential harms that could happen during data collection when reiterating the purposes of the study to them before the start of the interviews. In addition, an incentive of $20 CAD was given to participants as a stipend for their time.

3.4 Research Design

As noted earlier, the research design for this dissertation was interpretive phenomenology. In-depth interviews were employed to collect the required data for the study. Qualitative research interviews (in-depth interviews) provided the needed flexibility for me to understand the world from participants' standpoints, which allowed me to derive meaning of individuals' experiences, to unearth their lived world before any systematic descriptions (Kvale, 1996). The use of this qualitative data collection method also allowed me to engage with several types of participants (i.e., people with mental illness, family members) for information on the same phenomenon. This strategy afforded me the opportunity to obtain diverse views from participants to better understand experiences of familial mental illness stigma.

3.4.1 Study setting

The study was conducted in the London-Middlesex area of Southwestern Ontario, Canada. The population of London-Middlesex was 515,114 in 2021 per the last population census of Canada (Statistics Canada, 2021), with an annual population change of 1.7% from 2017 to 2021. In 2018-19, the London area of London-Middlesex was mentioned as one of the fastest-growing cities in Canada, with an annual growth of 2.3%, according to Statistics Canada estimate (Canadian Broadcasting Corporation News, 2020). London-Middlesex constitutes 3.4% of the Ontario population, with about 84.3% of the people living in the city of London (Statistics Canada, 2016).

Mental health service delivery in the London-Middlesex sub-region have undergone substantial changes over the years, concentrating on innovative models of care in both hospital-based and community-based mental health programs (Velji & Links, 2016). London-Middlesex has various health care institutions that handle both physical and mental health conditions. In the area of mental health care delivery, the London Health Sciences Center focuses on managing acute cases, whereas St. Joseph’s Health Care (Parkwood Institute) and St. Thomas Provincial Psychiatric Hospitals manage longer-term conditions (Mental Health Commission of Canada, 2015; Velji & Links, 2016). This structure has come about through 17 years of transformation and consolidation under the direction of Ontario’s Health Services Restructuring Commission in 1997 (St. Joseph’s Health Care Report, 2016; Velji & Links, 2016). At the community-level, community mental health and addictions services have been a priority focus area since regionalization and the start of the South West Local Health Integration Network (LHIN) in 2007. The LHIN is now known as "Home and Community Care Support Services - South West".

A primary community provider in the region is Canadian Mental Health Association (CMHA) Middlesex, which delivers various services (treatment, housing, community supports, and crisis services) for persons with mental illnesses and their families (CMHA Report, 2019). These services incorporate both mental health and addictions care. CMHA services include integrated housing models, such as transitional youth apartments to offer housing support to youth aged 16-26 with staff onsite to supervise them (CMHA Report, 2019). The scope of services provided by CMHA in the London region include: (1) 7,847 unique individuals living with mental illnesses registered in various programs; (2) 414 clients engaged in housing supports; (3) 1,597 clients supported by case management; (4) 9,994 visits for crisis assessment and response; and (5) 1,495 visits to the crisis stabilization space (CMHA Report, 2019).

3.4.2 Sampling and recruitment: A criterion sampling technique was employed to obtain data from both groups of participants (Moser & Korstjens, 2018; Polit & Beck, 2008). I interviewed 15 participants from each group. This sample or number was chosen acting on the advice of Creswell (1998) and Morse (1994) who suggested between 5 and 25 participants for phenomenological studies. Again, in hermeneutic or interpretive phenomenology investigations, researchers' intent is to recruit limited number of participants vis-à-vis a larger size to focus deeply on lived experiences in order to increase the likelihood of thick, rich, and unique stories relative to the phenomenon under study (Laverty, 2003). In the current study, I recruited people with mental illnesses and family members who support them in their daily care. All participants were interviewed separately.

Inclusion criteria for participants for the in-depth interviews were: (1) 24 years or older; (2) self-identifying as an individual living with mental illnesses or with a medical diagnosis of mental illnesses; (3) self-identifying as a family member of persons with mental illnesses; (4) speaks and understands English; (5) being a current resident in London-Middlesex; and (6) willing to participate in the study for 45-60 minutes. All persons who identify as people with mental illnesses or family members of persons with mental illnesses and are not resident in the London-Middlesex area were excluded from the study.

My goal was to explore experiences of familial mental illness stigma among a wide range of persons living with mental illnesses. Therefore, I recruited individuals (people with mental illnesses) 24 years or older to have a diverse view of familial mental illness stigma from participants. This allowed me to explore a diversity of events under the circumstances to reveal the essence, meaning, and value of participants' lived experiences. The distinct experiences presented by the various age groups (young adulthood through to the aged) offered an opportunity to critically reflect on key themes that might depict the meaning of the experiences (familial mental illness stigma) among persons with mental illnesses and their families. This also allowed me to understand the different dynamics of familial stigma that may exist with respect to individuals with a first onset of mental illness versus long-term and recurrent illness.

For recruitment, I sought the assistance of key connections in the community, such as primary care clinics, CMHA offices, and intercommunity health centers, who work directly with the individuals I intended to recruit, to have initial discussions on my behalf. This was done by providing project information to staff within the various community family practice and CMHA offices for them to post the project recruitment posters in public spaces on the unit. Project recruitment posters were also posted on social media and various notice boards across the city of

London. Apart from the diverse perspectives on familial mental illness stigma that family members bring to the study, their involvement helped in the creation of knowledge and understanding of the phenomenon to inspire research-to-action to bridge existing gaps within family systems. This knowledge translation could drive the enactment of specific policies and interventions to tackle familial mental illness stigma in society. The recruitment of participants for the in-depth interviews started after receiving ethics approval from Western University.

3.4.3 Data collection methods: Data collection commenced in May 2022 and ended in July 2022. In-depth interviews or one-on-one interviews were employed to collect information from all participants of the study. In-depth interviews remain one of the most common and relevant data collection techniques in qualitative research (Barker et al., 2005; Burns et al., 2007; Rhee et al., 2012; Whitaker et al., 2016). These in-depth interviews usually involve a conversation or discussion between researcher and participant, driven by a flexible interview guide that allows for follow-up questions, probes, and comments (DeJonckheere & Vaughn, 2019). Qualitative in-depth interviews tie in with my methodology and design since phenomenological research involves hearing the details of experiences that cannot be captured in sufficient depth through survey tools (Gubrium & Holstein, 2001). The semi-structured interview guide with open-ended questions offered me a platform for flexible dialogues with the participants to gain deeper understanding of their lived experiences of familial mental illness stigma. The researcher's appreciation of participants' lived experiences of the investigated phenomenon in phenomenological research is essential while garnering adequate data that cannot be obtained through other means to answer questions tailored in the study (Wimpenny & Gass, 2001). In this case, I aimed to listen with an open mind to learn from my participants during the interviews and to give an account that truly represents their lived experiences. Two semi-structured interview guides were prepared for data collection in this dissertation: (1) an interview guide for in-depth interview with persons living with mental illnesses; (2) an interview guide for in-depth interview with family members of persons living with mental illnesses. These interview guides were given to participants in advance of the interview to enable them to prepare adequately and feel relaxed during the interviews to provide sufficient depth of information on familial mental illness stigma. According to Gill et al. (2008), the provision of interview guides to participants ahead of interviews allowed participants to give good and detailed answers while preventing unnecessary surprises in the interviews. The interview guides were all drawn from two main frameworks by Link et al. (2004) and Fox et al. (2018), which address the measurement of mental illness stigma and its applicability to both the stigmatized and the stigmatizer. Link and colleagues (2004) focused on the systematic understanding of stigma and our ability to observe and determine it whilst Fox et al. (2018) centered on the expressions for understanding the processes of mental illness stigma that are important to the study of both the stigmatized and the stigmatizer. See Appendix D and E for the two interview guides.

All interviews were audio-recorded and transcribed with permission from participants. Participants were given individual forms on which to provide their demographic information, which was later replaced with pseudonyms to conceal their identity. While conducting the in-depth interviews, I had the opportunity to observe participants' behaviours and take notes on nonverbal communication cues that were used to complement the verbal interactions audio recorded during the interviews. The interviews took place via the Zoom web conferencing platform. I interviewed 15 participants with lived experiences of mental illnesses. In an interpretive phenomenology investigation, the researchers' intent is to recruit limited number of participants vis-à-vis a larger size to focus deeply on lived experiences to increase the likelihood of rich and unique stories relative to the phenomenon under study (Laverty, 2003). In addition to the in-depth interviews, I interviewed 15 family members or close relatives of persons with mental illnesses for their views on familial mental illness stigma. The family members' perspectives on familial mental illness stigma helped me to identify the commonalities and differences in the narratives put forward by their relatives living with mental illnesses and added another layer of information to broaden the sequence of events around familial mental illness stigma. Family members' perceptions of familial mental illness stigma in this study are instrumental in shaping existing policy interventions to create stigma-free milieus necessary to sustain families and warrant inclusiveness of all persons.

3.5 Analysis of Data

Situated within a broader consideration of phenomenology, Braun and Clarke's (2006) framework for thematic analysis in psychology was adopted to underpin the data analysis process. The combination of the two approaches brought a better appreciation of the experiences of familial mental illness stigma. This allowed us to identify categories and themes in the data and made strong inductive conclusions about familial mental illness stigma. Braun and Clarke's (2006) framework provides the following outline: (1) familiarizing yourself with your data; (2) generating initial codes; (3) searching for themes; (4) reviewing the themes; (5) defining and naming themes; and (6) producing the report.

The use of this analytical framework assisted the researcher to present the data obtained in systematic and transparent pathways for easy identification of patterns for inductive thematic assessment. As a researcher, my goal in this interpretive phenomenology analysis was to establish an explanatory or interpretative relationship with the interview transcripts to develop coherent themes that are central to the study objective and also represent the subjective accounts of participants. This interpretative connection was developed by engaging deeply with the transcripts and observation notes to understand participants' lived experiences before starting the textual analysis. This was followed by a more in-depth analytical or theoretical ordering while looking for linkages among clustering categories we were developing (see Smith & Osborn, 2003). As expressed by van Manen (1990), the analytical process in phenomenology is iterative, hence I continued to reflect on key themes that characterize the phenomenon (familial mental illness stigma) to determine structures of experience as the major themes. These themes were developed as I tried to understand the phenomenon (familial mental illness stigma). Verbatim statements from participants were used to support my major themes and subthemes.

Familiarisation in Braun and Clarke's framework is the first step of the analysis process, which allows the researcher to engage with the raw data in order to gain an accurate and deep understanding while acknowledging their meaning and patterns (Braun & Clarke, 2013, 2006; Creswell, 2013). Familiarisation starts with data preparation, and to ensure that this was well-executed, all 30 in-depth interviews were transcribed by the researcher. This was done by listening to the audiotapes of all interviews repeatedly and transcribing them verbatim into word processor files. To confirm the accuracy of the earliest transcriptions, the audio recordings were replayed many times and double-checked with the transcripts. I continued to reflect on the data by listening to the audiotapes and re-reading the transcripts, while visualizing each participant at the time of the interview to be able to appreciate and interpret the context in which they spoke to account for the full, detailed, and thick description of the data. While re-reading the transcripts, initial notes were made to augment possible ideas on first level coding. All these processes allowed the researcher to become familiarised with the data or to make casual observations of the dataset to set the pace for initial patterns and coding.

Immersing myself in the data and developing some foundational thoughts and impressions, I then began the next stage of the analysis, which was coding. Basit (2003) describes coding as a process where the researcher apportions tags or labels for allocating units to signify descriptive or inferential information gathered during a study. Coding “leads you [researcher] from the data to the idea, and from the idea to all the data pertaining to that idea” (Richards & Morse, 2007, p. 137). That is, coding is done to extract key information or concepts within the data in relation to the purpose of the study. Guided by the research questions and objectives, I commenced the coding process by assigning meaningful labels to segments of each transcript relevant to the study using words as well as short phrases and sentences (‘prejudice, appreciated and inclusive, and frustrated and overburdened’). These expressive labels conveyed appropriate information on segments of the data to the researcher. The labels were centered on participants’ opinions, actions, concepts, and activities pertinent to the study. I employed an open coding technique that allowed for inclusion and repetition of important concepts and opinions identified and categorised as codes in all segments of the data relative to the study objectives. Each of the 30 transcripts was coded separately before merging them into a table with various participants’ extracts or passages together with their unique identifiers. Consequently, the various initial codes were organized and arranged logically into higher level categories for thematic linkages or nexuses which paved the way for theme searching. The systematic assembling of codes into higher-level categories or subthemes was guided by specific research objectives. The proposed codes and categories were further reviewed by my supervisor.

The creation of themes started after the collation of codes to form higher-level categories. According to Braun and Clarke (2006), this procedure is iterative, and requires sorting codes and mapping various patterns into probable themes, as well as combining all key coded data extracts within the identified themes. At this stage, the researcher identifies a central organising thought—a “clear core idea or concept that underpins a theme” that speaks to the range of codes within the higher-level categories (Braun et al., 2015, p. 102). The central organising thought underpinning the themes allowed me to acknowledge and appreciate the codes captured throughout the entire dataset. Having re-read the categorised data and recognised the commonalities and connections within the data with respect to the various subthemes and potential themes, I reflected on the linkages between them to determine how best to pull together subthemes and themes to fit participants’ stories. To ensure consistency in my themes relative to the study objectives and questions, the initial or potential themes identified were reviewed and defined as per the Braun and Clarke’s (2006) framework.

The reviewing of themes “involves checking that the themes work in relation to both the coded extracts and the full dataset and may be necessary to collapse two themes together or to split a theme into two or more themes, or to discard the candidate themes altogether and begin again the process of theme development” (Clarke & Braun, 2013, p. 4). This calls for deeper reflections on potential themes to ensure a persuasive story that articulates the dataset. As the researcher, I re-read through all segments of the extracted data to better understand the themes while appreciating the discrepancies among themes. This quality control exercise allowed me to clearly define my themes uniquely, relative to the various research questions, for accurate accounts of participants’ voices or opinions. The review process also afforded me the opportunity to include data pertinent to the study that were not initially coded, ensuring complete and more compelling stories of participants. To ensure a captivating story, I rearranged all themes in a distinct fashion such that related themes are close to each other for coherence and readability. For instance, all identifiable themes reported from persons with mental illnesses were grouped together as well as those from close family members of persons with mental illnesses. At this point, I submitted a detailed table of all the analysis to my supervisor for revision prior to defining and naming of the themes.

Defining and naming themes is another critical area in data analysis where the researcher organises and write a comprehensive account of each theme. The definition of themes refers to the practice of producing concise themes that depict clear contents for each theme consistent with the central organising concept and have adequate depth to befit key sections of the investigative story (Terry et al., 2017). To fulfil this component of the framework in my study, I re-engaged with the categorised data for each theme and undertook a comprehensive analysis of each storyline portrayed or described to ascertain how it aligned with the larger storyline in the dataset relative to the research questions. Having gone through all this process, I sent the themes to my supervisor for review and further discussion of the preliminary themes. My supervisor took time to review the process again, which offered us the opportunity to reassess all the various themes together with their subthemes to ensure that the theme captures the actual meaning of extracted data segments. The themes were defined and tested with names that “give a clear indication of the content within the theme that draw the reader into the analysis” given the fact that “straightforward descriptive theme names work better than a ‘fun’ name that does not capture the theme” (Terry et al. 2017, p. 25). This analysis process produced 10 themes with various subthemes.

Producing the report is the final phase of the analytical process which gives the researcher an opportunity to present the data in a manner that helps readers to understand the story presented within and across themes. In the current study, themes and subthemes were organised to provide succinct logical accounts of the data supported by substantial evidence using direct data extracts or quotes. Data extracts that captured the essence of the study in relation to the research questions were made less complex and interpreted to offer the needed enlightenment of the data within the story, as outlined in Braun and Clarke's (2006) analytical framework.

3.6 Methodological Rigor

Rigor or trustworthiness in research focuses on quality with respect to the robustness and acceptability of results from an investigation. Rigor or trustworthiness often describes the degree of certainty in methods, data, and interpretation to guarantee the quality of a study (Pilot & Beck, 2014). In subjective research, it is about certainty in methods rather than certainty in presenting any singular 'correct' truth from the data. To ensure rigor in qualitative research, Guba and Lincoln (1989) and Shenton (2004) set out the following quality criteria: credibility, transferability, dependability, and confirmability. This dissertation included a combination of these criteria to enhance rigor.

3.6.1 Credibility: Credibility in qualitative research reflects the researcher's ability to follow basic guidelines to enhance confidence in the results of the study. Achieving credibility depends on many factors including a researcher's expertise, centring the experiences of participants, peer review and debriefing, embracing, and clarifying researcher bias, member checking, thick and rich descriptions, and external audits (Creswell, 2007; Patton, 2002). The above-mentioned techniques were followed to address the researcher's biases to maintain a commitment to the subjective reflections of participants' experiences at the end of the study. My own knowledge, experiences, and training as a public health researcher and a doctoral candidate offered me some integrity to acknowledge my personal biases and engage with participants by asking them the right questions and drawing my conclusions from participants' constructions to address the research questions. My expertise as a nurse allowed me to moderate the interviews in a friendly manner within a conducive environment that motivates participants to share their experiences of familial mental illness stigma with me for at least 45 minutes. Also, I was supported by my supervisory committee members who are highly experienced in all aspects of qualitative research techniques through their feedback on various proposal design drafts to enhance the trustworthiness of this study. My engagement with participants from the recruitment stages through interviews for a duration of at least 45 minutes granted me the chance to connect and learn from them to enhance the depth of the findings. The use of member checking allowed participants to verify subjective representations of their narratives. Guba and Lincoln (1989) identify member checking as one of the best approaches to ensuring credibility in qualitative research. Member checking offers opportunities for participants to agree or disagree with the direction that findings are taking. In this study, member checking was fulfilled by sending the final themes and subthemes to ten participants (five from each group) who accepted our invitation for feedback and approval. All selected participants agreed on the final themes.

Peer review and debriefing is another technique employed to ensure credibility. Peer review and debriefing entails soliciting opinions from individuals whose expertise permits them to question the researcher's findings to bring more clarity to the results. Peer review and debriefing involved the four professors who are members of my supervisory committee. The committee gave me expert advice on my interview guides prior to the data collection, and feedback on the written analysis. My primary supervisor first reviewed the analysis and invited me to a meeting to discuss the preliminary categories and themes. The themes were then revised and sent to the supervisory committee for comments. The constructive feedback from the committee members helped me to report on the experiences of my participants. Thick description adds to the means through which qualitative studies can attain credibility. Thick description involves a rigorous illustration that includes culturally situated meanings, rich, and concrete detail of individuals' experiences of a phenomenon (Bochner, 2000). The researcher's experience, knowledge, and understanding of the phenomena under study within a given context are key to demonstrate thick description. Thick description was also ensured by providing adequate details regarding both the data and the conclusions made from the data. This included direct quotations from the participants' narratives or linking anecdotes to back the findings of the study, which enables readers to draw meaningful conclusions for themselves.

3.6.2 Transferability: Transferability is the degree to which results of an investigation are valuable to diverse groups in different settings but with similar experiences (Polit & Beck, 2014). That is, transferability is the extent to which the conclusions of one study apply to other similar situations. Transferability can be sought by giving a comprehensive account of the study background, settings, and participants for readers to determine how best those illustrations could be compared to other experiences elsewhere (Amankwaa, 2016; Connelly, 2016; Shenton, 2004). In this study, I pursued transferability through the provision of adequate details on the study background, context, and methods. The availability of thick description of the study procedures allows other investigators and readers to follow through with the study results to consider their broader relevance. This analysis could be of interest to policy-makers on social and community services, family members of persons living with mental illnesses, community mental and social workers, researchers in health and social services.

3.6.3 Confirmability: Confirmability implies adequate steps taken to enhance the ability to trace back the findings to the words of participants (Connelly, 2016; Shenton, 2004). To ensure confirmability in qualitative research, the investigator should keep the raw data, field notes, and transcripts for the qualitative study as evidence for other researchers (Nowell et al., 2017). Confirmability of this study was ensured by documenting in detail all data, including observational notes gathered from the field, per the ethical guidelines of the investigation. Most importantly, each step of the evolving analysis was documented so that the analysis process of moving from data to themes is evident. This includes multiple tables of codes, categories, and themes.

References

Barker, K. K., Bosco, C., & Oandasan, I. F. (2005). Factors in implementing interprofessional education and collaborative practice initiatives: Findings from key informant interviews. *Journal of Interprofessional Care*, *19*(sup1), 166-176. https://doi.org/10.1080/13561820500082974.

Basit, T. N. (2003). Manual or electronic? The role of coding in qualitative data analysis. *Educational Research 45*(2), 143–54.

Beck, C. T. (1994). Phenomenology: Its use in nursing research. *International journal of nursing studies*, *31*(6), 499-510.

Benner, P. (1994). Hermeneutic phenomenology: A methodology for family health and health promotion study in nursing. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, Caring, and Ethics in Health and Illness* (pp. 71-72). Thousand Oaks, CA: Sage.

Benoist, J. (2003). Husserl and Bonzano. In M. T. Tymieniceka (Ed.), *Phenomenology world-wide. Foundations-expanding dynamics-life-engagements. A guide for research and study* (pp. 94-97). London: Kluwer Academic.

Bochner, A. (2000). Criteria against ourselves. *Qualitative Inquiry*, 6, 266-272. https://doi.org/10.1177/107780040000600209

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: SAGE Publications.

Braun, V., Clarke, V., and Terry, G. (2015). Thematic analysis. In P. Rohleder and A. Lyons (Eds.), *Qualitative research in clinical and health psychology* (pp. 95–113). Basingstoke: Palgrave MacMillan.

Brinkmann, S., & Kvale, S. (2015). *Interviews: Learning the Craft of Qualitative Research Interviewing* (Vol. 3). Thousand Oaks, CA: Sage.

Burns, F. M., Imrie, J. Y., Nazroo, J., Johnson, A. M., & Fenton, K. A. (2007). Why the (y) wait? Key informant understandings of factors contributing to late presentation and poor utilization of HIV health and social care services by African migrants in Britain. *AIDS Care*, *19*(1), 102-108. DOI: 10.1080/09540120600908440

Canadian Broadcasting Corporation News. (2020, February). London population growth rate among fastest in Canada. Retrieved from https://www.cbc.ca/news/canada/london/london-population-1.5464669.

Canadian Mental Health Association. (2019). CMHA Middlesex-Annual-Report 2018-2019. Retrieved from https://cmhamiddlesex.ca/ . Accessed on February 28, 2021.

Chase, S. E. (2005). *Narrative Inquiry: Multiple Lenses, Approaches, Voices*. In N. K. Denzin, & Y. S. Lincoln (Eds.), The Sage Handbook of Qualitative Research: Third Edition (pp. 651-679). London, Thousand Oaks, CA, and New Delhi: Sage.

Clarke, V. and Braun, V. (2013) Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The Psychologist, 26* (2). pp. 120-123. ISSN 0952-8229 Available from: http://eprints.uwe.ac.uk/21155

Connelly, L. M. (2016). Trustworthiness in qualitative research. *Medsurg Nursing*, *25*(6), 435.

Amankwaa, L. (2016). Creating protocols for trustworthiness in qualitative research. *Journal of Cultural Diversity*, *23*(3).

Creswell, J. W. (1998). *Qualitative Inquiry and Research Design: Choosing among Five Traditions*. Thousand Oaks, CA: SAGE.

Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five traditions* (2nd ed.). Thousand Oaks, CA: Sage.

Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approach*. Sage publications.

Creswell, J. W., Plano Clark, V. L., Gutmann, M. L., & Hanson, W. E. (2003). Advanced mixed methods research designs. *Handbook of Mixed Methods in Social and Behavioral Research*, *209*(240), 209-240.

Creswell, J.W. (2003). *Research design: Qualitative, quantitative, and mixed methods approach*. (2nd ed.) Thousand Oaks: Sage.

Crotty, M. (1998). The foundations of social research: Meaning and perspective in the research process. London: Sage.

Crotty, M. (2003). The Foundations of Social Research: Meaning and Perspectives in the Research Process, London: Sage Publications, 3rd edition.

DeJonckheere, M., & Vaughn, L. M. (2019). Semi-structured interviewing in primary care research: a balance of relationship and rigour. *Family Medicine and Community Health*, *7*(2). http://dx.doi.org/10.1136/fmch-2018-000057

Dowling, M. (2007). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies, 44*(1), 131-142. Doi: 10.1016/j.ijnurstu.2005.11.026

England, K. V. L (1994). Getting personal: Reflexivity, Positionality, and Feminist Research. *The Professional Geographer, 46*(1), 80–89.

Flood, A. (2010). Understanding phenomenology. *Nurse Researcher*, *17*(2), 7–15. https://doi.org/10.7748/nr2010.01.17.2.7.c7457

Fox, A. B., Earnshaw, V. A., Taverna, E. C., & Vogt, D. (2018). Conceptualizing and Measuring Mental Illness Stigma: The Mental Illness Stigma Framework and Critical Review of Measures. *Stigma and Health*, *3*(4), 348–376. https://doi.org/10.1037/sah0000104

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, *13*(1), 1-8.

Gallagher, S. (2012). What Is Phenomenology? In: Phenomenology. Palgrave Philosophy Today. Palgrave Macmillan, London. https://doi.org/10.1057/9781137283801_2

Geanellos, R. (2000). Exploring Ricoeur’s hermeneutic theory of interpretation as a method of analyzing research texts. *Nursing Inquiry*, 7(2), 112-119.

Gearing, R. E. (2004). Bracketing in research: A typology. *Qualitative Health Research*, *14*(10), 1429-1452.

Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Methods of data collection in qualitative research: interviews and focus groups. *British Dental Journal*, *204*(6), 291-295.

Gill, M. J. (2020) Phenomenological approaches to research, in Mik-Meyer, N. and Järvinen, M (Eds.) Qualitative Analysis: Eight approaches, London: Sage, pp. 73-94.

Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*. Sage.

Gubrium, J., & Holstein, J. (Eds). (2001). *Handbook of interview research: context and method.* Thousand Oaks, CA: Sage Publications.

Heidegger, M. (1962). Being and time. New York: Harper. (Original work published 1927).

Polkinghorne, D. (1983). *Methodology for the human sciences: Systems of inquiry*. Albany: State University of New York Press.

Higgs, Joy & Trede, Franziska (2009). Framing research questions and writing philosophically. In Joy Higgs, Debbie Horsfall & Sandra Grace (Eds.), *Writing qualitative research on practice* (pp.13-26). Rotterdam: Sense Publishers.

Hofer, B. K. (2004). Epistemological understanding as a metacognitive process: Thinking aloud during online searching. *Educational Psychologist*, *39*(1*)*, 43-55,

Holmes, A. G. D. (2020). Researcher Positionality--A Consideration of Its Influence and Place in Qualitative Research--A New Researcher Guide. *Shanlax International Journal of Education*, *8*(4), 1-10.

Husserl, E. (2002). *The shorter logical investigations*. Routledge.

Husserl, E. (2012). *Ideas pertaining to a pure phenomenology and to a phenomenological philosophy: First book: General introduction to a pure phenomenology* (Vol. 2). Springer Science & Business Media.

Koch, T. (1995). Interpretive approaches in nursing research: The influence of Husserl and Heidegger. *Journal of Advanced Nursing, 21*(5)*,* 827-836.

Koschorke, M., Padmavati, R., Kumar, S., Cohen, A., Weiss, H. A., Chatterjee, S., Pereira, J., Naik, S., John, S., Dabholkar, H., & Balaji, M. (2017). Experiences of stigma and discrimination faced by family caregivers of people with schizophrenia in India. *Social Science & Medicine*, *178*, 66-77.

Kvale, S. (1996). *InterViews*. Thousand Oaks, CA: Sage Publications.

Laverty, S. (2003). Hermeneutic phenomenology and phenomenology: A comparison of Historical and methodological considerations. *International Journal of Qualitative Methods, (2)*3, 21-35.

Lincoln, Y., & Guba, E. (1985). Naturalistic inquiry. Beverly Hills: Sage Master, Peter (1999) Editorial. *English for Specific Purposes*, *18*, 102-4.

Link, B. G., Yang, L. H., Phelan, J. C., & Collins, P. Y. (2004). Measuring mental illness stigma. *Schizophrenia Bulletin*, *30*(3), 511-541.

Livingston, J. D. (2013). Mental illness-related structural stigma: The downward spiral of systemic exclusion. Calgary, Alberta: Mental Health Commission of Canada. Retrieved from www.mentalhealthcommission.ca. Accessed January 12, 2021.

Lopez, K. A., & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge. *Qualitative Health Research*, *14*(5), 726-735.

Maher, F. A., & Tetreault, M. K. T. (2001). *The feminist classroom: Dynamics of gender, race, and privilege*. Rowman & Littlefield Publishers.

Mascayano, F., Toso-Salman, J., Ho, Y. C. S., Dev, S., Tapia, T., Thornicroft, G., Cabassa, L.J., Khenti, A., Sapag, J., Bobbili, S.J., & Alvarado, R. (2020). Including culture in programs to reduce stigma toward people with mental disorders in low-and middle-income countries. *Transcultural Psychiatry*, *57*(1), 140-160. https://doi.org/10.1177/1363461519890964

Mental Health Commission of Canada. (2015). *Guidelines for Recovery-oriented practices*. Mental Health Commission of Canada.

Merriam, S. B., Johnson-Bailey, J., Lee, M. Y., Kee, Y., Ntseane, G., & Muhamad, M. (2001). Power and positionality: Negotiating insider/outsider status within and across cultures. *International Journal of Lifelong Education*, *20*(5), 405-416.

Morse, J. M. (1991). Qualitative nursing research: A free-for-all. *Qualitative nursing research: A contemporary dialogue*, 14-22.

Morse, J. M. (1994). Designing funded qualitative research. In Denizin, N. K. & Lincoln, Y. S., *Handbook of qualitative research* (2nd Ed). Thousand Oaks, CA: Sage.

Moser, A., & Korstjens, I. (2018). Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. *The European Journal of General Practice*, *24*(1), 9–18. https://doi.org/10.1080/13814788.2017.1375091

Mostert, W. (2002). Phenomenology: Discovering new meanings of pedagogy within the lived experience. *A paper presented at the Association for Active Educational Researchers. Brisbane, Australia: December* 1-5. Retrieved from https://www.aare.edu.au/data/publications/2002/mos02453.pdf.

Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.

Narayan, K. (1993) How native is a ‘‘native’’ anthropologist? *American Anthropologist,* 95, 671–686.

Takacs, D. (2002). Positionality, epistemology, and social justice in the classroom. *Social Justice*, *29*(4 (90), 168-181.

Neubauer, B. E., Witkop, C. T., & Varpio, L. (2019). How phenomenology can help us learn from the experiences of others. *Perspectives on Medical Education*, *8*(2), 90-97. https://doi.org/10.1007/s40037-019-0509-2

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, *16*(1),13 https://doi.org/10.1177%2F1609406917733847

Patton, M. (2002). *Qualitative research and evaluation methods* (3rd edition). Thousand Oaks, CA: Sage Publications.

Penner, J. L., & McClement, S. E. (2008). Using phenomenology to examine the experiences of family caregivers of patients with advanced head and neck cancer: Reflections of a novice researcher. *International Journal of Qualitative Methods*, *7*(2), 92-101.

Polit, D.F., & Beck, C.T. (2014). *Essentials of nursing research: Appraising evidence for nursing practice* (8th ed.). Philadelphia, PA: Wolters Kluwer/Lippincott Williams & Wilkins.

Polit, D. F., & Beck, C. T. (2008). *Nursing research: Generating and assessing evidence for nursing practice*. Lippincott Williams & Wilkins.

Ponterotto, J. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of Counseling Psychology, 52*(2), 126-136. doi:10.1037/0022-0167.52.2.126

Reiners, G. M. (2012). Understanding the differences between Husserl's (descriptive) and Heidegger's (interpretive) phenomenological research. *Journal of Nursing & Care*, *1*(5), 1-3.

Rhee, J. J., Zwar, N. A., & Kemp, L. A. (2013). Advance care planning and interpersonal relationships: a two-way street. *Family Practice, 30*(2), 219-226. https://doi.org/10.1093/fampra/cms063

Richards, L., & Morse, J. M. (2007). *Readme first for a user's guide to qualitative methods* (2nd ed.). Thousand Oaks, CA: Sage.

Savin-Baden, M., & Major, C. H. (2013). Qualitative Research: The Essential Guide to Theory and Practice. *Qualitative Research: The Essential Guide to Theory and Practice Routledge*, *10*, 11.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*(2), 63–75.

Smith, J. A., & Osborn, M. (2003). *Interpretative Phenomenological Analysis*. In J. A. Smith (Ed.), Qualitative Psychology: A Practical Guide to Methods (pp. 53-80). London: Sage.

Sokolowski, R. (2000). *Introduction to phenomenology*. Cambridge university press.

Spielgelberg, H. (1976). Doing phenomenology. The Hague, the Netherlands: Martinus Nijhoff. Streeton, R., Cooke, M., & Campbell, J. (2004). Researching the researchers: using a snowballing technique. *Nurse Researcher*, *12*(1), 35-47.

St. Joseph's Health Care Annual Report. (2016). St. Joseph's Health Care Annual Report 2015-2016. Retrieved from https://www.sjhc.london.on.ca/about-us/about-st-josephs-health-care-london/annual-report.

Statistics Canada. (2016). 2016 Canadian Census. Retrieved from https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/index-eng.cfm.

Statistics Canada. (2021). 2021Canadian Census. Retrieved from https://www12.statcan.gc.ca/census-recensement/2021/as-sa/fogs spg/page.cfm?dguid=2021S0503555&topic=1&lang=E

Tassone, B. G. (2017). The relevance of Husserl's phenomenological exploration of interiority to contemporary epistemology. *Palgrave Communications*, *3*(1), 1-11. https://doi.org/10.1057/palcomms.2017.66

Terry, G., Hayfield, N., Clarke, V., & Braun, V. (2017). Thematic analysis. *The SAGE handbook of qualitative research in psychology*, *2*, 17-37.

TCPS-2. (2014). Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*.

Van Manen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy* (2nd Ed.). London, Canada: The Althouse Press.

Van Manen, M. (2002). *Writing in the Dark: Phenomenological Studies in Interpretive Inquiry*. London, ON, Canada: The Althouse Press.

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy* (2nd ed.). SUNY Press.

Van Manen, M., Higgins, I., & van der Riet, P. (2016). A conversation with Max van Manen on phenomenology in its original sense. *Nursing & health sciences*, *18*(1), 4-7.

Varkey, B. (2020). Principles of clinical ethics and their application to practice. *Medical Principles and Practice*, *29*(6), 514-525. https://doi.org/10.1159/000509119

Velji, K., & Links, P. (2016). Mental Healthcare Delivery in London-Middlesex Ontario-The Next Frontier. *Healthcare Quarterly (Toronto, Ont.)*, *18*, 57-60.

Whitaker, K. M., Wilcox, S., Liu, J., Blair, S. N., & Pate, R. R. (2016). Patient and Provider Perceptions of Weight Gain, Physical Activity, and Nutrition Counseling during

Pregnancy: A Qualitative Study. *Women's Health Issues: Official Publication of the Jacobs Institute of Women's Health*, *26*(1), 116–122. https://doi.org/10.1016/j.whi.2015.10.007

Willig, C. (2001). Introducing qualitative Research in Psychology Adventures in Theory and Method ‘. Buckingham Philadelphia. *Open University Press.*

Wimpenny, P., & Gass, J. (2001). Interviewing in phenomenology and grounded theory: Is there a difference? *Journal of Advanced Nursing 31*(6), 1485-1492.

Wojnar, D. M., & Swanson, K. M. (2007). Phenomenology: an exploration. *Journal of Holistic Nursing*, *25*(3), 172-180.

Chapter 4

The Experiences of Familial Mental Illness Stigma Among Individuals Living with Mental Illnesses

Abstract

Persons with mental illnesses may experience stigma from their immediate family members in addition to other forms of stigma. Using semi-structured interviews, we investigated experiences of familial mental illness stigma among 15 people diagnosed with mental illnesses in a mid-sized city in Canada. We identified five themes that speak to participants' experiences of familial mental illness stigma and ways to reduce it. The themes include: diagnosis as a ‘double-edged sword,’ potential familial isolation, familial stigma as societal stigma localized, stories of acceptance, and confronting potential familial mental illness stigma. Participants’ narratives indicate that familial mental illness stigma is rooted in the broader social or public stigma, which sees its way into familial relations as well. This stigma takes various forms, including relationship bias or unfair treatment, breakdown in romantic relationships, loss of status, verbal and emotional abuse, exclusion from decision-making, and alienation within their immediate and extended families. Familial mental illness stigma experiences negatively impact participant’s psychological well-being and personal empowerment. However, participants also shared ways that family members create supportive environments or actively confront or prevent stigma. Overall, this study has contributed to knowledge on mental illness stigma, particularly familial mental illness stigma from the perspective of participants living with a mental illness in a high-income country. Suggestions for future research include a focus on strategies to prevent ongoing familial mental illness stigma, and large-scale studies to explore familial mental illness stigma to understand why families might perpetrate stigma.

Keywords: Familial mental illness stigma, persons with mental health problems, interpretive phenomenology, qualitative research, thematic analysis

4.1 Introduction and purpose

Mental illnesses are health conditions that involve changes in emotion, thinking, or behaviour that are associated with distress or problems functioning in social, work, or family activities (APA, 2018). While the World Health Organization (WHO) has prioritized mental health promotion as a key to global development, mental illnesses continue to impact overall well-being worldwide and are significantly related to years of life lost due to illness (WHO, 2019). Unfortunately, in addition to the illnesses themselves, much of this negative impact is due to mental illness stigma (Livingston, 2013; Stuart, 2017). Therefore, it is important to find practical ways to reduce mental illness stigma through policy, programs, and best practices.

This study investigates the lived experiences of individuals with a diagnosis of mental illness in terms of stigma from family members, and how they deal with potential familial mental illness stigma. We also look at the forms of familial stigma within the family system and how these impact individuals. Familial mental illness stigma herein denotes “stigma experienced by individuals from within the family or close relatives due to their mental instability or ailment: that is, families as perpetrators of stigma against their relatives with mental illnesses and not as those being stigmatized” (Adu et al., 2021, p. 3).

4.2 Overview of mental illness stigma

Stigma has been described as a mark of shame, or disapproval, that results in an individual being rejected, discriminated against, and/or prohibited from participating in several different aspects of society (Goffman, 1963; WHO, 2001). Link and Phelan (2006) have conceptualized stigma as the co-occurrence of five interrelated components (i.e., labeling, stereotyping, separation, status loss, and discrimination) in the context of social power. Stigma can involve labeling ─ a process whereby individuals are defined by a trait deemed socially undesirable such as certain health conditions (e.g., HIV/AIDS, some cancers, mental illness, leprosy, Tuberculosis, etc.). Labelling produces a social distance with a deliberate or implicit effort to prevent people from social interactions within their environment (Adu et al., 2022; Lucas & Phelan, 2012). Mental illness stigma is a priority concept in the extant mental health literature due to its harmful impact on individuals and society at large (Corrigan et al., 2014; Follmer & Jones, 2018; Lucas & Phelan, 2012; Mittal et al., 2012).

The stigma of mental illness has been characterized as a multifaceted problem, owing to its hindrance to the global fight for mental wellness including in relation to economic development (Abbey et al., 2011; Knaak et al., 2017; WHO, 2019). Mental illness stigma often functions as a medium through which society exploits, rejects, isolates, and prevents persons with mental illnesses from enjoying their social and economic rights (Abbey et al., 2011; Stuart, 2017; WHO, 2019). This, in effect, tends to separate persons with a diagnosis of mental illness from those without such diagnoses, and further excludes them from participating fully in activities within their communities (Knaak et al., 2017; WHO, 2019). It is also reported that the attitudes of the public towards persons with mental illnesses may prevent help-seeking from health and social supports, which can contribute to social and health problems such as unemployment, substance use, and homelessness (Corrigan et al., 2014; Government of Canada, 2020; WHO, 2019). Ongoing discrimination towards individuals with mental illnesses could result in status loss with negative impacts on self-esteem and self-efficacy, creating barriers to a positive recovery journey.

Despite the known negative impacts of stigma on persons with mental illnesses globally, mental illness stigma continues to occur at every level of society, including institutions of public services (social, health, legal, prison, education, and other community services) and within families (Adu et al., 2022; Livingston, 2013; Nyblade et al., 2019; Stuart, 2017). People with a suspected or diagnosed mental illness may conceal their condition to avoid social harassment that perpetuates psychological distress (Public Health Agency of Canada, 2006; van der Sanden et al., 2016). Therefore, changes need to be made to prevent stigma and associated social exclusion experienced by persons living with mental illnesses to stop the cycle of impeded social interactions and aggravated health conditions. These changes are essential, particularly within the family system where mental illness stigma may operate more subtly. Literature to date has identified family mental illness stigma as a reality in many families (Adu et al., 2021; Aldersey & Whitley, 2015; O’Reilly et al., 2019; Östman & Kjellin, 2002; Paul & Nadkarni, 2017); however, these studies are comparatively scarce compared to other forms of stigma such as stigma by association, public or social stigma, and self-stigma. In our recent meta-synthesis of the empirical literature on familial mental illness stigma in high-income countries in the last two decades (2000-2020), we found 28 articles, with only 4 situated in Canada (Adu et al., 2022). The current study sheds light on the lived experiences of familial mental illness stigma and how it is confronted among persons with a diagnosis of mental illnesses in Ontario, Canada, and thus, adds to the extant literature on mental illness stigma, particularly stigma enacted by family members towards their loved ones. The overall objective of this work is to create knowledge to be used in better addressing and reducing familial mental illness stigma.

4.3 Methods

4.3.1 Design

An interpretive phenomenology design was adopted to understand the lived experiences of familial stigma among persons with mental illnesses, how it impacts familial relationships, and how individuals living with mental illness cope with this stigma. Martin Heidegger held the view that phenomenological investigation is interpretative, which allows researchers to analyze the experiences of others and connect them to their own interpretations and other forms of knowledge (Heidegger, 1962). Interpretive phenomenology is deeply connected with hermeneutics, or how we interpret communications, texts, or even pre-understandings. Hermeneutics has been explained as a process and method capable of revealing concealed human experiences and relations as well as delving deeper into a given phenomenon than a mere description of core concepts and essences to look for actual meanings rooted in normal life practices (Lopez & Willis, 2004; Spielgelberg, 1976). This is appropriate in the study context where there might be hesitation to discuss mental illness stigma occurring within one's own family. Ultimately, there is an overlap between what is termed interpretive phenomenology and hermeneutic phenomenology, and herein the term interpretive phenomenology is used. The focal point of interpretive research is on what human beings experience rather than what they consciously identify with, which are often connected to sociocultural and political settings (Lopez & Willis, 2004). In this study, the phenomenon of familial mental illness stigma is explored with analysis into the social practices that construct, perpetuate, or prevent this phenomenon.

Interpretive phenomenology as a research methodology is suitable for describing and interpreting the lived experiences of familial mental illness stigma among persons with mental health problems. This study adopts van Manen's (1997) six practical interactive approaches for interpretive phenomenological inquiry to understanding the phenomenon of familial mental illness stigma. The approaches consist of: "(1) orientating oneself to the phenomenon of interest and explicating assumptions and pre-understandings; (2) investigating experiences as lived through conversational interviews rather than as we conceptualize them; (3) reflecting upon and conducting thematic analysis which characterizes the phenomenon and interpretations through conversations; (4) describing the phenomenon through the art of writing and re-writing (rethinking, reflecting, and recognizing), which aims at creating in-depth writing; (5) maintaining a strong and oriented relation to the fundamental question about the phenomenon, and (6) balancing the research context by considering parts and wholes" (van Manen, 1997, p. 30). In keeping with van Manen's (1997) practical interactive approaches, we offer herein a description of the lived experiences of people with familial mental illness stigma in the context of their everyday life and contributions to the social construction of stigma.

Ethical approval for this study was obtained from the Western University's Human Research Ethics Committee (#119602).

4.3.2 Study setting

The study was conducted in the London-Middlesex area of southwestern Ontario, Canada. The population of London-Middlesex was 515,114 in 2021 per the last population census of Canada (Statistics Canada, 2021), qualifying as a mid-sized city. Canada's mid-sized cities were described as those with populations over 300,000 and under two million based on Statistics Canada's definition of mid-sized Census Metropolitan Areas (Tassonyi, 2017).

London-Middlesex has several healthcare institutions that handle both physical and mental health conditions. In the area of mental health care delivery, the London Health Sciences Center focuses on managing acute cases, while St. Joseph's Health Care (Parkwood Institute) and St. Thomas Provincial Psychiatric Hospitals focus on treating longer term mental health illness (Mental Health Commission of Canada, 2015; Velji & Links, 2016). Community mental health services are provided via primary care providers as well as specialized community mental health organizations, the largest of which is the Canadian Mental Health Association.

4.3.3 Recruitment

We employed a criterion sampling technique to recruit participants for this interpretive phenomenology study. This allowed us to engage a subset of the adult population living with mental illness who were interested in discussing familial stigma. The distinct experiences presented across different ages of participants offered an interesting variety, with participants representing differing lengths of time since initial diagnosis and variable times for families to adapt (or not) to conditions. This allowed us to understand the different dynamics of the familial stigma that may exist for individuals with a first onset versus long-term and recurrent illness. The target age for recruitment was aged 24 or older, recognizing that experiences of adults differ from those of youth and older adults. Recruitment was conducted with the assistance of key connections in the community such as family physician practice clinics, CMHA offices, and community health centers who work directly with the target population. The local organizations who support the target population posted the recruitment materials in their facilities.

The participants included 15 people living with mental illnesses in the London-Middlesex area of Ontario, Canada. Inclusion criteria for participants for the in-depth interviews included: (1) being 24 years or older; (2) self-identifying as an individual living with mental illnesses; (3) speaks and understands English; (4) being a current resident in London-Middlesex area; and (5) being willing to participate in the study for 45-60 minutes. The exclusion criteria for participants recruitment included: (1) persons with mental illnesses who were not residents of the London-Middlesex area; (2) persons with mental illnesses who were less than 24 years of age; (3) unable to communicate in and understand English; (4) unwilling to participate in the study for 45-60 minutes.

4.3.4 Data collection

In-depth interviews were conducted with all participants between May and July 2022. In-depth interviews allow for both specificity and flexibility of content (DeJonckheere & Vaughn, 2019). This allowed us to explore participant experiences to a degree of depth not afforded via other methods. The researcher’s appreciation of participants’ lived experiences of familial mental illness stigma was essential to create a space where participants could share in-depth ab out their experiences; the lead researcher who conducted the interviews used years of nursing and social service clinical experience to engage respectfully with participants. The researcher helped create a positive environment by opening with general questions to get to know participants, using active listening, and regularly thanking participants for their discussion. With the permission of participants, all interviews were audio recorded and transcribed in the end of every session.

All interviews were recorded on Zoom and transcribed. The confidentiality of participants was ensured, and all participants signed the informed consent form at the start of the meeting. Brief demographic information was collected from each participant, which was later anonymized via the use of pseudonyms to conceal their identity. While conducting the in-depth interviews, observation notes were taken regarding nonverbal communication cues that were used to supplement the verbal interactions audio recorded during the interviews.

Table 1: Interview Guide

1. Can you tell me a bit about the history of your mental health?	8. Can you tell me a bit about your family member who lives with a mental illness?
2. When did you first feel that maybe your mental health wasn't as good as it could be?	9. How long have they been living with a diagnosis?
3. Did others ever comment on your mental health?	10. What kind of support do they receive? How often do you see them?
4. Thinking more about the experience of living with a mental illness, what has it been like for you?	11. How would you describe your experiences of having a family member who lives with a mental illness?
5. Have you ever felt discriminated against because of your mental illness?	12. What have been the most important things you have learned through this? What have been the largest challenges they have faced?
6. Have you ever experienced discrimination from a family member in particular?	13. What have been the largest challenges for you personally? etc.
7. [If yes] Can you tell me more about how that has felt?	**Demographic data** Participants unique identification numbers Age Gender Race and ethnicity Marital status Occupation Level of education Diagnosis

4.3.5 Data Analysis

Data analysis for this study was guided by Braun and Clarke's (2006) framework to produce textual accounts that reflect participants' experiences of familial mental illness stigma. Braun and Clarke's (2006) framework provides the following stepwise process: (1) familiarizing oneself with the data; (2) generating initial codes; (3) searching for themes; (4) reviewing the themes; (5) defining and naming themes; and (6) producing the report. The purpose of this interpretive phenomenology analysis was to extract key aspects of the participants' experiences that answer the research questions. The interpretative process unfolded by engaging repeatedly with the transcripts and observation notes to understand participants' lived experiences followed by detailed textual analysis. Line-by-line engagement with the transcripts led to proposing and then applying codes. This was followed by a more in-depth analytical or theoretical ordering while looking for linkages among codes and preliminary categories to form clusters and themes.

The various codes were organized into categories, from which initial themes emerged. Identification of themes was an iterative process of reviewing various sets of data with particular attention to how they pull together. Rigor was sought via discussion across the research team of codes, categories, and themes with associated illustrative quotes and continual revisions through analysis and writing. The research team had a post-analysis interaction as well as member checking with five selected participants who agreed to verify our final subthemes and themes to facilitate the trustworthiness and credibility of the findings. The ultimate review of themes was done by all members of the research team to confirm the study objectives. Themes and subthemes were supported by selected data excerpts as illustrated in the findings below.

4.4 Findings

Eleven participants were female, three were male, and one person identified as nonbinary. The mean age of the participants was 36 years. All 15 participants were of Caucasian descent in a mid-sized city in Ontario, Canada. All participants had at least high school diplomas. Five had graduate degrees.

Table 2: Socio-demographic characteristics of study participants

Participant ID	Age Range	Gender	Marial Status	Level of Education	Race/Ethnicity
PWMI_2	30-34	F	Married	College	Caucasian
PWMI_4	20-24	F	Single	Graduate	Caucasian
PWMI_7	25-29	F	Single	College	Caucasian
PWMI_8	40-44	M	Divorce	College	Caucasian
PWMI_9	35-39	F	Common law partner	High school	White Canadian
PWMI_10	40-44	F	Single	College	Caucasian
PWMI_12	40-44	F	Common law partner	Graduate	White Canadian
PWMI_16	35-39	F	Married	High school	White Canadian
PWMI_17	40-44	F	Married	College	Canadian
PWMI_20	35-39	F	Single	Undergraduate	Caucasian
PWMI_22	30-34	F	Single	Graduate	Caucasian
PWMI_23	30-34	Non-binary	Single	Graduate	White European
PWMI_27	30-34	M	Married	Graduate	Caucasian
PWMI_28	30-34	M	Separated	College	Caucasian
PWMI_31	30-34	F	Married	Undergraduate	Caucasian

Key: PWMI-Persons with mental illness

Analysis of participants' presentations of their lived experiences resulted in five major themes: (1) diagnosis as a 'double-edged sword'; (2) potential familial isolation; (3) familial stigma as societal stigma localized; (4) stories of acceptance; and (5) confronting potential familial mental illness stigma.

4.4.1 Diagnosis as a 'Double-edged Sword'

The combined narratives of our participants indicated both positive and negative effects after their formal diagnoses of mental illnesses. We have differentiated these experiences through the sub-themes of: 'a huge relief' and 'unfair treatment'.

A Huge relief**:** A diagnosis of a mental illness can be a relief, particularly if families are supportive and services are available. It can be a form of validation if the individual suspected what they were experiencing or was seeking a formal categorization of their experiences. Some participants felt liberated after their diagnoses, particularly if a diagnosis opened doors to treatment:

> I felt relieved and validated and understood the problem confronting me. I was able to prepare and implement tools that could alleviate outbursts or hyper-vigilance connected to my daily life. I went on to do some background research on my diagnosis and the best course of action to support myself and also be in a position to openly explain it to people. In this case, I will be able to know the risk factors connected to my condition to help reduce my symptoms (Participant 2).

> It was comforting to know that a name existed for what I have been experiencing and there was a path to pursue that could help make it more manageable. Felt quite good after my diagnosis. It felt good to have a diagnosis and a plan (Participant 27).

Diagnoses could also be a relief where family members presented a degree of doubt about the validity of their experiences:

> My diagnosis was a huge relief for me because I had known it for many years. I was just waiting for a doctor to confirm it to enable me to look at treatment options for the borderline personality that are extremely limited. So, for me, it was a relief from some fear. It's kind of a hopeless diagnosis but at that point, it was like okay, thank God, someone who's educated and knows what they're talking about confirmed it (Participant 7).

> Before my diagnosed with depression, one of my family members thought I was lazy which was really hurtful. Not understanding what I was going through at that time, but luckily after my diagnosis, my family came to understand me. However, one of my siblings recently became very judgmental toward me and he started saying things like, I was lazy and should work more and stuff like that. …. Maybe, he will think I have a victim mentality so it is difficult to know what he would say if I informed him of the complex PTSD (Participant 9).

***Unfair treatment*:** Conversely, some participants felt rejected by their families, particularly their parents, due to a diagnosis of mental illness. The insecurity experienced by these participants was not helpful for their mental health recovery due to the ongoing emotional conflicts within the immediate environment. Two participants stated how biased their fathers were toward them compared to the rest of the family members:

> I was devastated for being treated differently by my family, especially my dad because of a mental illness diagnosis. Dad hid sensitive issues from me when every other member of the family was aware of [family member's health crisis] (Participant 7).

> I feel like my dad judges me a bunch more than my other siblings. I feel he looks down upon me due to my diagnosis hence he judges me differently than my sister which to me is discriminatory (Participant 10).

Persons with mental illnesses may experience stigma around their diagnosis in terms of differential treatment tied into perceptions of how personal character is linked to mental illness. One participant shared:

> My older brother and I have been diagnosed with mental health issues. And we are both seen as the black sheep of the family. Hence, we're considered less reliable and trustworthy (Participant 16).

Also, the unfair treatment meted out to some participants made them feel helpless within their households. The negative attitude exhibited by family members contributed to the distress that participants endured after their diagnoses of mental illnesses. A participant explained how they felt deserted by their family members due to a diagnosis:

> I felt more secluded and more rejected for being treated differently within my family because of my diagnosis. That was hard for me at that time when I needed the support of my family (Participant 17).

4.4.2 Potential Familial Isolation

A common implicit form of stigma was isolation. Participants discussed the potential for isolation from family members under the following subthemes: breakdown of romantic relationships and isolation/loneliness.

Breakdown of romantic relationships**:** For some participants, their mental illness was perceived as a barrier having intimate relationships:

> Living with mental illness makes life unlivable. I can't work. I rarely go out and romantic relationships are basically off the table. (Participant 7).

> My ex-wife makes me feel that there is no care in the world. Yeah, she was very selfish and pessimistic with my diagnosis, and this created a lot of violent reactions in the form of arguments. …. (Participant 28).

For others, it is the lack of understanding of their illness that leads to relationship breakdown:

> Oh boy, it's been a battle. I have had days, where I feel totally fine and others, where I feel like everything is wrong with me. I've had

> relationships fall apart because my partners do not understand me (Participant 10).

Another participant described:

> My past romantic relationships have been complicated because of the diagnosis… The false narratives around mental illnesses have corrupted the mind of the public and they don't even believe if you are positive in a relationship in the mix of any ongoing symptoms (Participant 7).

***Isolation/loneliness*: ** Apart from preventing or undermining intimate relationships, mental illness stigma was also perceived as isolating participants from their family members, contributing to increased feelings of loneliness. Without family members' openness to discussing their health conditions, some participants internalized their experiences.

> Mental illness makes it difficult for me to relate to people. And it makes it difficult for others to relate to me as well. So, in my world, I internalize a lot of issues. As a working adult, I still have a lot of challenges when it comes to reaching out and making good choices because I am very self-conscious, and this affects my self-esteem…. (Participant 22).

Another participant described their opinion on the turn of events within the family post-diagnosis, where they lack the ability to share their needs with family members:

> I feel like I'm not included in a lot of stuff that happens in my family. Hence, I sometimes feel like an outsider within the family all because

> of my diagnosis. Before my diagnosis, they were a little bit more open with asking me stuff, but now they just keep me out of it everything under the pretense of they don't want to worry me (Participant 10).

Several participants identified a lack of knowledge of specific mental illnesses by family members as a factor that accounted for various discriminations and stigma against persons with mental illness. A participant commented:

> I think part of it is a lack of understanding, and even if one reads everything about borderline personality, until one has lived experience, one may not fully understand it. As well, people don't like to be around individuals who are constantly negative… (Participant 7).

Some family members were preferential towards other ‘healthy’ relatives while paying less attention to individuals with mental illnesses. Good family relationships devoid of any partiality could result in social support for persons with mental illnesses. However, several of our participants reported unfair treatment within the family, which negatively impacted their mental health. A participant commented:

> Um, …I've never been included for different reasons. I was the youngest in the family and because of my mental illness, my mom doesn't involve me in anything. My dad doesn't include me anymore since they split up. My brother is kind of living his own life and he's

> getting married … but I've met his fiancée once. My brother just kept me out of his life (Participant 7).

This participant also added:

> I have been discriminated against by family members in the sense that there's a feeling in my family that mental illness doesn't exist, but there are so many mental illnesses that run through the family (Participant 20).

4.4.3 Familial Stigma as Societal Stigma Localized

In considering stigma experienced from their family members, or more generically speaking to their thoughts on familial stigma, participants noted that this form of stigma is inseparable from more general societal stigma around mental illness. That is, familial stigma is just one form by which more general mental illness stigma is enacted. Familial stigma as societal stigma localized is composed of four subthemes: ‘perceived dangerousness’; ‘loss of status or perceived incapability’; and ‘false narratives around mental illnesses.’

Perceived dangerousness**:** Participants noted that the general social narrative of people living with mental illness as “dangerous” was taken up uncritically by family members and applied to their own experiences:

> I think the family members are scared and unpredictable of their loved ones due to their mental illnesses. I think it also borders on the family's lack of understanding of mental illnesses. The family also does not take steps to do a lot of work to understand mental illnesses (Participant 16).

> I think others are scared of persons with mental illnesses due to the way they behave. Some see them as dangerous within the family or persons capable of hurting others around them (Participant 2).

Loss of status/ perceived incapability**:** Another social perception of mental illness is that of decreased capability. Mental illness is sometimes seen as a social disability by some families which may result in loss of status:

> I think it's just a bad family dynamic that needs fixing. Family members may assess, fault finding or blame you for petty issues because of a diagnosis. It may just be jockeying for power where the affected person is always seen as incapable (Participant 8).

One aspect of broader social stigma is the idea of mental illness as a “shameful” condition. One participant shared how this unfolded within their own family:

> I think sometimes family members discriminate against their loved ones with mental illnesses to deal with their shame. For example, my family members thought I was lazy before my assessment and diagnosis not knowing they had mental health issues that weren't dealt with. Also, I think a lot of the time it's intergenerational. After my depression diagnosis, I found out about the existence of depression within both sides of the family, but people didn't talk about it (Participant 10).

False narratives around mental illnesses**:** Most of our participants reported that misinformation and lack of understanding of mental health issues at the family level continue to be the driving force behind the discriminatory attitudes of family members against their relatives with mental illnesses. A participant remarked:

> I think there's a lot of misunderstanding about mental illness. A lot of people think someone who's mentally ill can’t do anything for themselves. Again, the family feels that there's too much to deal with especially when the affected person isn't trying hard enough to bring anything to the table. That is, a lot of it borders on misunderstanding and misinformation about mental health and mental illnesses (Participant 9).

4.4.4 Stories of Acceptance

While the focus was on experiences of stigma, several participants were also intentional in sharing the positive journeys they have had with their family members. They shared explicit ways in which family members showed acceptance, the opposite of enacting stigma. This included noting family members' understandings of mental illnesses that resulted in providing both practical and emotional support. Some participants stated:

> My family has been very supportive since my diagnosis. When I took a year off school to take care of my mental health, stayed with them for the entire period. They took me to all appointments and also engaged me in conversations. Anytime I felt upset and just needed to vent they will allow me a space to do so…. (Participant 23).

> Um, my family plays a very big role in my recovery. The family keeps observing me and usually keep me out of triggers when

> necessary. If I feel threatened, they are in a position to redirect me. They always push me to seek more support when necessary (Participant 2).

Some participants perceived their families as safety nets anytime they felt overwhelmed with emotions. Practical and emotional support from family members made some participants feel included within their families. A participant noted:

> …, my mom has given me some financial support and she sometimes sent me groceries. Mom lives in a different city with my stepdad but any time they are in town, I am given a ride to pick up my prescriptions. Mom used to go to the doctor with me if I needed her support in listening to what the doctor discussed with me. Mom also picks me up anytime I am having a bad day to play hockey (Participant 7).

Another participant outlined similar thoughts: "My husband has been supportive of anything that I needed to do. Be it conversational or going on medication when I was on that or talking to somebody else" (Participant 31).

Where relationships were positive and free of stigma, family members were seen as part of the recovery journey: "In the long term, I see my family playing a supportive role in my recovery. Even when I eventually move out of their house, I can always talk to them if I'm having any issues or seek advice" (Participant 23).

4.4.5 Confronting Potential Familial Mental Illness Stigma

Participants were not passive in considering experiences of familial mental illness stigma. Rather, they shared ways in which they were confronting this stigma themselves or speculated on ways that stigma could be reduced. In this way, the experience of familial mental illness stigma was not simply one of disempowerment, but also one in which participants empowered themselves. Participants expressed strategies to confront familial mental illness stigma in four subthemes: ‘education’ (social contact-based education and familial education); ‘normalizing the symptoms of mental illnesses’; ‘selective versus full disclosure’; and ‘concealment’.

Education**:** Because familial mental illness stigma is a function of broader social stigma, as noted in the theme above, participants saw public education as a pathway to reducing personal experiences of stigma. Participants saw ongoing public dialogue and understanding of mental illness as beneficial:

> We have to keep talking about mental illnesses more positively like what Bell Let’s Talk[1] is doing of late. I think mental illnesses that are more severe need to be publicized more because we hear about anxiety and depression so much whereas, personality disorders are looked at more negatively… people with schizophrenia are misunderstood and considered dangerous in society… need for us to debunk a lot of myths and this will demand time and effort from people in the position of power with listening ears (Participant 7).

---

[1] Bell Let's Talk is a public health education campaign by the Canadian telecommunications company, Bell Canada, in their bit to raise awareness and combat stigma against mental illness.

Another participant centred the lived experiences of individuals in this type of education:

> I think there should be more people listening to persons with mental illness to understand their problems instead of just trying to get a response that…. I think listening is the biggest key that will lead to different good outcomes concerning reducing mental illness stigma (Participant 28).

Many participants also highlighted the need for mass media to change their approach toward the presentation of mental health problems in the news. Participants questioned why news reporters and presenters often concentrated mostly on the negative aspects of persons with mental illnesses without showing the good things that some individuals with mental health issues had done or could do:

> I think a lot of mental illness stigma is from the media which needs to be checked. …, there are movies portraying persons with multiple personality disorders and one of the personalities was a serial killer and that was the plot; signifying that people with mental illness are bad or harmful, which adds to the wrong perceptions within the public space. The media should be more circumspect by showing more positive aspects of mental illnesses than the negatives. The media should help society to change their views on severe mental illnesses like schizophrenia and the like for people to know that persons with mental illness can live a normal life and are not crazy (Participant 23).

When it comes to family education in particular, participants noted that persons with mental illnesses (PWMIs) are often put in the position of needing to educate their own families to reduce stigma. They noted that this should be better done through formal support:

> Oh my God for anybody with a mental illness, I think the number one thing they want is empathy, especially from their family members. Better access to mental health services, including various psychotherapies is important for people to be able to individually work on themselves. There is also the need for support systems to better handle conversations with family members who might not be open to a mental illness diagnosis (Participant 31).

Normalizing the symptoms of mental illnesses**:** Participants suggested anti-stigma campaigns to make mental health concerns part of everyday conversation. Several participants pointed to correcting the myriad of false impressions about persons with mental illnesses regarding their capabilities and inabilities. A participant requested society to pay more attention to the competencies of persons with mental illnesses than their challenges:

> I think society needs to stop treating people with mental illness as if they are incapable. I think society needs to change the language that is used toward people with mental illnesses. Society needs to change all preconceived notions about people with mental illnesses such that if one is in a manic stage, we would not consider that person crazy. Policymakers need to look at our healthcare system to understand the frustrations of persons with mental illnesses when it comes to seeking

> help at every level be it access to therapy, hospitalization, or psychiatric assessment. …. (Participant 31).

For some participants, the normalization of mental illnesses could be done by engaging the media to continue the talk about the positive contributions of PWMI. That is, emphasizing the acceptance of PWMI within the social realm will also pave way for family members to de-stigmatize their loved ones with a diagnosis:

> I think more education and de-stigmatizing ‘it’ [mental illness]. More people talking about it..., for it to be a normal part of everyday conversations without judgment. I think the media have done some great work and now people in high-status roles such as actors and sports are speaking about mental illnesses. This in a way will even normalize it more (Participant 17).

Another participant made the same point: “I think there is a need for lots of public education to raise awareness of mental illnesses to reduce the stigma associated. The normalization process can be done through movies, advertisements, and even school curricula” (Participant 12).

Disclosure**:** That is, leading the conversation. For some participants, being open about their experiences and driving the normalization of mental illnesses was a part of how they personally confronted stigma. For these participants, disclosure to family members gave them the opportunity to educate them or redirect them to mental health professionals for the best answers to difficult questions about their diagnosis. The participants believed full disclosure was an important step in reducing familial stigma:

> I think there is a need to talk with professionals about ways to break the diagnosis to family members. Possibly, I will set aside time to have a conversation to educate family members on what professionals say about mental illnesses. If the family asks more questions or comments negatively, I will redirect them to talk with their family doctor or mental health professionals for more education. I will continue to educate them on the best ways to support me through this is… I will also tell my close friends about the diagnosis to get their support (Participant 17).

Concerning the above strategy to confront potential familial mental illness stigma, other participants remarked:

> I sought out a diagnosis soon after I got to know about my problem and openly talk about my struggles and demystify it to my partner and my children. … as a frontline worker with a mental illness experiencing workplace trauma, moral injury, and the stigma that comes with being unwell in the workplace, I openly talk about it (Participant 2).

> Yeah, everyone who knows me is aware of my mental illness. I don't hide it by any means…. Sometimes you're talking to some people who have gone through the same problem, and although you don't know them, …, then you'll just go into a dialogue with them (Participant 8).

4.5 Discussion

Persons living with mental illnesses can face ongoing stigma, including that enacted by their close relatives— familial mental illness stigma. Our findings suggest that familial mental illness stigma is very much interconnected with the broader public mental illness stigma. Rather than being fully distinct, participants saw value in addressing mental illness stigma both within and beyond families. By using a phenomenological approach, we have centred the experiences of participants to understand the contextual relationships; for example, noting how for some having a formal diagnosis of mental illness creates clarity and understanding, and for others it is seen as increasing their risk of stigmatization within the family.

We have proposed five aspects of familial mental illness stigma notable among participants. These included: diagnosis as a ‘double-edged sword (positive and negative effects following a diagnosis), potential familial isolation (possible exclusion once a diagnosis is confirmed), familial stigma as societal stigma localized (familial mental illness stigma engrained in broader social stigma), stories of acceptance, and confronting potential familial mental illness stigma (strategies to reduce familial mental illness stigma). Each of these domains was present in some stories of participants, although there were notable differences in levels of support and levels of stigma experienced by participants. Some participants shared directly about their experiences of stigma within their families. Others who had very positive personal experiences speculated more generically on the familial mental illness stigma encountered by others.

Across the experiences there is a considerable potential compounded impact of familial mental illness stigma. Those whose symptoms were not understood in advance of diagnosis often encountered increased stigma at diagnosis, or hid diagnoses, and lived with ongoing challenges with family (such as isolation). In a Canadian context where family often plays a key role in supporting ongoing recovery, stigma did not simply influence how participants felt about themselves but could also directly impede their recovery journey. These conclusions are congruent with the findings of previous studies that underscore the after-effects of persons labeled with mental illnesses to include the potential for loss of social status, poor housing or homelessness, unemployment, social isolation, and poor health care and suicidality (Link & Phelan, 2001; Mejia-Lancheros et al., 2021; Oexle et al., 2017, Rüsch et al., 2018). As well, isolation due to mental illness stigma can result in self-stigma and its social and psychological implications on the individual's self-esteem and self-efficacy— having validated their circumstances against the public perception of mental illnesses (Corrigan et al., 2009; Dubreucq et al., 2021; Rüsch et al., 2005).

Another significant finding identified by this study was the risk of breakdown of romantic relationships. Romantic relationships are often the most important familial relationship, and participants spoke to both impediments and breakdown of relationships with partners due to mental illness stigma. While some of our participants were still married and receiving maximum support from their partners toward recovery, several others suffered divorce or separation that they attributed directly to their illnesses. This further impacted their mental health and impeded recovery. This observation is consistent with earlier studies which found that a diagnosis of mental illness can lead to breakdown in relationships, or concealment as a protective process capable of creating issues of credibility (Amankwaa, 2003; Ladd, 2018; Rivera-Segarra et al., 2014; van der Sanden et al., 2015).

Noticeably, familial mental illness stigma is entrenched in broader social stigma. Societal views on mental illnesses are not differentiated from individual families, as families are part of society. Therefore, the misconceptions connected with mental health problems within public settings also diffuse to various families at the community level, which are then enacted in households. For instance, the perceived dangerousness of persons with mental illnesses reported by some participants in this study could be a cumulative effect of what exists within public narratives regarding serious mental illness. This can be very specific stigma related to exclusive conditions such as schizophrenia which are framed as "dangerous" within public narratives (Ghiasi et al., 2022; Gottfried & Christopher, 2017; Watson et al., 2001). The alleged dangerousness of affected individuals through media reporting can be attributed to why some family members might isolate PWMI within the family system.

Exclusion from the circle of information within the family was another challenge that PWMIs faced. Several of our participants revealed that their families considered them as "lesser" due to their illness. The family, therefore, excluded them from family discussions, especially important matters that needed attention from all family members. Some individuals experience a loss of status at the family level, particularly where affected persons were highly positioned within the family structure before their mental illness diagnosis. Loss of status within one's family can have cumulative effects on their self-worth and further deteriorate their ability to exercise autonomy in the family as they become mindful of the socially endorsed exclusions. This finding is consistent with a considerable body of evidence that loss of social status within the family unit among PWMIs leads to negative psychological effects (Iseselo et al., 2016; Larson & Corrigan, 2008; Umberson & Karas Montez, 2010; Rössler, 2016).

The recovery of PWMIs is linked to the combined support of family members, social support services, and health professionals (Bjørlykhaug et al., 2021; Larson & Corrigan, 2008; O'Reilly et al., 2019; Public Health Agency of Canada, 2006). This documented evidence is paralleled to our findings that regardless of the difficulties confronting families when a relative is diagnosed with one or more mental illnesses, continuous understanding and support (practical and emotional) within the family is vital to the recovery and rehabilitation of affected family members. Some participants saw this support as a safety net to rely on as part of a positive recovery journey. Likewise, some participants attested to the myriad of supports received from health professionals while taking steps to improve their mental health. This finding aligns with that of Larson and Corrigan (2008) that psychiatrists and other health professionals have contributed immensely to reducing the negative impact of family stigma. If there are available social support systems with commitments from family members of PWMIs, individuals will be able to better manage their recovery.

Given the many roles played by the family unit in supporting PWMI, it could be difficult for affected individuals in their home environment if they are victimized by some family members with stigmatizing beliefs. Some study participants disclosed selective versus full disclosure and concealment as strategies to deal with familial mental illness stigma. Strategic or selective disclosure is a known approach used by persons with PWMIs to carefully identify whom to share their diagnosis with to sidestep the societal discrimination and devaluation that at times comes with full disclosure of mental health problems (Corrigan et al., 2018; Hyman, 2008; (Karnieli-Miller et al., 2013; Rüsch & Kösters, 2021; Thoits, 2011). In their quest to reduce the harmful consequences of familial mental illness stigma, some participants of this study employed strategic disclosure to share their mental health issues with a few reliable relatives for support. On the contrary, other participants fully disclosed their mental health diagnosis to family members for support and to prevent the psychological stress of having to hide their symptoms during critical periods. For these participants, educating family members about their conditions to correct any preconceived notions about mental illnesses before a disclosure helped in reducing stigma at the family level. Although disclosure of a mental illness diagnosis in the social realm comes with both advantages and disadvantages (Evans-Lacko et al., 2012; Hyman, 2008; Quinn, 2018; Rüsch et al., 2019), disclosure within one's immediate environment has the likelihood to reduce stigma, strengthen intimate relationships, improve social support, and quality of life (Brouwers et al., 2020; Corrigan, 2022; Corrigan & Rao, 2012; Rüsch et al., 2019). Despite the social benefits connected with the disclosure of a mental illness diagnosis within one's family, some participants of this study adopted concealment to reduce familial mental illness stigma because they were unsure of the consequences of disclosure. This observation closely aligned with the findings of past studies that concealment in a stigmatizing environment is a realistic choice that is usually not driven by self-stigma or shame (Rüsch & Kösters, 2021). That said, irrespective of the environment of PWMIs, their previous experiences of stigma within the public space can play a role in hindering their ability to disclose a diagnosis (Bril-Barniv et al., 2017; Rusch et al., 2014). Further, concealment in this sense was a necessity to receive equal treatment and to prevent any conflict that their disclosure might bring to the family in the long-term (Bril-Barniv et al., 2017). A few of our participants reported on familial-driven concealment, particularly where family members were aware of their mental health challenges and pressured them to conceal their illness to protect the family and the affected individual against the impacts of social stigma. This presupposes that stigmatizing behaviours of some family members against their loved ones may be well intentioned. That is, by concealing the mental illness, families may be striving to be supportive or to protect them from possible societal discrimination. While this strategy can help protect the family's interest in keeping news of the illness among themselves, it could have ramifications for both the family and PWMIs in regard to access to support.

4.6 Research Implications

The findings of our study highlight the existence of mental illness stigma within family systems. Findings also point to issues confronting PWMIs concerning decision-making and information sharing within families, with implications for self-stigma and future concealment. Further, our findings—combined with those of previous studies—underscore disclosure and concealment as strategies to reduce familial and other forms of mental illness stigma. Both approaches have downstream impacts on PWMI and their relatives (Bril-Barniv et al., 2017; Rüsch et al., 2019). To help curtail these consequences, some participants recommended public education in the form of persuasive communication on serious mental illness using social contact-based education and familial education. For these participants, all forms of mental illness stigma start from social stigma; hence, transformative education to sensitize public perceptions could help reduce familial mental illness stigma. Therefore, we propose an increase in discussions around social contact-based education with intentionality, where persons with lived experiences of mental illnesses and those without will converge to have conversations on mental health issues and ways to reduce stigma. We also recommend that practitioners pay more attention to family members to understand their potential for stigmatizing beliefs while supporting affected persons in recovery. While future research should be focused on strategies to prevent the ongoing familial mental illness stigma for all mental health challenges, we recommend that future research also focus on understanding the nuances of why family members might continue to perpetuate stigma.

4.7 Policy Implications

Based on our findings, reducing familial mental illness stigma at the family level requires action by policy-makers to develop systems that ensure a transformative approach to curb societal stigma against PWMIs. For instance, there is the need for some community and social service resources to be directed toward public education (transformative and social contact-based education) to reduce the known preconceived notions about mental illnesses within society at-large, as seen in the work of the Mental Health Commission of Canada (MHCC) and Headspace in Australia. In this context, the experiences of PWMIs will be appreciated by society to help bridge the existing ‘we and them’ gap. We suggest that such anti-stigma campaigns should continue to be enhanced to make mental illness part of everyday conversation and continue the normalization process of mental illness symptoms in the social realm. Further, the normalization of mental illnesses could be achieved through continuous engagement of both traditional and social media providers to confront stigmatizing presentations of mental illness as they occur.

4.8 Limitations

Our study is limited by the age restriction (24 and above) which prevented us from including adolescents or children living with mental illnesses. The study is also narrowly focused in terms of gender, given that only three males participated in the study compared to eleven females, all of whom were Caucasian. The study, therefore, lacks diversity, as most of the findings were from English-speaking, adult, and white female perspectives. Data were collected through the Zoom platform owing to the Covid-19 restrictions which made it challenging to directly recruit more participants and to ensure diversity across participants. Future researchers wishing to build on the conclusions of this study should pay specific attention to the context in which these data were collected.

4.9 Conclusion

This study has contributed to knowledge on mental illness stigma, particularly familial mental illness stigma among participants who live in a high-income country. Participants' stories indicated familial stigma experiences negatively affected their psychological well-being and personal empowerment. This study affirms the existence of familial mental illness stigma, even though it is often the most unspoken or unacknowledged form of stigma. Familial mental illness stigma at times results in relationship bias or unfair treatment within families, and further impacts some participants’ mental health and impedes their recovery. It is worth mentioning that not all family members stigmatized their relatives with mental illnesses per our participants’ narratives. Some participants had the full support of family members toward their mental health recovery, while others felt mistreated. Some of this mistreatment seemed explicitly ill-intended whereas other actions appeared to be attempts by family members to protect their loved one, but in doing so demonstrated how their condition was stigmatized or stigmatizing. Most notably, our study revealed familial mental illness stigma as a societal stigma localized at the family level. That is, family members’ fear of social stigma due to their association with relatives diagnosed with mental illnesses (associative stigma) may have compelled some of them to save face, but in doing so made their loved one feel more isolated. The findings help us understand the interconnected nature of different forms of mental illness stigma. The study participants recommended broader discussions on the future of mental illness and social stigma using social contact-based education. We propose further studies to include longitudinal research that comprises PWMIs, family members, and health professionals to explore the connections between associative stigma and familial mental illness stigma.

Acknowledgments

We thank all participants who shared their unique stories with the research team on this sensitive topic. We hope this work will promote broader conversations around familial mental illness stigma to influence policy and practice to create enabling environments at the family level to foster all-inclusiveness.

References

Abbey, S., Charbonneau, M., Tranulis, C., Moss, P., Baici, W., Dabby, L., Gautam, M., & Pare, M. (2011). Stigma and discrimination. *Canadian Journal of Psychiatry*, *56*(10), 1-9.

Adu, J., Oudshoorn, A., Anderson, K. K., Marshall, C. A., Stuart, H., & Stanley, M. (2021). Policies and interventions to reduce familial mental illness stigma: A scoping review of empirical literature. *Issues in Mental Health Nursing*, *42*(12):1123-1137 https://doi.org/10.1080/01612840.2021.1936710.

Adu, J., Oudshoorn, A., Anderson, K., Marshall, C. A., & Stuart, H. (2022). Experiences of familial stigma among individuals living with mental illnesses: A meta-synthesis of qualitative literature from high-income countries. *Journal of Psychiatric and Mental Health Nursing*. 1–26. https://doi.org/10.1111/jpm.12869

Aldersey, H. M., & Whitley, R. (2015). Family influence in recovery from severe mental illness. *Community Mental Health Journal*, *51*(4), 467–476. https://doi.org/10.1007/s10597-014-9783-y

Amankwaa, L. C. (2003). Amankwaa, L. C. (2003). Postpartum depression among African-American women. *Issues in Mental Health Nursing*, *24*(3), 297-316.

American Psychiatric Association. (2018). *What Is Mental Illness?* Retrieved from https://www.psychiatry.org/patients-families/what-is-mental-illness.

Bjørlykhaug, K. I., Karlsson, B., Hesook, S. K., & Kleppe, L. C. (2021). Social support and recovery from mental health problems: A scoping review. *Nordic Social Work Research*, 1-32. https://doi.org/10.1080/2156857X.2020.1868553

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. https://doi. org/10.1191/1478088706qp063oa

Bril-Barniv, S., Moran, G. S., Naaman, A., Roe, D., & Karnieli-Miller, O. (2017). A qualitative study examining experiences and dilemmas in concealment and disclosure of people living with serious mental illness. *Qualitative Health Research*, *27*(4), 573-583.

Brouwers, E. P. M., Joosen, M. C. W., van Zelst, C., & Van Weeghel, J. (2020). To disclose or not to disclose: A multi-stakeholder focus group study on mental health issues in the work environment. *Journal of Occupational Rehabilitation*, *30*(1), 84–92. https://doi.org/10.1007/s10926-019-09848-z

Canadian Broadcasting Corporation News. (2020, February). London population growth rate among fastest in Canada. Retrieved from https://www.cbc.ca/news/canada/london/london-population-1.5464669

Corrigan, P. W. (2022). Coming out proud to erase the stigma of mental illness. *World Psychiatry, 21*(3), 388. https://doi.org/10.1002/wps.21016

Corrigan, P. W., Mittal, D., Reaves, C. M., Haynes, T. F., Han, X., Morris, S., & Sullivan, G. (2014). Mental health stigma and primary health care decisions. *Psychiatry Research*, *218*(1-2), 35-38. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4363991/

Corrigan, P. W., Rüsch, N., & Scior, K. (2018). Adapting disclosure programs to reduce the stigma of mental illness. *Psychiatric Services,* 69:826–828. https://doi.org/10.1176/appi.ps.201700478

Corrigan, P.W., Larson, J.E., & Rüsch, N. (2009). Self-stigma and the "why try" effect: impact on life goals and evidence-based practices. *World Psychiatry 8*(2):75–81.

DeJonckheere, M., & Vaughn, L. M. (2019). Semi-structured interviewing in primary care research: a balance of relationship and rigour. *Family Medicine and Community Health*, *7*(2). http://dx.doi.org/10.1136/fmch-2018-000057

Dubreucq, J., Plasse, J., Franck, N. (2021). Self-stigma in serious mental illness: a systematic review of frequency, correlates and consequences. *Schizophrenia Bulletin*, 47(5):1261-1287. https://doi.org/10.1093/schbul/sbaa181

Follmer, K. B., & Jones, K. S. (2018). Mental illness in the workplace: An interdisciplinary review and organizational research agenda. *Journal of Management*, *44*(1), 325-351. https://doi.org/10.1177/0149206317741194

Ghiasi, N., Azhar, Y., & Singh, J. (2022). Psychiatric illness and criminality. In *StatPearls [Internet]*. StatPearls Publishing. Retrieved from Available from: https://www.ncbi.nlm.nih.gov/books/NBK537064/

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice-Hall.

Gottfried, E. D., & Christopher, S. C. (2017). Mental Disorders Among Criminal Offenders: A Review of the Literature. *Journal of Correctional Health Care: The Official Journal of the National Commission on Correctional Health Care*, *23*(3), 336–346. https://doi.org/10.1177/1078345817716180

Government of Canada. (2020). A Primer to Reduce Substance Use Stigma in the Canadian Health System. Retrieved from https://www.canada.ca/en/public-health/services/publications/healthy-living/primer-reduce-substance-use-stigma-health-system.html

Heidegger, M. (1962). Being and time. New York: Harper. (Original work published 1927). https://doi.org/10.1177/0020764019867358

Hyman, I. (2008). Self-Disclosure and Its Impact on Individuals Who Receive Mental Health Services. HHS Pub. No. (SMA)-08-4337 Rockville, MD. Center for Mental Health Services, Substance Abuse and Mental Health Services Administration. Retrieved from https://store.samhsa.gov/product/Self-Disclosure-and-Its-Impact-on-Individuals-Who-Receive-Mental-Health-Services/sma08-4337

Karnieli-Miller, O., Perlick, D. A., Nelson, A., Mattias, K., Corrigan, P., & Roe, D. (2013). Family members' of persons living with a serious mental illness: Experiences and efforts to cope with stigma. *Journal of Mental Health*, 22, 254–262

Knaak, S., Mantler, E., & Szeto, A. (2017, March). Mental illness-related stigma in healthcare: Barriers to access and care and evidence-based solutions. In *Healthcare management forum* (Vol. 30, No. 2, pp. 111-116). Sage CA: Los Angeles, CA: SAGE Publications.

Ladd, W. (2018). "Born out of fear": A grounded theory study of the stigma of bipolar disorder for new mothers. *Qualitative Report*, *23*(9), 2081–2104.

Larson, J. E., & Corrigan, P. (2008). The stigma of families with mental illness. *Academic Psychiatry*, *32*(2), 87-91. https://doi.org/10.1176/appi.ap.32.2.87

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review Sociology*, 27:363–385

Link, B. G., & Phelan, J. C. (2006). Stigma and its public health implications. *The Lancet*, *367*(9509), 528-529. https://doi.org/10.1016/S0140-6736(06)68184-1

Link, B. G., Yang, L. H., Phelan, J. C., & Collins, P. Y. (2004). Measuring mental illness stigma. *Schizophrenia Bulletin*, *30*(3), 511-541.

Livingston, J. D. (2013). Mental illness-related structural stigma: The downward spiral of systemic exclusion. Calgary, Alberta: Mental Health Commission of Canada. Retrieved from www.mentalhealthcommission.ca.

Lopez, K. A., & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge. *Qualitative Health Research*, *14*(5), 726-735.

Lucas, J. W., & Phelan, J. C. (2012). Stigma and Status: The Interrelation of Two Theoretical Perspectives. *Social Psychology Quarterly*, *75*(4), 310–333. https://doi.org/10.1177/0190272512459968

Mejia-Lancheros, C., Lachaud, J., Woodhall-Melnik, J., O'Campo, P., Hwang, S. W., Stergiopoulos, V. (2021). Longitudinal interrelationships of mental health discrimination and stigma with housing and well-being outcomes in adults with mental illness and recent experience of homelessness. *Social Science and Medicine*, 268:113463 https://doi.org/10.1016/j.socscimed.2020.113463

Mental Health Commission of Canada. (2015). *Guidelines for Recovery-oriented practices*. Mental Health Commission of Canada. Retrieved from https://www.mentalhealthcommission.ca/wp-content/uploads/drupal/MHCC_RecoveryGuidelines_ENG_0.pdf

Mittal, D., Sullivan, G., Chekuri, L., Allee, E., & Corrigan, P. W. (2012). Empirical studies of self-stigma reduction strategies: a critical review of the literature. *Psychiatric Services*, *63*(10), 974-981. https://doi.org/10.1176/appi.ps.201100459

Nyblade, L., Stockton, M. A., Giger, K., Bond, V., Ekstrand, M. L., Mc Lean, R., Mitchell, E. M., La Ron, E. N., Sapag, J. C., Siraprapasiri, T., & Turan, J. (2019). Stigma in health facilities: why it matters and how we can change it. *BMC Medicine*, *17*(1), 25. DOI: https://doi.org/10.1186/s12916-019-1256-2.

O'Reilly, C. L., Paul, D., McCahon, R., Shankar, S., Rosen, A., & Ramzy, T. (2019). Stigma and discrimination in individuals with severe and persistent mental illness in an assertive community treatment team: Perceptions of families and healthcare professionals. *International Journal of Social Psychiatry*, *65*(7-8), 570–579.

Oexle N, Rüsch N, Viering S et al (2017). Self-stigma and suicidality: a longitudinal study. European Archives of Psychiatry and Clinical Neuroscience, 267(4):359–361.

Östman, M., & Kjellin, L. (2002). Stigma by association: Psychological factors in relatives of people with mental illness. *British Journal of Psychiatry*, *181*(6), 494–498. https://doi.org/10.1192/bjp.181.6.494

Paul, S., & Nadkarni, V. V. (2017). A qualitative study on family acceptance, stigma and discrimination of persons with schizophrenia in an Indian metropolis. *International Social Work*, *60*(1), 84–99. https://doi.org/10.1177/0020872814547436

Public Health Agency of Canada. (2006). The human face of mental health and mental illness in Canada 2006. Retrieved from https://www.phac-aspc.gc.ca/publicat/human-humain06/pdf/human_face_e.pdf.

Quinn, D. M. (2018). When stigma is concealable: the costs and benefits for health. In: Major B, Dovidio JF, Link BG (eds). *The Oxford handbook of stigma, discrimination, and health*. University Press, Oxford, pp 287–299.

Rivera-Segarra, E., Rivera, G., López-Soto, R., Crespo-Ramos, G., & Marqués-Reyes, D. (2014). Stigmatization experiences among people living with borderline personality disorder in Puerto Rico. *Qualitative Report*, *19*(15), 1–18.

Rüsch N, Angermeyer MC, Corrigan PW (2005). Mental illness stigma: concepts, consequences, and initiatives to reduce stigma. *European Psychiatry*, *20*(8): 529–539.

Rüsch, N., Corrigan, P. W., Waldmann, T., Staiger, T., Bahemann, A., Oexle, N., ... & Becker, T. (2018). Attitudes toward disclosing a mental health problem and reemployment: a longitudinal study. *The Journal of Nervous and Mental Disease*, *206*(5): 383-385.

Rüsch, N., & Kösters, M. (2021). Honest, Open, Proud to support disclosure decisions and to decrease stigma’s impact among people with mental illness: Conceptual review and meta-analysis of program efficacy. *Social Psychiatry and Psychiatric Epidemiology*, *56*(9), 1513-1526. https://doi.org/10.1007/s00127-021-02076-y

Rüsch, N., Malzer, A., Oexle, N., Waldmann, T., Staiger, T., Bahemann, A., Wigand, M.E., Becker, T., & Corrigan, P. W. (2019). Disclosure and quality of life among unemployed individuals with mental health problems: a longitudinal study. *The Journal of Nervous and Mental Disease*, *207*(3), 137-139.

Spielgelberg, H. (1976). Doing phenomenology. The Hague, the Netherlands: Martinus Nijhoff.

Streeton, R., Cooke, M., & Campbell, J. (2004). Researching the researchers: using a snowballing technique. *Nurse Researcher*, *12*(1), 35-47.

Statistics Canada. (2021). 2021Canadian Census. Retrieved from https://www12.statcan.gc.ca/census-recensement/2021/as-sa/fogs spg/page.cfm?dguid=2021S0503555&topic=1&lang=E

Stuart, H. (2017). Stigma: Mark of shame or complex social process? In S. Hamid-Balma. Visions, Recovery: stigma and inclusion (pp. 5-7). BC Partners for Mental Health and Addictions Information and funded by BC Mental Health and Substance Use Services, an agency of the Provincial Health Services Authority. Retrieved from http://www.heretohelp.bc.ca/

Tassonyi, A. T. (2017). The context and challenges for Canada's mid-sized cities. *SPP Research Paper No, 10*(9). Retrieved from https://www.policyschool.ca/wp-content/uploads/2017/05/Mid-Sized-Cities-Tassonyi.pdf

Umberson, D., & Karas Montez, J., (2010). Social relationships and health: A flashpoint for health policy. *Journal of Health and Social Behavior*, *51*(1_suppl), S54–S66. https://doi.org/10.1177/0022146510383501

van Der Sanden, R. L., Bos, A. E., Stutterheim, S. E., Pryor, J. B., & Kok, G. (2015). Stigma by association among family members of people with a mental illness: A qualitative analysis. *Journal of Community & Applied Social Psychology*, *25*(5), 400–417. https://doi.org/10.1002/ casp.2221.

van der Sanden, R. L., Pryor, J. B., Stutterheim, S. E., Kok, G., & Bos, A. E. (2016). Stigma by association and family burden among family members of people with mental illness: the mediating role of coping. *Social Psychiatry and Psychiatric Epidemiology*, *51*(9), 1233-1245. https://doi.org/10.1007/s00127-016-1256-x

van Manen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy* (2nd Ed.). London, Canada: The Althouse Press.

Velji, K., & Links, P. (2016). Mental Healthcare Delivery in London-Middlesex Ontario-The Next Frontier. *Healthcare quarterly (Toronto, Ont.)*, *18*, 57-60.

Watson, A., Hanrahan, P., Luchins, D., & Lurigio, A. (2001). Mental health courts and the complex issue of mentally ill offenders. *Psychiatric Services*, *52*(4), 477-481.

World Health Organization. (2001). The World Health Report: 2001: Mental health: New understanding, new hope. Geneva: World Health Organization.

World Health Organization. (2019). *The WHO special initiative for mental health (2019-2023): universal health coverage for mental health* (No. WHO/MSD/19.1). World Health Organization. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/310981/WHO-MSD-19.1-eng.pdf.

Yang, C. T., Narayanasamy, A., & Chang, S. L. (2012). Transcultural spirituality: The spiritual journey of hospitalized patients with schizophrenia in Taiwan. *Journal of Advanced Nursing*, *68*(2), 358–367. https:// doi.org/10.1111/j.1365-2648.2011. 05747.x

Chapter 5

Negotiating familial mental illness stigma: the role of family members of persons living with mental illnesses

Abstract

This study explores the lived experiences of family members of individuals with mental illnesses and how they address potential familial mental illness stigma. Previous studies have concentrated on self, social, and associative stigma and its impacts on families and persons with mental illnesses. Far less work has considered family members as perpetrators of mental illness stigma towards their loved ones with mental health concerns. We conducted this study with 15 participants who were family members of persons with mental illnesses using semi-structured qualitative interviews. The in-depth interviews were followed by inductive analysis using Braun and Clarke's (2006) technique for thematic analysis. Participants' views on familial mental illness stigma and ways to reduce this were reported in five key themes. The themes included: (1) layered perspectives of social and familial stigma; (2) family-related stigma; (3) complex interplay of family relationships and mental illness; (4) confronting stigma personally; and (5) envisioning a better future. The uncertainties connected with mental illnesses and the increased social stigma were conceptualized as contributors to familial mental illness stigma as ways to prevent potential associative stigma. Participants suggested the need for more social contact-based education and positive media reporting to correct the ongoing fallacies around mental illnesses. This study highlights how higher-order reforms to social systems and services would support both families and those living with mental illnesses to have more positive experiences.

Keywords: familial mental illness stigma, social stigma, associative stigma, family members and persons with mental illnesses, interpretive phenomenology

5.1 Introduction and purpose

Untreated mental illness leads to significant morbidity and mortality outcomes (Liu, et al., 2017; Walker et al., 2015). In Canada, mental illnesses have been found to contribute significantly to disability, affecting 1 in every 5 people (Centre for Addiction and Mental Health, 2019; Public Health Agency of Canada, 2019). Globally, over 70% of persons with mental illnesses do not have access to treatment, and much of this is attributed to stigma (Corrigan et al., 2014; Evans-Lacko et al., 2012; Henderson et al., 2013). There is high social vulnerability and marginalization linked to mental illnesses (Compton & Shim 2015; Otten et al., 2021). Such social vulnerabilities can make life complex for individuals with mental health concerns, diagnosed or otherwise, as well as their immediate families, especially in situations where lack of access to mental healthcare services makes families struggle to meet basic health needs while searching for treatment for their loved ones (Knaak et al., 2017; Ngui et al., 2010).

Individuals with mental health challenges often encounter multifaceted problems due to the ongoing stigma that is associated with their illnesses (NIMH, 2019; WHO, 2010, 2012). Goffman was one of the first to theoretically unpack stigma, describing it as a social construct that transmits stereotypes, which are deeply rooted in society. According to Goffman, such negative stereotypes lead to dishonor and avoidance in relation to the individual’s (race, ethnicity, and religion), physical deformities (e.g., deafness and blindness), and what Goffman termed at that time as blemishes of character (e.g., addiction and mental disorders) [Goffman, 1963]. The social devaluation that the stigmatized person experiences reduces their full ability to participate in social life in their community (Goffman, 1963). As much as mental illnesses are regarded as a personal problem (Malla et al., 2015), mental health problems are a familial experience as well, given that most regular support for individuals with mental illnesses is provided by immediate family members or partners (Canadian Mental Health Association [CMHA], 2007; 2018). Global research identifies mental illness stigma as a key contributor to the vulnerability and social exclusion of people with mental health concerns within their neighborhood or immediate environment (CMHA, 2018; Knaak et al., 2015; WHO, 2012, 2019).

The stigma associated with mental illness has been widely studied (Corrigan & Watson, 2002; Knaak et al., 2017; Link & Phelan, 2001; Livingston, 2013). Nevertheless, many of these studies explored stigma from the public or from mental health professionals (Huggett et al., 2018; O’Reilly et al., 2019; Park & Park, 2014; Paul & Nadkarni, 2017). Other studies have also focused on stigma by association, (i.e., stigma experienced by health professionals or the ill person’s close family members) (Kulik et al., 2008; Nyblade et al., 2019; O’Brien et al., 2015; Östman & Kjellin, 2002; van Der Sanden et al., 2013; 2015; 2016). What is very limited in the literature is consideration of the stigma perpetrated by the individual’s family members (familial mental illness stigma) towards their relative who has been diagnosed with a mental illness. The paucity of literature in familial mental illness stigma may limit tools in place to address this stigma.

Research has acknowledged that some individuals are stigmatized by family members, which results in emotional distress and lack of practical support (Adu et al., 2021; Koschorke et al., 2017; Mascayano et al., 2015). Experiences of discrimination and humiliation within the family system may compel affected individuals to conceal their mental health problems from close relatives, thereby hampering ongoing treatment and social support for these individuals (Adu et al., 2021; Koschorke et al., 2017; Larson & Corrigan, 2008; Park & Park, 2014). A thorough understanding of familial mental illness stigma is crucial due to the potential existence of exclusionary behaviors towards persons with mental illnesses by their own families (Livingston, 2013; Mfoafo-M'Carthy, & Sossou, 2017).

The complex role of family members in relation to both social support and perpetration of stigma has been explored among relatives of persons diagnosed with schizophrenia, including the lived experience of parents involved in caring for young people experiencing a first episode of psychosis (Aldersey & Whitley, 2015; Barnable et al., 2006; Clarke & Winsor, 2010; Hamilton-Wilson & Conroy, 2012). Though some of these studies focused on family experiences of mental illness-related stigma, there is still a lack of focus on the stigma that originates from within the family towards close relatives with mental illness. The role of the family in supporting relatives with mental illnesses in relation to social and emotional assistance is evident in the extant literature (Brackertz et al., 2018; Family Mental Health Alliance, 2006; Livingston, 2013; Pirkis et al., 2010; Public Health Agency of Canada, 2006). This notwithstanding, it is prudent for researchers to ponder on stigma enacted by some family members towards their close relatives with mental illnesses due to the multi-faceted nature of mental illness stigma.

Familial mental illness stigma occurs when family members or close relatives enact stigma through labelling, stereotyping, prejudice, and discrimination against a family member with mental illnesses. In Canada, about 11 million (38%) Canadians aged 15 and above have at least one immediate or extended family member who lives with a mental health concern, diagnosed or otherwise (MHCC, 2012; Pearson, 2015; Pearson et al., 2013). Of Canadian families with a loved one living with a mental health concern, nearly 71% of them felt that their own livelihoods were impeded by their relatives' illness (MHCC, 2012; Pearson, 2015; Pearson et al., 2013). Just like the other forms of stigma, familial mental illness stigma could also be multi-faceted, warranting special attention in global research for scholars and practitioners to understand the unique experiences of both patients and family members. In this way, we could develop interventions to support families in addressing the stigma they knowingly or unknowingly may perpetrate against their relatives. This current study, therefore, explores the lived experiences of family members of individuals with a diagnosis of mental illness in Ontario, Canada and how they address potential familial mental stigma. The objective of the study is to help fill some notable gaps about familial mental illness stigma, contribute to the anti-stigma literature, and promote evidence-based practices and policies towards stigma reduction in our communities.

5.2 Methods

5.2.1 Design

An interpretative phenomenological study was conducted with family members of individuals with lived experiences of mental illnesses. We pursued this study to unearth the essence, interpret, and describe the meaning of the phenomenon (familial mental illness stigma) among this population in Ontario (London-Middlesex area), Canada. The phenomenological research method allows for a "systematic, explicit, self-critical, and intersubjective study of its subject matter, of lived experience" (van Manen, 1990, p. 11). This method was chosen for the study because an interpretive phenomenology allows researchers to delve into and interpret language, lived experience, and social relationships of participants as well as the meanings ascribed to those experiences (Lopez & Willis, 2004).

The study design enabled the researchers to establish an interpretative phenomenological stance to gain insight into the phenomenon while appreciating the participants' narratives (Schoppmann et al., 2007). Interpretive phenomenology is also best enacted through the creation of an enabling environment that allows both the investigator and research participants to co-construct the meaning of the phenomenon through interactional processes including dialogue (Moustakas, 1994; van Manen, 1990; Smith, 2019). Ideally, interpretive phenomenology often moves beyond the recognition of the fundamental nature or outcome of the phenomenon (description) to unearth the meanings that humans ascribe to their lived experiences within a particular setting (Lopez & Willis, 2004). The interpretive phenomenology approach, together with interpretative phenomenology analysis, allowed the researchers and participants in this study the needed flexibility in the explanatory process of the phenomenon while the investigators observed the emergent themes as active members of the study as the interviews unfolded (Pringle et al., 2011; Smith et al., 2009). That is, the interpretive phenomenology analysis is a subjective process whereby the researcher co-creates knowledge with those who have experiences to share, then layers on interpretation to this knowledge in a form of reconstruction. The study was approved by the institutional review board of Western University (#119602).

5.2.2 Participants

Fifteen adults living in a mid-sized city in Ontario, Canada were enrolled in the study via criterion sampling. The participants were family members or close relatives of persons with mental illnesses. All participants consented to partake in the study before the commencement of interviews.

Recruitment: The research team placed advertisements in family health practices, community health centers, and educational institutions to canvass participants. The advertisement was also shared via flyers on various social media platforms including Facebook, Twitter, and LinkedIn.

Inclusion/exclusion criteria. Participant selection was based on the following criteria: (1) being 24 years or older; (2) self-identified as a family member or close relative of a person or persons with mental illnesses; (3) spoke and understood English; (4) being a current resident in London-Middlesex area; and (6) willingness to participate in the study for 45-60 minutes. We excluded all persons who identified as family members or close relatives of people with mental illnesses and were not resident in the London-Middlesex area to avoid anticipated variations in the availability of services and supports.

5.2.3 Data Collection

Participants were interviewed using a semi-structured interview guide. The interviews were recorded on Zoom and transcribed verbatim. Each participant was assigned a pseudonym by the interviewer to ensure confidentiality. Participants’ identities were further protected by ensuring that all voice files and transcripts were encoded and stored on a computer protected via encryption. The interview guide included questions related to participants' experiences, and their understanding of familial mental illness stigma (see Table 2 for sample questions from the interview guide). Each in-depth interview lasted between 45 and 60 minutes. Participants were given $20 in appreciation for their time.

Table 1: Participants' demographic information

Participant ID	Age Range	Gender	Relationship to person with mental illness	Marital Status	Level of Education	Race/Ethnicity
FM_1	45-49	Female	Daughter	Separated	Graduate	Caucasian
FM_3	55-59	Female	Sister	Married	Undergraduate	Caucasian
FM_5	25-29	Female	Sister	Single	Graduate	Caucasian
FM_6	50-54	Female	Sister	Married	Graduate	Caucasian
FM_11	50-54	Female	Daughter	Married	Graduate	Caucasian
FM_13	40-44	Female	Daughter	Common law partner	Graduate	Caucasian
FM_14	35-39	Female	Daughter	Common law partner	High school	White Canadian
FM_15	25-29	Female	Sister	Single	Undergraduate	Middle East
FM_18	30-34	Female	Sister	Married	Undergraduate	White Canadian
FM_19	70-74	Female	Mother	Divorce	Graduate	Caucasian
FM_21	40-44	Female	Daughter	Married	Undergraduate	Caucasian
FM_24	30-34	Non-binary	Daughter	Single	Graduate	White European
FM_25	50-54	Female	Sister	Married	Graduate	Caucasian
FM_26	60-64	Female	Sister	Common law partner	Graduate	Caucasian
FM_30	45-49	Female	Sister	Separated	College	Caucasian

Key: FM-Family members

Table 2: Interview Guide

1. So, before we get into specifics, I want you to talk about mental illness stigma more generally. What kind of mental illness stigma do you think people experience in Canada today?	5. How would you describe your experiences of having a family member who lives with a mental illness? a. What have been the most important things you have learned through this? b. What have been the largest challenges they have faced? c. What have been the largest challenges for you, personally?
2. Do you think stigma has gotten any better in recent years?	6. Has this experience changed how you understand mental illness? a. [If yes] How so?
3. What do you think causes mental illness stigma?	7. Now let's talk specifically about stigma. Do you believe your [family member] experiences of stigma are because of their illness? a. What kinds of stigma do they experience? b. Have you ever been present when you saw them being discriminated against because of their illness? What was that like?
4. You've been invited to this study because of being the family member of a person diagnosed with a mental illness. Can you tell me a bit about your family member who lives with a mental illness? a. How long have they been living with a diagnosis? b. What kind of supports do they receive? c. How often do you see them?	8. In this study we hypothesize that family members themselves might stigmatize their loved ones with a mental illness. Personally, do you feel like anyone in your family has acted in ways that are discriminatory towards your loved one with a mental illness? (a) How supportive have your family members been towards the care of your relative through their illness? b. [If you provide a lot of direct support yourselves] What kind of activities do your family members help you with? c. How do you feel about the help they give you?
9. Thinking honestly about your experiences through this all, do you think your attitude towards your loved one has changed since they started experiencing symptoms of mental illnesses? a. How was your relationship with your relative before their diagnosis? b. How close are the two of you now?	10. If you were ever to notice family members treating your loved one poorly because of their mental illness, how do you think you would address these negative behaviours? a. Is [family member] involved in family decision-making? If so, how often do you seek their opinion on important matters that need attention from all family members?
11. What is your opinion about other extended family and friends knowing about the diagnosis of your relative? a. Do you ever [yourself] feel embarrassed about their illness?	12. Has your relative's diagnosis had any impact on you in terms of your relationships with others? How comfortable are you discussing your relative's diagnosis with close friends?
13. In conclusion, what do you think can be done to reduce negative behaviours towards people with mental illnesses?	Do you have any questions or comments for me?
Demographic data Participants unique identification numbers Age Gender Race and ethnicity Marital status Occupation Level of education	

5.2.4 Data analysis

Braun and Clarke’s (2006) technique for thematic analysis was employed to organize the data for the study. The approach involves six stages: (a) familiarizing oneself with the data; (b) generating initial codes; (c) generating themes; (d) reviewing the themes; (e) defining and naming themes; and (f) producing the report. In keeping with the analytic techniques, two members of the research team listened to the audiotapes of all interviews repeatedly and transcribed them verbatim into word processor files. We confirmed the accuracy of the earliest transcriptions by replaying the audio recordings and double-checking with the transcripts. We continued to reflect on the data by listening to the audiotapes and re-reading the transcripts while reflecting on each participant at the time of the interview to appreciate and interpret the context in which they spoke. This allowed us to account for the full, detailed, and thick description of the data. Having familiarized ourselves with the data, we manually started the coding process, underpinned by the research objectives, by assigning meaningful labels to segments of each transcript pertinent to the study using words and short phrases. The various initial codes were prearranged and organized logically into higher-level categories for thematic linkages or nexuses which paved the way for theme development. Three researchers sorted the codes and mapped the various patterns into probable themes while combining all key coded data extracts within the identified themes. Having re-read the categorized data and recognized the commonalities and connections within the data, we formed the subthemes. All five co-authors reviewed and commented on the potential subthemes and themes to ensure both relevance of the findings to the research questions as well as maintaining and uniquely representing participants’ voices or opinions. The analytic report was drafted by two team members and the full research team read and made changes to ensure succinct logical accounts of the data supported by substantial evidence and using direct quotes. In addition to the post-analysis interactions by the research team to establish the validity of the findings, five participants accepted our invitation to review and comment on the final themes with these comments taken into consideration for the final interpretation.

5.3 Findings

Themes were organized inductively from the study data to understand the lived experiences of familial mental illnesses stigma and how it can be reduced among family members. The participants' views are articulated through five themes generated in our analysis. These included: (1) layered perspectives of social and familial stigma; (2) family-related stigma; (3) complex interplay of family relationships and mental illness; (4) confronting stigma personally; and (5) envisioning a better future.

5.3.1 Layered Perspectives of Social and Familial stigma

Participants’ viewpoints of their lived experiences demonstrate that they acknowledge the existence of such intricate connections between social and associative stigma. Familial mental illness stigma appears to have a link with social stigma. Familial mental illness stigma could exist when social stigma is at work within a social interaction. Family members often try to avoid social stigma, but in the end, may perpetrate familial mental illness stigma which could further result in self-stigma. Layered perspectives of social and familial stigma comprised three subthemes: public/social stigma; social exclusion or abandonment; and labeling and social distancing.

Public/social stigma**:** The World Health Organization (WHO) has explained public or social stigma in the context of health as a bias against people who may live with the diagnoses or symptoms of certain illnesses, and are treated negatively alongside their caregivers, family, and friends in every fabric of society (WHO, 2020). Persons with mental illnesses are known to be socially stigmatized within their communities. Participants in this study reiterated the existence of social stigma in Canada against persons with mental illnesses. They noted the avoidance and /or discrimination of such people from certain employment opportunities as well as from performing certain key roles within society, which has further contributed to widening the inequality gaps in society. A participant expressed:

> I think general ostracization, they are not included socially. It's really hard for people with mental illness to get jobs and find housing in Canada. And sometimes it's hard for persons with mental illnesses to get proper medical care (Participant 14).

Participants also contended that the ongoing stereotypes of persons with a diagnosis of mental illnesses are often extended to their family members. A participant recounted their ordeal with social stigma while caring for the younger brother living with schizophrenia:

> “But with us, people just like wanting to stay away like nobody wanted to touch... My brother himself was so ashamed as he lost all his friends. I remember one time when my brother was released from the hospital and his roommate came in with us to support him, his family didn't want him to be with my brother, because he had been in the psychiatric hospital. And other young people didn't want to be around him. My brother died without any empathy from his friends” (Participant 6).

Social exclusion**:** Social exclusion in this study denotes an individual with mental illness's inability to participate fully in activities within their family due to ongoing discriminatory behavior from relatives. Some participants reported the difficulties associated with their family members being diagnosed with mental illnesses in relation to interactions with their in-laws. A critical observation by a participant shows that their in-laws did not want to engage willingly with the brother living with mental illnesses compared with other members of the family:

> My in-laws sometimes struggle to communicate with my brother diagnosed with mental illness. I sense the feeling of almost holding back from really getting to know him, and it feels like a very forced conversation when they're talking to him, so … (Participant 18).

Analysis of our data also revealed that some participants cut links with family members diagnosed with mental illnesses to save themselves from the psychological anguish often experienced by family caregivers. Other close relatives excluded affected family members to avoid the many hurtful reports about their relatives by others. One participant stated:

> They [family members] have been hands-off. …, hurtful things have been said about my mom since her diagnosis. My sister said she did not want to be told how many times mom had been saved by laying on train tracks. I think she couldn’t allow that trauma constantly to disturb her. It’s too much. To maintain her own sanity and stability so that she is not in a constant state of panic and worry, you have to let her go, hence my sister deserted mom (Participant 1).

Labeling and socially distancing**:** Socially distancing in this context implies family members or close relatives of persons living with mental illnesses avoiding them and not wanting to have any close association with them, especially when in a social context. Living with a mental illness without a good family network could be impairing and ultimately delay recovery. Participants reported that some families avoided their loved ones and also dissociated themselves after their diagnoses instead of embracing and supporting them toward recovery. For instance, one participant narrated how their mom was labeled and isolated by the immediate family members because her presence at social events caused some members of the extended family to lose interest in the occasion:

> During the family get-together, Christmas, or any other occasion people wouldn’t come; many will immediately ask if mom is going to be there. And if she was, no one else was going to attend. That’s clear… and my ex-partner would not like my mum any time his mom is around. … we try to have both mums together and of course, under normal circumstances having two mothers-in-law together in one place is often tenuous. Too very dominant… but they would never sit at the same table together (Participant 1).

The labeling of persons due to a mental illness within their family could lead to a lack of social support and low self-esteem as well as loneliness and social distancing within the immediate environment. A family member described how their mom labeled her son and kept calling him names due to a diagnosis of mental illness:

> My mom has always labeled my brother as sick because of his mental illness diagnosis. She has always used that term, he's sick. He has an illness, and it's a very deficit, ... And it took me a long time to realize that and to sort of try and counter that a little bit, and only in my later years have I been able to do that (Participant 11).

5.3.2 Family-related Stigma

Familial stigma herein is simply the extension of stigma to other family members by their own relative's experience. In this study, the fear of stigma from the public due to their relationship with the family member (stigma by association) resulted in some families excluding their relatives with mental illnesses from social events or socially distancing themselves. In hindsight, a participant stated vividly their discriminatory behaviors toward their brother due to a diagnosis. They failed to invite them to their wedding reception for fear of causing a scene during the celebration, which could lead to a loss of social status within the family. The brother's exclusion from the wedding could also impact their mental health and validate any related self-stigma:

> Yes, I have discriminated against my brother because I excluded him from my wedding. I was just thinking about this the other day, I got married at 25 years, and I didn't invite him because he wasn't mentally stable. I didn't want him to cause a scene or require any energy that I didn't have or didn't want others to be distracted. I didn't want him to ruin my perfect day (Participant 11).

A participant expressed their views in relation to familial mental stigma using the following statements: "Yeah, my brother definitely experienced stigma within his nuclear family since the whole family did not want anything to do with him because he uses substances. And he was subsequently sent out of the house by our parents" (Participant 5). While some participants demonstrated close relationships with their family members with a mental illness, their children discriminated against them by refusing to have dinner together:

> In terms of discrimination, I think sometimes maybe my kids at 22 and 25; are not so enthusiastic to have a family dinner with their uncle. I think they might be if he did not have mental illness right because there's not a lot of talk about and just his appearance going on…. that's funny (Participant 3).

5.3.3 Complex Interplay of Family Relationships and Mental Illness

The relational interactions families have around mental illnesses sit within the context of already frequently complex familial relationships. Family members subjectively perceived that complex relational experiences are intertwined with their perspectives on mental illnesses. These subjective experiences of family members were discussed under the following subthemes: loss of social status within the family; exclusion from family decision making; divorce/loss of romantic partners; neglect due to difficult behaviors; and compassion.

Loss of social status within the family**:** Some participants felt their loved ones were deserted by family members at a time they needed affection and support from them to improve their mental health. They described how some close relatives with mental illnesses were devalued leading to the loss of their social status within their family following a mental illness diagnosis. Some of the family members did not even consider their sick relatives as part of the family anymore:

> Yes, within our extended family only a minority of people would ever ask about my brother because of his mental illness diagnosis.
> Otherwise, he was just not brought up or he was not mentioned, and if you mentioned him, people would just try to change the subject. So, they never offer any help being it emotional or practical until he died (Participant 6).

Positive relationships, together with good social support networks within one's family are well-documented with respect to mental health recovery. However, several participants in this study reported that their loved one's mental illnesses brought conflicts within the family. The severity of their illness compelled some relatives to cut contact with the affected person. A participant described how their husband who was supportive of the relative's care also complained severally about the in-law's exaggerations:

> Mental illness is ingrained in our family and most of my mom's sisters have suffered from it. They've had periods of conflict and not spoken so... I'm sure my cousin doesn't speak to my mother anymore. They have no close relationship though they were somewhat close in my younger years. My husband who supports me has said many times that my mom exaggerates. I think … we all move through ups and downs in life. But the chronicity of my mom's sort of helplessness… (Participant 25).

Exclusion from family decision making**:** The exclusion of persons with mental illnesses from family decision making after a diagnosis could be tantamount to loss of status within one's family, especially if the affected persons were consulted on important family matters before their diagnoses. Some study participants discussed how their family members were excluded from all family decision-making due to a diagnosis of substance use disorders, a move that can affect one's self-esteem:

> My brother is not involved in any decision-making in the family. He's cut off from all family activities. Even his own mother's care in the nursing home, the mother obviously just doesn't prefer him to be

> involved. I suppose or trust that he can make those decisions, but he's definitely not involved at all (Participant 5).

Several family members shared their views on the exclusion of persons with lived experiences of mental illnesses from family decision-making and indicated how these family actions can further inhibit them from improving their mental health. A participant stated:

> My brother is often involved in family discussions, not decisions. We had a death in my family a couple of years ago and he was involved in those discussions. For sure, just to make sure that everyone was on the same page and understanding but when it came down to decision-making, he was not involved in that process (Participant 18).

***Divorce/loss of romantic partners*:** If an individual has a romantic partner, their support can be key to managing health challenges, including mental illnesses. Nevertheless, some participants' stories in this study indicated that their partners mistreated them while struggling with a mental illness. A family member mentioned:

> Mom was divorced after 35 years of marriage in 2005 and dad deserted her because of her mental illnesses. I assisted her by purchasing clothes, setting up things like a meal on wheels, essentially just talking to her every day, and later became her advocate and got her into community services until she went into in-patient care due to frequent relapses (Participant 1).

Another participant expressed this concerning divorce issues connected with family relationships and mental illnesses:

> Mom was beautiful… and I had a very positive regard for her as a child. Mom was divorced by my dad due to her mental illness diagnosis. I started to have a different opinion of her when she was hospitalized (Participant 25).

***Neglect due to difficult behaviors*:** This subtheme describes how persons with mental illnesses were deserted by some family members due to their atypical behaviors or inability to keep boundaries. A family member stated:

> I was about 20 years when I left home to start my own life. My brother started living on the street by the time I returned. I lost track of him for a little while and then found him in an apartment. I moved out West … and I didn't have a lot of contact with him for several years. My mom told him to leave because they started having a lot of conflicts and just my mom as a single mom and my brother became very difficult, very delusional partying all night with drugs. He was not helping around the house, and he dropped out of school. My mom received advice from the therapist or somebody that she should kick him out of the house for her own preservation (Participant 11).

The increased neglect of persons with mental illnesses by family members can further worsen their already weakened mental health due to a lack of social support and emotional stress. Participants' accounts showed that such actions protect families from psychological stress and prevent family members from developing mental health problems themselves:

> I was seeing my mom about once a week. There was a period of about four years after her diagnosis when we did not have any contact and

> that was a time when I have two kids, and they were small, and mom’s behavior was dramatic, unpredictable, and demanding. And it was happening over some time like a couple of years where there was a growing concern. And we had an argument, and she was very mean to me, and rude to me verbally, and hung up on the phone on me, and I just decided that I needed to set a boundary for my own well-being, and I didn't reach out to her, and it was very difficult. One of the hardest things I have gone through, yeah and then I decided to reconnect and wrote a letter, and we began to reconnect again (Participant 25).

Other participants disclosed how their loved ones’ difficult temperament and abusive nature caused them to stay apart:

> I normally see my dad a few times every year. I haven't seen him at all since the pandemic, but... Dad has anxiety and anger problems, so it is really hard to deal with him. And even though he did go for anger management, he still struggles with his anger. Dad was abusive in the past and he still sometimes does not agree with you (Participant 14).

Compassion**:** Whereas some participants in the study expressed disappointment regarding the challenging behaviors of family members with mental illnesses, others were compassionate towards their loved ones after diagnosis. Certainly, some participants at times got frustrated at the turn of events, but they remained committed to the care of their family members:

> I don't think my attitude toward my daughter has changed since her diagnosis. I’ve always been supportive and continue to do my best for

> her. I'm sure I get frustrated sometimes, but I don't know if that's really a change. Her brother probably is more engaged with her than before. Because she does reach out to him more and I believe he understands that she needs the support (Participant 19).

Another family member revealed:

> …my attitude towards my brother has changed over the years since his diagnosis because it's been so long. It's been many decades and I've changed and grown as an adult. And he hasn't gone through the same life phases and 'normal' life phases (Participant 11).

Participants' accounts also pointed to compassion towards the affected person with mental illnesses within the family because family members show maturity and understanding of relatives' mental illnesses. Some family members also engaged their loved ones in an open conversation to restore hopes and aspirations in life despite the diagnosis:

> As I got older, and his mental health got more severe and leading up to his bipolar diagnosis it changed completely. The biggest thing that changed for me was when he first attempted suicide. That was a huge awakening really for all of us because we always took him seriously but once that happens like we became very alert. It was scary and so we realized that we needed to support him in any way that we could.
> … as I've gotten older, and I've had more open and honest conversations with him (Participant 18).

5.3.4 Confronting Stigma Personally

Many participants shared ideas about how familial mental illness stigma could be confronted at the family level knowing that family members and close relatives can be the perpetrators of stigma. Participants discussed confronting stigma personally under the following subthemes: familial education on mental illness; initial concealment/strategic disclosure; selective versus full disclosure; non-discrimination; and advocacy against familial prejudice.

***Familial education on mental illness*:** Some participants underscored the importance of family education on mental health problems in reducing familial mental illness stigma. These family member participants noted that in-depth knowledge of mental illnesses is the way forward to understanding the lived experiences of their loved ones with mental illnesses and appreciating them within the family. A participant indicated how this could be achieved through social contact-based education:

> Persons with mental illnesses deal with stigma by educating their family members and themselves. They find good support and ensure that they are confident in themselves. Stigma is a lack of education on mental illnesses… understand that mental health problems are something we all experience, and we can accept it and help one another (Participant 15).

Several family members in this study proposed family education by persons with mental illnesses. This approach acknowledges the expertise of those living with mental illnesses in their own experiences and as educators of others. Awareness was seen as a pathway towards reduced stigma:

> I think it is challenging for individuals diagnosed with mental illness to deal with stigma, including familial stigma. I think they first need to understand their illness and know that their illness is no different than cancer or diabetes. They need to understand their illness so they can explain it to others. I think they need to be opened to talking about their illness and perhaps find the people in their lives and family that are more understanding, empathic, and willing to support them. Not everyone in your circle or … but some family members will try to listen and try to understand them … I think the more awareness we have about mental illness and stigma in general the more we can change the stigma. I think it takes a lot of learning, listening, and empathy to understand someone with a mental illness (Participant 21).

Initial concealment/ strategic disclosure and full disclosure**:** While stigma may be directly confronted, other approaches of avoidance were noted. Limited disclosure was one means of avoiding stigma. Most participants in our study revealed both selective and full disclosure of a mental health problem of their relatives to other family members or the public as a form of coping with their loved ones' illnesses as well as the associative stigma at the family level. Selective disclosure implies that not all persons within their social space or family will be informed about the mental health problems of the affected family member. Participants' views show that they used selective disclosure to reduce the stigma connected with mental illnesses. One of the participants said:

> There are levels of privacy I would say depending on who I am interacting with and ways that I would deal with someone's attitude towards my family. If it is a distant person at a social event, for example, I would just be very factual describing briefly that my brother lives with a chronic disability, I might say schizophrenia, but I might not depend on whether I want that person to judge me or not, or…I make an in-the-moment decision about whether the person is trustworthy, meaning whether they will think negatively of me, or… some base factual knowledge themselves (Participant 11).

Another participant recounted:

> I am still not very comfortable talking with extended family members about my brother's mental illness. But I think with friends, we may talk about it. That is, with really close friends. I don't think that I would want to talk about it with anybody at my workplace. Colleagues may sometimes see something in the news like a mother losing a child or something, right, and they'll make a comment, and I might need to remind them that my mother lost a child, and they don't seem to equate it in the same way (Participant 6).

Some participants also adopted full disclosure as an approach to reducing mental illness stigma. Some participants were fully opened about their loved ones' mental health conditions by discussing them with friends and other family members. A family member disclosed how being open about their relative's illness offered them the opportunity to reduce stress by sharing their problems with others, allowing for advice and support when need be:

> I was kind of embarrassed 30 years ago… anything about it, and I thought that he would recover at some point or get better. I’m pretty open about his diagnosis even though I don't go talking about his diagnosis. I think it's much better now than it was 30 years ago I can say to people I have one sibling, and this is his situation. And he's not able to work and I'm his caregiver and I do not hide it (Participant 3).

Some participants noted that talking about mental health conditions within families was an opportunity to educate other people on mental illnesses and psychotropic medications. The participants emphasized how beneficial disclosure was to their mental health as it relieved them of the pressure and psychological stress of having to conceal their family member's condition from other relatives, close friends, and co-workers. A participant mentioned:

> I’ve gotten a lot less shy about telling people that my brother had paranoid schizophrenia… you know I have a brother who lives with paranoid schizophrenia. He lives in a special housing situation for people who were on the street, and now he's not, and when people who will often say, well, if they just take their medication… Then I pipe up and say you know, and I say that's not the way… I will try to educate people to inform them that it's not just about taking medication. Taking medication is not a complete solution for anybody or everybody who has mental health challenges (Participant 26).

***Non-discrimination*:** Some family member participants expressed how they developed expertise in understanding mental illnesses. Their understanding of mental illnesses led to the provision of social and practical support to affected family members without any form of prejudice. The absence of prejudice within the family environment brought inclusiveness among households which was good emotionally to improve their mental health. This valuing of non-discrimination was expressed by one of the participants:

> No, I don’t think she experiences any stigma within the family. I think generally her perfect family seems to have an open mind and understanding of her condition. I think we’ve all become more informed throughout the process now compared to perhaps the early stages when we had some misconceptions about it. I know that my son has concerns about the medications, but I don’t know if there may be some stigma associated with that (Participant 19).

Some participants were more explicit in sharing their views on the open-minded or unbiased attitude of family members toward relatives with mental illnesses. It was noticeable that several participants were well-informed about their relatives’ diagnoses and agreed to support them on the path to recovery: “I don’t think anyone within our family will stigmatize her because of the diagnosis. As a family, we've been educated about her diagnosis, and everyone knows what to do to support her. We really understand the problem at hand” (Participant 15).

In the same vein, a participant narrated how their loved one was treated by the family post-diagnosis:

> I would say nobody in our family stigmatizes my brother because mom was still alive when he was first diagnosed, and she spent quite a bit of time with him... My sister, a nurse practitioner, was very good about dealing with him. My other sister who suffered from mental illness herself was very open and took him to live with her for 10

> years. I would… but he and I were closest growing up. We've continued to communicate, and I haven't had as much direct contact with him. Our in-laws and children have been fine and comfortable with him. He came home for our mom's funeral and people approached him and talked to him (Participant 26).

***Advocacy against familial prejudice*:** Some participants discussed strategies they used in dealing with the unfair treatment of family members, whereas others suggested approaches they will employ in avoiding maltreatment of their loved ones should it arise. Many participants planned to intercede on behalf of their loved ones by calling out stigma and taking the opportunity to educate others on mental illnesses and the associated misconceptions. According to a participant, the involvement of family members in public education initiatives should be a way to bridge the 'we and them' gap within the public sphere:

> If [I] found any family member abusing my mom because of her diagnosis, I would call them out on it. And I would try and educate them on what I know about depression and bipolar disorder as well as mental illnesses, in general, to help reduce the 'we and them' gap (Participant 13).

Similarly, another participant explained how they supported their family member against familial prejudice within the household:

> …I called my sister who deserted mom for 20 years for us to deal with mom's belongings. After a long struggle, my sister did come with her husband and one of their sons, at 19, who has never seen mom before…they all had something negative to say about mom. I

> quickly jumped in and defended mom by telling them that mom had been in psychosis for the last two years, so her home is in disarray. Please, as you enter the apartment and all things that come out of your mouth need to have a lens of empathy. As mom was sick and didn't have the needed support hence, I was having to address this very firmly with my sister. That is, I didn't want to hear snide remarks that she was not part of the last 20 years of, you know, being a part of her life…. (Participant 1).

5.3.5 Envisioning a Better Future

While narrating their lived experiences with mental illnesses over the years in the care of impacted relatives, family members noted that transforming services would reduce the social harms that may be translating into stigmatizing actions of family members. The resulting themes included: reforms in access policies to mental healthcare and free access to quality support services. These suggestions by family members, however, were contingent on adequate funding for quality mental health programs at all levels to support persons with mental illnesses.

***Reforms in access policies to mental healthcare*:** Transformations in access to mental healthcare included recommendations that policy-makers should ensure the availability of care to all who need it. Participants considered free access to care as a key step to improving the well-being of individuals with mental illnesses and the de-stigmatization process, which could lead to better health and social outcomes. For instance, a participant stated:

> I think policymakers/governments could do a better job. There is the need to do more public education around it [mental illnesses]. In terms of policies, I think my daughter has received very good care

> and it's never been a case where she hasn't been able to access it. She can have access to the crisis team, which is working for her… lots of people may be having challenges with access hence policy-makers could improve access to care for people with mental illnesses (Participant 19).

Another participant reflected on the lack of diversity of available support services for persons with mental illnesses with respect to both older and younger populations, which to them, tends to benefit the younger generation with more interventions. The participants believed there should be more outreach and less confined ways to ensure diversity in terms of who can access service:

> …there's an older generation of individuals like my brother, who have been living with a diagnosis for so long and they're caught between worlds. People who are more newly diagnosed are getting the benefit of the changing approaches to care which are becoming more compassionate and becoming more trauma and violence informed. But people like my brother have gone too far into being discriminated against and mistreated and excluded to the point where there are no real programs that can help them. …. (Participant 11).

***Free access to quality support services*:** The provision of adequate and free mental health support services in our communities was advocated by several participants. During the interviews, participants advocated for more creativity in mental health-related system design as well as adequate funding for mental health programs. One participant explained:

> …. challenging to figure out how to deliver services. Better and more person-centered, but I think that there's room for more creativity in

> how those policies roll down the programs they run. And I think we need more funding for people's mental well-being. I think people need access to key publicly paid-for short and brief interventions (Participant 25).

Likewise, other participants proposed: "I think policy-makers can do more to support persons living with mental illnesses in our communities. There should be more free quality support that's accessible" (Participant 24). Another participant intimated:

> I believe that policy-makers should do more to help people with mental illnesses who are struggling with a disability. Checks are very limited, so if my brother didn't have a house that my mother bought him, he would have been in the worst condition by now (Participant 30).

5.4 Discussion

We conducted this study to explore the lived experiences of family members of persons with a diagnosis of mental illness and how they enact or address potential familial mental illness stigma. Findings of this research revealed both the potential for existence of familial mental illness stigma at the family level perpetrated by some family members or close relatives towards their loved ones, along with actions taken to prevent or reduce this stigma. It is worth noting that the high educational levels of participants might have influenced their perspectives of familial mental illness stigma as high education can relate to high income, and therefore access to additional private supports. Participants' stories showed that familial mental illness stigma is interconnected with other social sources of mental illness stigma. Blame was also pointed towards healthcare systems wherein inadequate services were rebuked for increasing the types of stressors that might lead to discriminatory behaviours. The more that individuals were forced to depend on their immediate families for daily needs, the more tension was felt within some families. In the end, participants of this study underscored potential policies and interventions necessary to transform the existing services to make persons with mental illnesses more independent. Our study adds to the existing body of literature on various forms of stigma, filling in some of the gaps, specifically how family members themselves navigate familial mental illness stigma (Adu et al., 2021, 2022; Chen et al., 2013; Corrigan, 2022; Frieh, 2020; Suto et al., 2012; van Der Sanden et al., 2015).

Stigma within families does not sit apart from other family dynamics, but rather the multi-layered interconnectivity of family relations pre-dates diagnosis and the accompanying symptoms of mental illness. These complexities sometimes add to both positive and negative existing familial relationships. For instance, some families responded to symptoms and diagnoses with compassion, and in most cases, family members provided resources to support the mental health of their relatives; however, it was noted that at times this support was focused on family members protecting themselves from associative mental illness stigma. Where these concerns were the greatest, some family members isolated their loved ones living with mental illnesses. This might have unintended harms related to the prevention of access to support. These findings are analogous to those on the fear of associative stigma that compels some family members to reduce social contact with their relatives with mental health issues and in the end, stop supporting them both emotionally and practically (Suto et al., 2012; Stuart et al., 2014a, 2014b; van Der Sanden et al., 2015). Some family members engaged in concealment, which may have had negative implications for access to care. This social exclusion was also extended to other social events within their local communities. These observations align with other findings that most persons with lived experiences of mental illnesses are excluded to some degree from family and community participation (Adu et al., 2022; Rössler, 2016; van Der Sanden et al., 2013, 2015). Such exclusions have implications on the self-worth and personal empowerment of the affected individual, which in turn, could prolong their recovery.

The study participants acknowledged frustrations and stressors connected to the care of persons with mental illnesses as part of the complex interplay within family systems and situate blame for mental illness stigma within this experience. The frustrations included blaming the individual experiencing an illness for the symptoms of their condition. This reproach is felt by the individual and can become a barrier to recovery as they hide their challenges from family members. In this context, disclosure is challenging, often “a double-edged sword” as those living with mental illnesses navigate the potentials of either support or stigma from their loved ones (Corrigan et al., 2010; Umberson & Karas Montez, 2010).

Our findings revealed that if family members lack knowledge or carry societal misconceptions about mental illnesses, they can perpetuate social isolation and emotional distress of their loved ones. Our participants highlighted other family members who would exclude those with mental illnesses from opportunities to exercise autonomy or power within the family unit. This exclusionary approach parallels experiences that persons living with mental illnesses encounter devaluing stereotypes in other social contexts such as school or workplaces (Link & Phelan, 2001; Lucas & Phelan, 2012; Rössler, 2016). Therefore, there is no guarantee that all those who face exclusion in broader society will find solace within the family unit.

While participants noted the ways that their loved ones are stigmatized within their families, they also provided recommendations for how society can do a better job at creating a supportive context. Some of them focused on individual level interventions such as increasing understanding of mental illnesses within families. The family members also suggested transformative education with a focus on social contact-based education to correct some common fallacies and fears about mental illnesses. This is grounded in the idea that erroneous beliefs regarding mental health issues have contributed to the persistence of public stigma as well as stigma within families. Using positive media stories and social contact-based education with intentionality is promoted, where persons with lived experiences are given platforms to exchange ideas with members of the public on mental illnesses to reinforce societal understanding of mental health problems. This approach is evidence-based and tends to reduce the rising social stigma in public spaces which could have a ripple effect on other forms of stigma (Adu & Oudshoorn, 2022; Stuart et al. 2014a, 2014b; The National Academies Press, 2016). Participants noted that addressing broader social stigma of mental illnesses should translate positively into family interactions as well.

A focus on recommendations for improving understanding was related to the ideas of diagnosis, familial education, and disclosure. Participants' reports on strategic disclosure or selective versus full disclosure are consistent with previous studies, which revealed that strategic disclosure allows individuals to find safest ways to tell their story (Adu et al., 2021, 2022; Rüsch et al., 2017; Üçok et al., 2011). If individuals have the luxury to educate their family members before a full disclosure is made, it can create a safer context (Brouwers et al., 2020; Corrigan, 2022; Evans-Lacko et al., 2012; Reavley & Jorm, 2015), including the prevention of familial mental illness stigma. Family members' understanding of their loved one's mental health challenges through familial education by the affected individuals could potentially lead to both practical and emotional support within their immediate environment.

5.5 Policy implications

While the aforesaid approaches look to reducing stigma at the individual level, participants highlighted that transformation of healthcare systems would create a better context for stigma to be mitigated. Unfortunately, the social stigma of mental illnesses continues to be present in the fabric of society, including across high-income countries. Reducing social stigma is an ambitious but necessary endeavor to support families and their relatives with mental illnesses.

Further, participants in this study identified the need for health systems reforms where equal attention will be given to curative and preventative services. Participants felt reforms in the mental health systems could be fundamental to reducing the wait time for initial assessments to avoid undue complications before a diagnosis is determined. Early detection and treatment have been found to result in a good prognosis. Good policies with adequate funding for programs to support persons with mental illnesses in the management of their symptoms will be vital in bridging the existing ‘we and them’ gap within the social realm.

5.6 Limitations

Our findings represent the perspectives of family members (particularly women) of persons with mental illnesses in a single mid-sized city in Ontario, Canada. Data were collected through the Zoom platform due to the Covid-19 restrictions which made it difficult to do any direct recruitment of participants to increase diversity of experiences. Therefore, there are potential limits to the transferability of these findings to other social contexts. Also, since the researchers sought to recruit only persons who could speak and understand English, there are limitations related to diverse cultural experiences of stigma, a culturally mediated phenomenon.

5.7 Conclusion

Our findings confirm the existence of familial mental illness stigma from the viewpoints of family members of persons with mental illnesses in a high-income country and add to the growing body of literature on mental illness stigma. While the presence of familial mental illness stigma is acknowledged in current literature, the particularities of how this is lived and navigated have received little study. Family members largely situated familial mental illness stigma within broader stressors of limited services as well as broader social stigma. Confronting stigma both directly and at these root causes should improve the well-being of those living with mental illnesses, including openness of access to services. Participants suggested the need for more social contact-based education and positive media messaging to correct ongoing misconceptions around mental illnesses. The study participants also recommended reforms in health service access and community services to better equip individuals with lived experiences of mental illnesses to meet their needs and ultimately optimize empowerment and independence. Therefore, transformation of familial mental illness stigma sits within other calls for enhancing mental health and social services across Canada.

Acknowledgments

We are grateful to all the participants in this study who shared their lived experiences to make this research possible. We hope that their suggestions will influence research, policy, and practice in services intended to support persons with mental illnesses and their families.

References

Adu, J., Oudshoorn, A., Anderson, K., Marshall, C. A., & Stuart, H. (2022). Experiences of familial stigma among individuals living with mental illnesses: A meta-synthesis of qualitative literature from high-income countries. *Journal of Psychiatric and Mental Health Nursing*. 1–26. https://doi.org/10.1111/jpm.12869

Adu, J., & Oudshoorn, A. (2022). Social contact: A human approach to mental illness stigma. Retrieved from https://bppblog.com/2022/07/21/socialcontact-a-human-approach- to-mental-illness-stigma/

Adu, J., Oudshoorn, A., Anderson, K.A., Marshall, C.A., Stuart, H., & Stanley, M. (2021). Policies and Interventions to Reduce Familial Mental Illness Stigma: A Scoping Review of Empirical Literature. *Issues in Mental Health Nursing Journal*, *42*(12):1123-1137. https://doi.org/10.1080/01612840.2021.1936710.

Aldersey, H. M., & Whitley, R. (2015). Family influence in recovery from severe mental illness. *Community Mental Health Journal*, *51*(4), 467-476. DOI: 10.1007/s10597-014-9783-y

Barnable, A., Gaudine, A., Bennett, L., & Meadus, R. (2006). Having a sibling with schizophrenia: A phenomenological study. *Research and Theory for Nursing Practice*, *20*(3), 247. DOI: 10.1891/rtnp.20.3.247

Brackertz, N., Wilkinson, A., & Davison, J. (2018). Housing, homelessness, and mental health: towards systems change. *AHURI Research Paper, Australian Housing and Urban Research Institute Limited, Melbourne*.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi. org/10.1191/1478088706qp063oa

Brouwers, E. P. M., Joosen, M. C. W., van Zelst, C., & Van Weeghel, J. (2020). To disclose or not to disclose: A multi-stakeholder focus group study on mental health issues in the work environment. *Journal of Occupational Rehabilitation*, *30*(1), 84–92. https://doi.org/10.1007/s10926-019-09848-z

Canadian Mental Health Association. (2007). Poverty and mental illness. Retrieved from https://ontario.cmha.ca/documents/poverty-and-mental-illness/

Canadian Mental Health Association. (2018). Mental health in the balance: Ending the health care disparity in Canada. *Canadian Mental Health Association*. Retrieved from https://cmha.ca/wp-content/uploads/2018/09/CMHA-Parity-Paper-Full-Report-EN.pdf.

Centre for Addiction and Mental Health. (2019). Mental illness and addiction: Facts and statistics. Retrieved from https://www.camh.ca/en/driving-change/the-crisis-is-real/mental-health-statistics.

Chen, F. P., Lai, G. Y. C., & Yang, L. (2013). Mental illness disclosure in Chinese immigrant communities. *Journal of Counseling Psychology*, *60*(3), 379–391. https://doi.org/10.1037/a0032620

Clarke, D., & Winsor, J. (2010). Perceptions and needs of parents during a young adult's first psychiatric hospitalization: “we’re all on this little island and we're going to drown real soon”. *Issues in Mental Health Nursing*, *31*(4), 242-247. DOI: 10.3109/01612840903383992

Compton, M. T., & Shim, R. S. (2015). The social determinants of mental health. *Focus*, *13*(4), 419-425. https://doi.org/10.1176/appi.focus.20150017

Corrigan, P. W. (2022). Coming out proud to erase the stigma of mental illness. *World Psychiatry*, *21*(3), 388. https://doi.org/10.1002/wps.21016

Corrigan, P. W., Mittal, D., Reaves, C. M., Haynes, T. F., Han, X., Morris, S., & Sullivan, G. (2014). Mental health stigma and primary healthcare decisions. *Psychiatry Research*, *218*(1-2), 35-38. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4363991/

Corrigan, P. W., Morris, S., Larson, J., Rafacz, J., Wassel, A., Michaels, P., Wilkniss, S., Batia, K., & Rüsch, N. (2010). Self-stigma and coming out about one's mental illness. *Journal of Community Psychology*, *38*(3), 259–275. https://doi.org/10.1002/jcop.20363

Corrigan, P.W. & Watson, A.C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, Vol.1, 16-20.

Evans-Lacko, S., Brohan, E., Mojtabai, R., & Thornicroft, G. (2012). Association between public views of mental illness and self-stigma among individuals with mental illness in 14 European countries. *Psychological Medicine,* 42(8), 1741-1752. [1]. 10.1017/S0033291711002558

Evans-Lacko, S., London, J., Japhet, S., Rüsch, N., Flach, C., Corker, E., Henderson, C., & Thornicroft, G. (2012). Mass social contact interventions and their effect on mental health related stigma and intended discrimination. *BMC Public Health*, *12*(1), 489. https://doi.org/10.1186/1471-2458-12-489

Family Mental Health Alliance. (2006). Caring together: Families as partners in the mental health and addiction system. Canadian Mental Health Association, Ontario.

Frieh, E. C. (2020). Stigma, trauma and sexuality: The experiences of women hospitalised with serious mental illness. *Sociology of Health & Illness*, *42*(3), 526–543. https://doi.org/10.1111/1467-9566.13034

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon & Schuster.

Hamilton Wilson, J., & Conroy, S. (2012). *First Episode Psychosis: The Experience of Parent Caregivers* [ProQuest Dissertations Publishing]. http://search.proquest.com/docview/1152020928/

Henderson, C., Evans-Lacko, S., & Thornicroft, G. (2013). Mental illness stigma, help seeking, and public health programs. *American Journal of Public Health*, *103*(5), 777–780. https://doi.org/10.2105/AJPH.2012.301056

Huggett, C., Birtel, M. D., Awenat, Y. F., Fleming, P., Wilkes, S., Williams, S., & Haddock, G. (2018). A qualitative study: experiences of stigma by people with mental health problems. *Psychology and Psychotherapy: Theory, Research and Practice*, *91*(3), 380-397. DOI: 10.1111/papt.12167

Knaak, S., Mantler, E., & Szeto, A. (2017, March). Mental illness-related stigma in healthcare: Barriers to access and care and evidence-based solutions. In *Healthcare management forum* (Vol. 30, No. 2, pp. 111-116). Sage CA: Los Angeles, CA: SAGE Publications.

Knaak, S., Szeto, A. C.h, Fitch, K., Modgill, G., & Patten, S. (2015). Stigma towards borderline personality disorder: effectiveness and generalizability of an anti-stigma program for healthcare providers using a pre-post randomized design. *Borderline Personality Disorder and Emotion Dysregulation*, *2*, 9. https://doi.org/10.1186/s40479-015-0030-0

Koschorke, M., Padmavati, R., Kumar, S., Cohen, A., Weiss, H. A., Chatterjee, S., Pereira, J., Naik, S., John, S., Dabholkar, H., & Balaji, M. (2017). Experiences of stigma and discrimination faced by family caregivers of people with schizophrenia in India. *Social Science & Medicine*, *178*, 66-77. http://dx.doi.org/10.1016/j.socscimed.2017.01.061

Kulik, C. T., Bainbridge, H. T., & Cregan, C. (2008). Known by the company we keep: Stigma-by-association effects in the workplace. *Academy of Management Review*, *33*(1), 216-230. https://doi.org/10.5465/amr.2008.27752765

Larson, J. E., & Corrigan, P. (2008). The stigma of families with mental illness. *Academic Psychiatry*, *32*(2), 87-91. http://dx.doi.org/10.1176/appi.ap.32.2.87

Link, B. & Phelan, J. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27:363-385. DOI: https://doi.org/10.1146/annurev.soc.27.1.363

Liu, N. H., Daumit, G. L., Dua, T., Aquila, R., Charlson, F., Cuijpers, P., Druss, B., Dudek, K., Freeman, M., Fujii, C., Gaebel, W., Hegerl, U., Levav, I., Munk Laursen, T., Ma, H., Maj, M., Elena Medina-Mora, M., Nordentoft, M., Prabhakaran, D., Pratt, K., … Saxena, S. (2017). Excess mortality in persons with severe mental disorders: a multilevel intervention framework and priorities for clinical practice, policy and research agendas. *World Psychiatry: Official Journal of the World Psychiatric Association (WPA)*, *16*(1), 30–40. https://doi.org/10.1002/wps.20384

Livingston, J. D. (2013). Mental illness-related structural stigma: The downward spiral of systemic exclusion. Calgary, Alberta: Mental Health Commission of Canada. Retrieved from www.mentalhealthcommission.ca.

Lopez, K. A., & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge. *Qualitative Health Research*, *14*(5), 726-735.

Lucas, J. W., & Phelan, J. C. (2012). Stigma and Status: The Interrelation of Two Theoretical Perspectives. *Social psychology quarterly*, *75*(4), 310–333. https://doi.org/10.1177/0190272512459968

Malla, A., Joober, R., & Garcia, A. (2015). "Mental illness is like any other medical illness": a critical examination of the statement and its impact on patient care and society. *Journal of psychiatry & neuroscience: JPN*, *40*(3), 147. https://doi.org/10.1503/jpn.150099

Mascayano, F., Armijo, J. E., & Yang, L. H. (2015). Addressing stigma relating to mental illness in low-and middle-income countries. *Frontiers in Psychiatry*, *6*, 38.

Mental Health Commission of Canada. (2012). Changing Directions, Changing Lives: The Mental Health Strategy for Canada. Calgary: Alberta. Retrieved from http://strategy.mentalhealthcommission.ca/download/

Mfoafo-M'Carthy, M., & Sossou, M. A. (2017). Stigma, discrimination, and social exclusion of the mentally ill: The case of Ghana. *Journal of Human Rights and Social Work*, *2*(4), 128-133.

Moustakas, C. (1994). Phenomenological research methods. Thousand Oaks, CA: Sage.

National Academies of Sciences, Engineering, and Medicine. (2016). Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change. Washington, DC: The National Academies Press. https://doi.org/10.17226/23442.

National Institute of Mental Health. (2019). Mental Health Information. Retrieved from https://www.nih.gov/about-nih/what-we-do/nih-almanac/national-institute-mental-health-nimh.

Ngui, E. M., Khasakhala, L., Ndetei, D., & Roberts, L. W. (2010). Mental disorders, health inequalities and ethics: A global perspective. *International Review of Psychiatry (Abingdon, England)*, *22*(3), 235–244. https://doi.org/10.3109/09540261.2010.485273

Nyblade, L., Stockton, M. A., Giger, K., Bond, V., Ekstrand, M. L., Mc Lean, R., ... & Turan, J. (2019). Stigma in health facilities: why it matters and how we can change it. *BMC Medicine*, *17*(1), 25. DOI: https://doi.org/10.1186/s12916-019-1256-2

O'Brien, A., Ashby, G. A., White, S., & Crame, J. (2015). What do general psychiatrists do? A question posed to medical students and the general population. *Journal of Mental Health*, *24*(3), 126-128. DOI: 10.3109/09638237.2014.971149

O'Reilly, C. L., Paul, D., McCahon, R., Shankar, S., Rosen, A., & Ramzy, T. (2019). Stigma and discrimination in individuals with severe and persistent mental illness in an assertive community treatment team: Perceptions of families and healthcare professionals. *International Journal of Social Psychiatry*, *65*(7-8), 570-579. DOI: 10.1177/0020764019867358

Östman, M., & Kjellin, L. (2002). Stigma by association: psychological factors in relatives of people with mental illness. *The British Journal of Psychiatry*, *181*(6), 494-498.

Otten, D., Tibubos, A. N., Schomerus, G., Brähler, E., Binder, H., Kruse, J., ... & Beutel, M. E. (2021). Similarities and differences of mental health in women and men: A systematic review of findings in three large German cohorts. *Frontiers in Public Health*, *9*, 553071. https://doi.org/10.3389/fpubh.2021.553071

Park, S., & Park, K. S. (2014). Family stigma: A concept analysis. *Asian Nursing Research*, *8*(3),165-171. https://doi.org/10.1016/j.anr.2014.02.006

Paul, S., & Nadkarni, V. V. (2017). A qualitative study on family acceptance, stigma and discrimination of persons with schizophrenia in an Indian metropolis. *International Social Work*, *60*(1), 84-99. https://doi.org/10.1177%2F0020872814547436

Pearson, C. (2015). *The impact of mental health problems on family members*. Statistics Canada. Retrieved from https://www150.statcan.gc.ca/n1/pub/82-624-x/2015001/article/14214-eng.pdf

Pearson, C., Janz, T., & Ali, J. (2013). Mental and substance use disorders in Canada. Health at a glance. Statistics Canada Catalogue no. 82-624-X. http://www.statcan.gc.ca/pub/82-624-x/2013001/article/11855- eng.htm

Pirkis, J., Burgess, P., Hardy, J., Harris, M., Slade, T., & Johnston, A. (2010). Who cares? A profile of people who care for relatives with a mental disorder. *Australian & New Zealand Journal of Psychiatry*, *44*(10), 929-937.

Pringle, J., Drummond, J., McLafferty, E., & Hendry, C. (2011). Interpretative phenomenological analysis: A discussion and critique. *Nurse Researcher*. *18*(3), 20-24.

Public Health Agency of Canada. (2006). The human face of mental health and mental illness in Canada 2006. Retrieved from https://www.phac-aspc.gc.ca/publicat/human-humain06/pdf/human_face_e.pdf.

Public Health Agency of Canada. (2019). Data blog: Mental illness in Canada. Retrieved from https://health-infobase.canada.ca/datalab/mental-illness-blog.html

Reavley, N. J., & Jorm, A. F. (2015). Experiences of discrimination and positive treatment in people with mental health problems: Findings from an Australian national survey. *Australian & New Zealand Journal of Psychiatry, 49(10), 906–913. https://doi.org/10.1177/0004867415602068*

Rössler, W. (2016). The stigma of mental disorders: A millennia-long history of social exclusion and prejudices. *EMBO reports*, *17*(9), 1250–1253. https://doi.org/10.15252/embr.201643041

Rüsch, N., Rose, C., Holzhausen, F., Mulfinger, N., Krumm, S., Corrigan, P. W., Willmund, G. D., & Zimmermann, P. (2017). Attitudes towards disclosing a mental illness among German soldiers and their comrades. *Psychiatry Research*, *258*, 200–206. https://doi.org/10.1016/j.psychres.2017.08.028

Schoppmann, S., Schröck, R., Schnepp, W., & Büscher, A. (2007). ‘Then I just showed her my arms...’Bodily sensations in moments of alienation related to self-injurious behaviour. A hermeneutic phenomenological study. *Journal of Psychiatric and Mental Health Nursing, 14*(6), 587-597.

Smith, J. A. (2019). Participants and researchers searching for meaning: Conceptual developments for interpretative phenomenological analysis. *Qualitative Research Psychology, 16*(2): 166–181.

Smith, J.A., Flower, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.

Stuart, H., Chen, S. P., Christie, R., Dobson, K., Kirsh, B., Knaak, S., Koller, M., Krupa, T., Lauria-Horner, B., Luong, D., Modgill, G., Patten, S. B., Pietrus, M., Szeto, A., & Whitley, R. (2014a). Opening minds in Canada: targeting change. *The Canadian Journal of Psychiatry*, *59*(1_suppl), 13-18.

Stuart, H., Chen, S. P., Christie, R., Dobson, K., Kirsh, B., Knaak, S., Koller, M., Krupa, T., Lauria-Horner, B., Luong, D., Modgill, G., Patten, S. B., Pietrus, M., Szeto, A., & Whitley, R. (2014b). Opening minds in Canada: background and rationale. *The Canadian Journal of Psychiatry*, *59*(1_suppl), 8-12.

Suto, M., Lapsley, S. E., Livingston, J., Hole, R., Hinshaw, S., Michalak, E., & Hale, S. (2012). Stigma shrinks my bubble: A qualitative study of understandings and experiences of stigma and bipolar disorder. *Stigma Research and Action*, *2*(2), 85–92.

Üçok, A., Serbest, S., & Kandemir, P. E. (2011). Remission after first-episode schizophrenia: Results of a long-term follow-up. *Psychiatry Research*, *189*(1), 33–37. https://doi.org/10.1016/j.psychres.2010.11.013

Umberson, D., & Karas Montez, J., (2010). Social relationships and health: A flashpoint for health policy. *Journal of Health and Social Behavior*, *51*(1_suppl), S54–S66. https://doi.org/10.1177/0022146510383501

van der Sanden, R. L. M., Bos, A. E. R., Stutterheim, S. E., Pryor, J. B., & Kok, G. (2013). Experiences of stigma by association among family members of people with mental illness. *Rehabilitation Psychology*, *58*(1), 73–80. https://doi.org/10.1037/a0031752

van Der Sanden, R. L., Bos, A. E., Stutterheim, S. E., Pryor, J. B., & Kok, G. (2015). Stigma by association among family members of people with a mental illness: A qualitative analysis. *Journal of Community & Applied Social Psychology*, *25*(5), 400–417. https://doi.org/10.1002/casp.2221

van der Sanden, R. L., Pryor, J. B., Stutterheim, S. E., Kok, G., & Bos, A. E. (2016). Stigma by association and family burden among family members of people with mental illness: the mediating role of coping. *Social Psychiatry and Psychiatric Epidemiology*, *51*(9), 1233-1245. https://doi.org/10.1007/s00127-016-1256-x

van Manen, M. (1990) Researching lived experience: Human science for an action sensitive pedagogy. State University of New York Press, Albany

Walker, E. R., McGee, R. E., & Druss, B. G. (2015). Mortality in mental disorders and global disease burden implications: a systematic review and meta-analysis. *JAMA Psychiatry*, *72*(4), 334–341. https://doi.org/10.1001/jamapsychiatry.2014.2502

World Health Organisation (2010). Mental health and development: Targeting people with mental health conditions as a vulnerable group. WHO Press, Geneva. Retrieved from http://www.who.int/mental_health/policy/development/en/index.html

World Health Organization. (2012). Risks to mental health: An overview of vulnerabilities and risk factors. *Geneva: WHO*. Retrieved from https://www.who.int/publications/m/item/risks-to-mental-health

World Health Organization. (2019). The WHO Special Initiative for Mental Health (2019-2023): universal Health Coverage for Mental Health. Available from: https://apps.who.int/iris/handle/10665/310981.

World Health Organization. (2020). A guide to preventing and addressing the social stigma associated with COVID-19. Retrieved from https://www.who.int/publications/m/item/a-guide-to-preventing-and-addressing-social-stigma-associated-with-covid-19

Chapter 6: Summary, Conclusions, and Recommendations

This chapter summarizes the findings, conclusions, and limitations of the study. It also provides recommendations for policy, practice, education, and further research.

6.1 Thesis Overview

This study explored the experiences of familial mental illness stigma among individuals living with mental illnesses and their close relatives. Familial mental illness stigma is simply family members or close relatives perpetrating stigma against their loved ones with mental illnesses or mental health problems. This thesis is comprised of three analyses, each represented by a chapter herein that covered a portion of the overall objectives of the study. Familial mental illness stigma is rooted in societal stigma, hence this scholarly work has the potential to contribute to the development of strategies that broadly counter stigma, while also particularly addressing mental illness-related stigma within the family system.

Study 1 explored the scope of qualitative peer-reviewed literature that has contributed to the understanding of familial mental illness stigma in high-income countries for the past two decades. The outcome of the meta-synthesis showed that some family members or close relatives of persons with mental illnesses who have stigmatizing beliefs perpetrate stigma against their loved ones to ‘save face’. Again, the analysis pointed to familial mental illness stigma as harmful due to the likely alienation it brings within the home environment of affected persons. Study 2 looked at the experiences of familial mental illness stigma among individuals living with mental illnesses, and study 3 included perspectives of their family members.

6.2 Summary of Findings

Study 1. The goal of this study was to explore the existing literature on familial mental illness stigma among individuals with mental illnesses in high-income countries, with a focus on peer-reviewed papers, to understand the breadth of current literature. While the stigma connected to mental illnesses is considered universal, high-income countries were selected for this meta-synthesis as a springboard to familial mental illness stigma research in Canada. The focus of this meta-synthesis was peer-reviewed qualitative literature to understand the human experiences of familial mental illness stigma. The analysis produced seven themes that spoke of various forms of familial mental illness stigma and ways to reduce them. For instance, nondisclosure of mental illness was revealed to be risky due to possible hostility or isolation within the immediate environment of the affected person. Safe disclosure of mental health problems and social contact within the family system were found to be fundamental to ensuring emotional support for persons with mental health issues. Findings echo those of Adu et al. (2022) that familial mental illness stigma is one of the most hidden and particularly taboo forms of stigma enacted within some families.

The scarcity of empirical studies focused on familial mental illness stigma within the last two decades underscored the necessity for more primary research to inform policy and practice to create enabling environments for persons with mental health challenges and their families. Familial education was identified as a vital step for close relatives to appreciate the complexities of mental illness-related stigma and the need for them to support their loved ones with a diagnosis to prevent isolation and loneliness within families. As has been noted by the APA (2020) and Adu et al. (2022), the willingness of families to reduce stigma toward their relatives with mental illnesses is crucial for reducing the social exclusion accompanying mental illness.

Study 2. The goal of this study was to understand the experiences of familial mental illness stigma among individuals living with mental illnesses. Some persons living with mental illness may experience stigma from both their close relatives and extended family members, which could be influenced by public and associative mental illness stigma. The design for this study was interpretive phenomenology. The data analysis produced five themes elucidating participants' experiences of familial mental illness stigma and ways to confront them. The stories of participants demonstrated the existence of familial mental illness stigma in some families. Although enacted within the family unit, familial mental illness stigma is entrenched in broader societal stigma, which may influence the stigmatizing beliefs of some family members. The findings of this primary study also corroborated those of the meta-synthesis (Study 1), including unfair treatment, risk of divorce, loss of social status, emotional abuse, loneliness, and isolation— with social and health implications for both family members and affected individuals. It is worth noting that regardless of the mistreatment and exclusion reported by some participants with mental illnesses, many family members fully support their loved ones toward recovery, devoid of any noted incidents of stigmatization. Pirkis and colleagues (2010) as well as the Public Health Agency of Canada (2006) have similarly noted the key role that families can play in mental health support. Some participants also described disclosure and concealment of a mental illness or diagnosis as strategies they employed to confront familial mental illness stigma. The exclusion of persons with mental illnesses from decision-making and information sharing within families was identified as a challenge by some participants. This led to self-stigma and its related problems, including concealment.

Study 3. The purpose of this study was to explore how family members or close relatives of individuals with a diagnosis of mental illness address potential familial mental illness stigma. A critical look at the extant literature showed a paucity of primary research that examined family members as potential perpetrators of stigma against their loved ones with mental illnesses. While this study complements the findings of Study 2 in the same research setting, data were collected from family members. The purpose was to understand family members' perspectives and potential differences in the narratives put forward by their relatives living with mental illnesses. This adds layers of understanding for a complex social process. Family members' viewpoints on familial mental illness stigma and ways to reduce stigma yielded five themes. For example, it was noted that the misgivings or difficulties associated with mental health problems and the compounded public stigma may create a context for familial mental illness stigma to occur. Social stigma was influential in the ongoing family dynamics of people living with mental illness within the family system. Familial mental illness stigma can be worrisome due to the tendency to produce alienation within the affected person's home environment, hence, family members recommended social contact-based education (see for example Adu et al. 2022a, b; Adu & Oudshoorn, 2022) and positive media messages to reverse the increasing myths connected to mental health concerns (Robinson et al., 2017).

Family members of this study suggested promising approaches, including transformative education to openly confront all forms of mental illness stigma within public consciousness. These approaches are contingent on the provision of good social systems and health systems reforms. Some family members saw transformative education as a positive persuasive communication tool that could change societal attitude toward mental illness-related symptoms and correct some of the lingering misconceptions about mental health problems. Normalizing mental illness-related symptoms in the public realm was seen as vital to the creation of enabling environments at the societal level to foster belonging.

6.3 Strengths and Limitations

All three studies contribute in a complimentary manner to the overall story of the experiences of family mental illness stigma that evolved through this project. The experiences of mental illness stigma are understood through the existing literature, those who encounter the stigma, and those who are the potential enactors of stigmatizing views. While this approach lends an in-depth description of the experience of familial mental illness stigma, there are still some limitations to the approach taken. Data collection and analyses were limited to the perspectives of those living in a single city in a high-income country. Because stigma is social and cultural, there is no guarantee that Canadian experiences of mental illness stigma is translatable across other cultural contexts. Additionally, the qualitative design of the research does not allow for any conclusions regarding the scale at which familial mental illness stigma is occurring, and the presence or absence within our sample size cannot be extrapolated quantitatively. The location of data collection may also have influenced results, as recruitment was primarily of those living within a mid-sized urban environment with acute, tertiary, and community mental health services. Overall perspectives on mental illness may differ, for example, in more rural environments or environments where mental health services are not readily available.

Data collection was limited by the COVID-19 restrictions in place within the research setting. Public health protocols to control the spread of COVID-19 infections at the time did not permit in-person data collection. This impeded the ability to intentionally recruit to enhance diversity across social locations, for example, recruitment to ensure gender diversity, as reliance was on social media recruitment rather than recruitment within on-site mental health services. Data for this study primarily involved the views of women, with only three men and one gender-diverse person. All participants were White Caucasians with exception of one person who identifies a racialized person from the Middle East. Therefore, findings will miss out on important cultural nuances of different families and different perceptions of mental illness as stigma experiences may differ across different ethnic and cultural groups within Canada. The COVID-19 protocols in health institutions within the research settings also caused delays in obtaining ethics approval for the recruitment of health professionals as a potential third group of participants. Health professionals may have interesting perspectives to add regarding how they see familial mental illness stigma enacted in the families they support. Unfortunately, the perspective of health professionals was excluded as recruitment was not deemed feasible during the intensity of the pandemic. Lastly, in terms of diversity of the sample, this study focused on an adult population. We suspect that experiences of children and youth with familial mental illness stigma would differ from the experiences described by our participants.

6.4 Implications for Policy

Implications from the stories of participants as they relate to policies are two-pronged: one focusing more upstream on overall services, and one focusing more directly on mental illness stigma reduction. In terms of looking upstream, an underlying consideration throughout the stories of participants was the challenge to access sufficient and timely support for treatment and management of mental illnesses. Participants noted that stigma is often tied to behaviours connected to illness, and that if resources were sufficient to manage illness, these challenging familial interactions would be reduced. Therefore, this work emphasizes the need for health systems reforms to ensure adequate attention to both curative and preventative mental health services that has been called for by many others (Adu et al., 2022c; Corring et al., 2016; Kirby & Keon, 2004; Wiktowicz, 2005). Timely assessment and treatment are required for quality mental health care, and participants noted barriers to access. Broader support services based in communities that can walk people through challenges, such as working with their family around management of their illness, is an example of a systems approach that would create a better context to protect individuals. Beyond primary and acute care services, access to affordable psychotherapy and counseling can support medical treatment approaches (Mental Health Commission of Canada, 2017).

Secondly, in considering policy approaches to address mental illness stigma at a societal level, participants noted that familial stigma is often a broader social stigma being enacted locally. Non-discrimination policies are an appropriate starting point to consider how to reduce mental illness stigma, yet stigma continues to be seen in sensationalized presentations of serious mental illness (Rüsch, 2022; Thornicroft et al., 2022). Those living with mental illnesses and service providers can be advocates to enhancing non-discrimination policies that include familial mental illness stigma.

6.5 Implications for practice

Health care professionals' ability to advise family members on their potentially stigmatizing beliefs during service delivery is critical to reducing the ongoing familial mental illness stigma and other forms of stigma (Shamsaei et al., 2018; Sunderland & Mishkin, 2013). That is, a typical clinical practice can focus on family-centered care (Skundberg-Kletthagen et al., 2020; Ward et al., 2017), where persons with mental illnesses, family members, and service providers play key roles in promoting health and well-being of the affected individual. Through this approach, service providers may be able to uncover any hidden distress within the family connected to their clients' illnesses. Having identified the needs of both affected persons and families, health providers can then advise them based on their strengths and weaknesses. Persons with mental illnesses and their families should also have opportunities to be involved in the planning and development of mental illness-related stigma education and training programs. Including the voices of lived expertise is the best approach for stigma reduction (Adu et al., 2022b; Pietrus, 2013; The National Academies Press, 2016; Thornicroft et al., 2022).

Overall, our findings highlight once again that family members are a key source of support for persons with mental illnesses, but this is nuanced as they can also discriminate against their loved ones. Ideally, health professionals and other service providers should assess and understand how patients want family members to be involved in their care, what family member knowledge and understanding of mental illnesses are, and where they can facilitate access to the right resources for learning. In this case, health professionals might educate families on mental illnesses, particularly their loved one’s diagnosis, to mitigate ongoing anxieties regarding their prognosis. Family members understanding of their relatives’ conditions and ways to manage them helped in reducing familial mental illness stigma in some families, as has been found in other studies (Adu et al., 2022b; Ong et al., 2021).

Another aspect of mental health practice is public education to reduce stigma. As educators, health professionals can play a role in supporting high quality public messaging about mental illnesses more generally, as well as targeted stigma reduction. These messages contribute to the ongoing normalization of mental illnesses (Bayar et al., 2009; Pietrus, 2013; Stuart, 2016) via the provision of evidence-based knowledge about mental health. This could include more localized approaches such as a community-based stigma reduction programs whereby persons with mental illnesses are given a platform alongside their families to share experiences and connected at a personal level with those who may not have had these experiences. This social contact-based approach is congruent with evolving evidence regarding stigma reduction (Adu et al., 2022a; Adu & Oudshoorn, 2022; Griffiths et al., 2014; The National Academies Press, 2016). Health professionals can play a role in facilitating these approaches.

6.6 Implications for Education

Findings from this study have practical implications for the education of health care professionals and how this informs their interactions with persons living with mental health concerns and their family members. While most health professional students will presumably be familiar with mental illness stigma more broadly, stigma occurring within families might be an overlooked consideration. Through this research we have shown how familial mental illness stigma can increase what is already a high risk of social isolation. Students should be educated on all forms of stigma, including stigma by association, self-stigma, and familial stigma. While family-centred care is already a primary focus on many health professional education programs, educators should be sure to note that not all families are a positive source of support, or within families there are often varying perceptions and degrees of support.

6.7 Directions for Future Research

A major finding from this thesis is that familial mental illness stigma as ingrained in the broader societal stigma. The fight against familial mental illness stigma depends partly on active reduction in broader social mental illness stigma. Further research is needed to critically explore the connections between familial, public, and associative stigma to ascertain a baseline to inform anti-stigma programs seeking to reduce familial mental illness stigma in high-income countries and beyond. Researchers in high-income countries should undertake longitudinal studies that include persons with mental illnesses, family members, and health professionals to investigate the relationships between stigma by association and familial mental illness stigma, unpacking potential intervention points both within and beyond the family system. Consistent with the extant literature is the role of social contact-based education as transformative education in reducing mental illness stigma at the family and societal levels— researchers in high-income countries should continue exploring this possibility to assess its effectiveness in various modalities.

In the future, I hope to expand on this research by combining the knowledge of mental health professionals, individuals with lived experiences of mental illnesses, and family members in more intervention-based work that transforms stigma and enhances recovery experiences. I will expand this study to continue abroad, specifically in Ghana where I have practiced as a nurse and a hospital administrator, to understand differential cultural factors that influence familial stigma, and potentially differential intervention approaches. The long-term goal of this research program is to create knowledge to drive policy and practice and ensure the positive inclusion of persons with mental illnesses in their families and beyond.

6.8 Conclusion

This qualitative study reported on the findings from 15 persons with mental illnesses and 15 family members or close relatives of persons with mental health problems, as well as a review of current literature, to understand lived experiences of familial mental illness stigma and how it could be confronted within families. The study captured diverse forms of familial mental illness stigma that are often the most hidden types of stigma. Some family members in this study blamed the increasing stigma within the family system on the limited social and community services available to support the well-being of their loved ones, alongside public stigma. Familial education by persons with mental health problems was considered imperative to family members understanding of the complex interplay of mental illness stigma and the need for both emotional and practical support toward their recovery. Family members' perceptions of familial mental illness stigma in this study will be useful in shaping existing policy interventions to create supportive environments necessary to sustain families and permit the inclusiveness of all persons. Apart from the diverse perspectives on familial mental illness stigma that family members brought to the study, their involvement helped create knowledge and understanding of the phenomenon to inspire future research-to-action and bridge existing gaps within services and education.

Familial mental illness stigma can negatively impact psychological well-being and personal empowerment of persons living with mental illness. Many participants in this study experienced relationship breakdowns and divorce, which they perceived as prolonging their recovery. The fear of public stigma was identified as one of the causes of families themselves isolating their loved ones. However, participants' accounts showed that not all persons with a mental illness reported being mistreated or stigmatized by their family members. Several participants suggested reforms in health service access and community social services to adequately support and empower persons in Canada. Policies, interventions, and programs toward solutions to curtail familial mental illness stigma are needed to ensure inclusiveness at the family and societal level.

References

Adu, J., Oudshoorn, A., Anderson, K., Marshall, C. A., & Stuart, H. (2022a). Social contact: Next steps in an effective strategy to mitigate the stigma of mental illness. *Issues in Mental Health Nursing*, *43*(5), 485-488. https://doi.org/10.1080/01612840.2021.1986757

Adu, J., Oudshoorn, A., Anderson, K., Marshall, C. A., & Stuart, H. (2022b). Experiences of Familial Stigma among Individuals Living with Mental Illnesses: A Meta-Synthesis of Qualitative Literature from High-Income Countries. *Journal of Psychiatric and Mental Health Nursing*. https://doi.org/10.1111/jpm.12869

Adu, J., & Oudshoorn, A. (2022). Social Contact: A human approach to mental illness stigma. retrieved from https://bppblog.com/2022/07/21/social-contact-a-human-approach-to-mental-illness-stigma/

Adu, J., Oudshoorn, A., Van Berkum, A., Pervez, R., Norman, R., Canas, E., Virdee, M., Yosieph, L., & MacDougall, A. G. (2022c). System transformation to enhance transitional age youth mental health–a scoping review. *Child and Adolescent Mental Health*, *27*(4), 399-418. https://doi.org/10.1111/camh.12592

America Psychological Association. (2020). Stigma, Prejudice and Discrimination Against People with Mental Illness. Retrieved from https://www.psychiatry.org/patients-families/stigma-and-discrimination

Bayar, M. R., Poyraz, B. C., Aksoy-Poyraz, C., & Arikan, M. K. (2009). Reducing mental illness stigma in mental health professionals using a web-based approach. *The Israel Journal of Psychiatry and Related Sciences*, *46*(3), 226–230.

Corring, D. J., Whittall, S., MustinPowell, J., Jarmain, S., Chapman, P., & Sussman, S. (2016). Mental health system transformation: drivers for change, organizational preparation, engaging partners and outcomes. *Healthcare Quarterly*, *18*(Suppl), 6-11.

Elkington, K. S., Hackler, D., McKinnon, K., Borges, C., Wright, E. R., & Wainberg, M. L. (2012). Perceived Mental Illness Stigma Among Youth in Psychiatric Outpatient Treatment. *Journal of Adolescent Research*, *27*(2), 290–317. https://doi.org/10.1177/0743558411409931

Griffiths, K. M., Carron-Arthur, B., Parsons, A., & Reid, R. (2014). Effectiveness of programs for reducing the stigma associated with mental disorders. A meta-analysis of randomized controlled trials. *World Psychiatry: Official Journal of the World Psychiatric Association (WPA)*, *13*(2), 161–175. https://doi.org/10.1002/wps.20129

Kirby, M. & Keon, W. (2004). Report 1, Mental health, mental illness, and addiction: Overview of policies and programs in Canada. Retrieved from https://sencanada.ca/content/sen/Committee/381/soci/rep/report1/repintnov04vol1-e.pdf

Mental Health Commission of Canada. (2017). Options for improving access to counselling, psychotherapy and psychological services for mental health problems and illnesses. Retrieved from https://www.mentalhealthcommission.ca/wp-content/uploads/drupal/201707/Options_for_improving_access_to_counselling_psychotherapy and psychological services_eng.pdf

Ong, H. S., Fernandez, P. A., & Lim, H. K. (2021). Family engagement as part of managing patients with mental illness in primary care. *Singapore Medical Journal*, *62*(5), 213–219. https://doi.org/10.11622/smedj.2021057

Pietrus, M. (2013). Opening minds interim report. *Calgary, AB: Mental Health Commission of Canada*. Retrieved from https://www.mentalhealthcommission.ca/wp-content/uploads/drupal/opening_minds_interim_report_0.pdf

Pirkis, J., Burgess, P., Hardy, J., Harris, M., Slade, T., & Johnston, A. (2010). Who cares? A profile of people who care for relatives with a mental disorder. *Australian & New Zealand Journal of Psychiatry*, *44*(10), 929-937.

Public Health Agency of Canada. (2006). The human face of mental health and mental illness in Canada 2006. Retrieved from https://www.phac-aspc.gc.ca/publicat/human-humain06/pdf/human_face_e.pdf

Robinson, J., Bailey, E., Hetrick, S., Paix, S., O'Donnell, M., Cox, G., Ftanou, M., & Skehan J. (2017). Developing Social Media-Based Suicide Prevention Messages in Partnership With Young People: Exploratory Study. JMIR Mental Health;4(4): e40. DOI: 10.2196/mental.7847

Rüsch, N. (2022). *The stigma of mental illness: strategies against social exclusion and discrimination*. Elsevier.

Shamsaei, F., Nazari, F., & Sadeghian, E. (2018). The effect of training interventions of stigma associated with mental illness on family caregivers: a quasi-experimental study. *Annals of General Psychiatry*, *17*(1), 1-5. https://doi.org/10.1186/s12991-018-0218-y

Skundberg-Kletthagen, H., Gonzalez, M. T., Schröder, A., & Moen, Ø. L. (2020). Mental health professionals' experiences with applying a family-centred care focus in their clinical work. *Issues in Mental Health Nursing*, *41*(9), 815-823. https://doi.org/10.1080/01612840.2020.1731028

Stuart, H. (2016). Reducing the stigma of mental illness. *Global Mental Health (Cambridge, England), 3*, e17. https://doi.org/10.1017/gmh.2016.11

Sunderland, K., & Mishkin, W. (2013). *Guidelines for the practice and training of peer support*. Calgary, AB: Mental Health Commission of Canada. Retrieved from http://www.mentalhealthcommission.ca

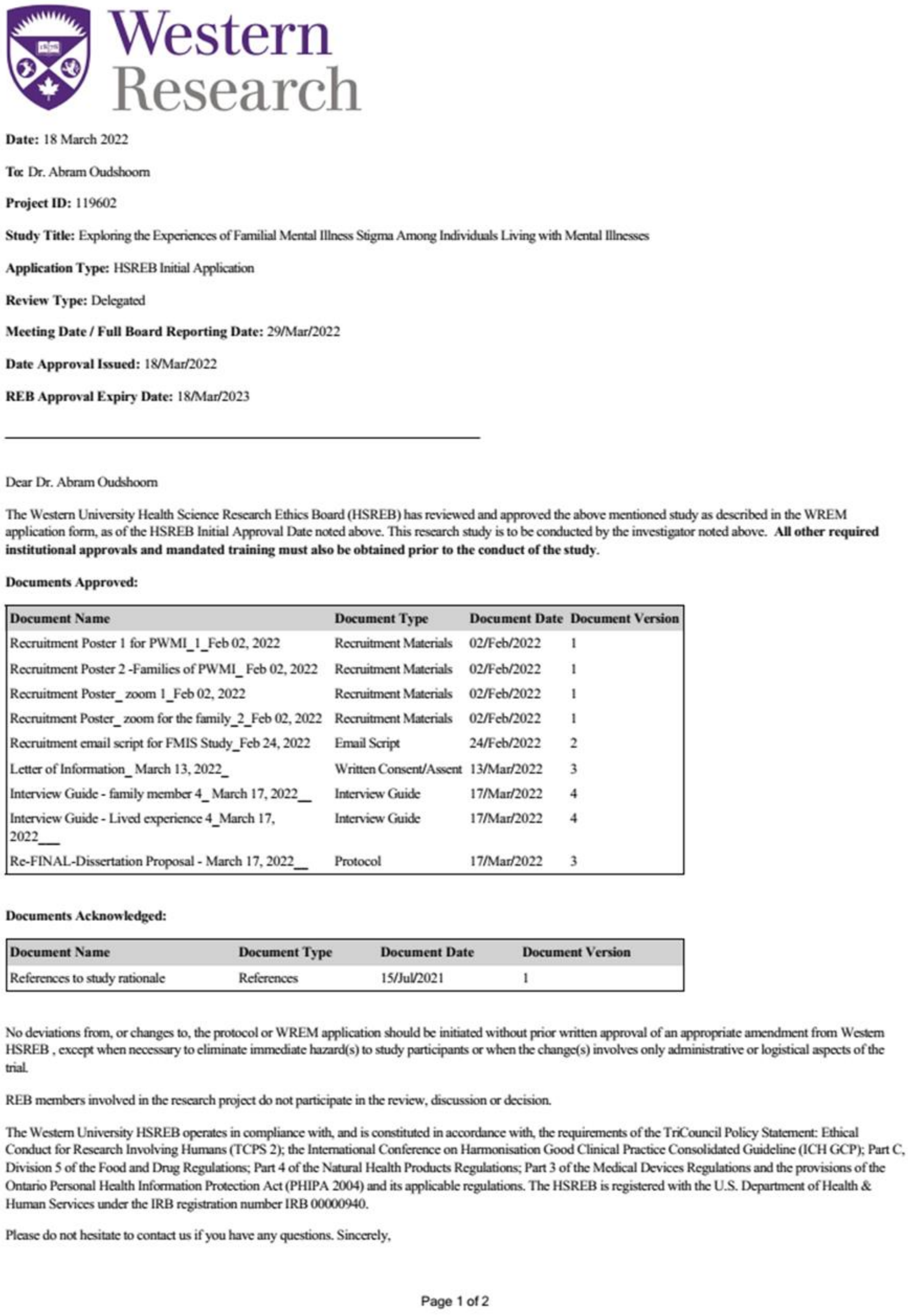
The National Academies Press (2016). Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change. Committee on the Science of Changing Behavioral Health Social Norms; Board on Behavioral, Cognitive, and Sensory Sciences; Division of Behavioral and Social Sciences and Education; National Academies of Sciences, Engineering, and Medicine.

Thornicroft, G., Sunkel, C., Aliev, A. A., Baker, S., Brohan, E., El Chammay, R., ... & Winkler, P. (2022). The Lancet Commission on ending stigma and discrimination in mental health. *The Lancet*, *400*(10361), 1438-1480.

Ward, B., Reupert, A., McCormick, F., Waller, S., & Kidd, S. (2017). Family-focused practice within a recovery framework: practitioners' qualitative perspectives. *BMC Health Services Research*, *17*(1), 234. https://doi.org/10.1186/s12913-017-2146-y

Wiktowicz, M. E. (2005). Restructuring mental health policy in Ontario: Deconstructing the evolving welfare state. *Canadian Public Administration*, *48*(3), 386-412.

Appendices



Western Research

Date: 18 March 2022

To: Dr. Abram Oudshoorn

Project ID: 119602

Study Title: Exploring the Experiences of Familial Mental Illness Stigma Among Individuals Living with Mental Illnesses

Application Type: HSREB Initial Application

Review Type: Delegated

Meeting Date / Full Board Reporting Date: 29/Mar/2022

Date Approval Issued: 18/Mar/2022

REB Approval Expiry Date: 18/Mar/2023

Dear Dr. Abram Oudshoorn

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. **All other required institutional approvals and mandated training must also be obtained prior to the conduct of the study.**

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Recruitment Poster 1 for PWMI_1_Feb 02, 2022	Recruitment Materials	02/Feb/2022	1
Recruitment Poster 2 -Families of PWMI_ Feb 02, 2022	Recruitment Materials	02/Feb/2022	1
Recruitment Poster_ zoom 1_Feb 02, 2022	Recruitment Materials	02/Feb/2022	1
Recruitment Poster_ zoom for the family_2_Feb 02, 2022	Recruitment Materials	02/Feb/2022	1
Recruitment email script for FMIS Study_Feb 24, 2022	Email Script	24/Feb/2022	2
Letter of Information_ March 13, 2022_	Written Consent/Assent	13/Mar/2022	3
Interview Guide - family member 4_ March 17, 2022__	Interview Guide	17/Mar/2022	4
Interview Guide - Lived experience 4_March 17, 2022___	Interview Guide	17/Mar/2022	4
Re-FINAL-Dissertation Proposal - March 17, 2022__	Protocol	17/Mar/2022	3

Documents Acknowledged:

Document Name	Document Type	Document Date	Document Version
References to study rationale	References	15/Jul/2021	1

No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB , except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions. Sincerely, Patricia Sargeant, Ethics Officer (psargean@uwo.ca) on behalf of Dr. Emma Duerden, HSREB Vice-Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix B: Letter of Information and Consent

Title of Study: Familial Mental Illness Stigma Study

Principal Investigator:
Prof. Abe Oudshoorn
Arthur Labatt Family School of Nursing
Western University
London, ON
N6A 5B9

Co-Investigator:
Joseph Adu
Health and Rehabilitation Sciences
Western University
London, ON
N6A 3K7

1. Invitation to Participate

You are invited to participate in a research project titled the ‘Familial Mental Illness Stigma Study’. The study is being conducted by investigators from Western University, Canada. This study will include those living with a mental illness and their family members or close relatives. The purpose of this letter is to provide you with information needed to make an informed choice about your potential participation in the study.

2. Purpose of this Study

The study aims to explore familial mental illness stigma as experienced by individuals living with a mental illness or mental illnesses.

3. Inclusion & Exclusion Criteria

Eligibility to participate in this study includes being:

1. An individual living with a mental illness or mental illnesses or a diagnosis of a mental illness
2. An individual aged 24 years and older
3. Family members/close relatives of an individual diagnosed of mental illness/ living with mental illnesses

4\. All participants should reside in London-Middlesex

4. Exclusion Criteria

1. All individuals who are 24 years and older who do not have symptoms of mental illnesses or a diagnosis of a mental illness within London-Middlesex
2. All individuals who are 24 years and older who have symptoms of mental illnesses or a diagnosis of a mental illness and live outside London-Middlesex
3. All individuals living with a mental illness or mental illnesses or a diagnosis of a mental illness, and are below 24 years of age within London-Middlesex
4. Family members/close relatives of individuals without a diagnosis of mental illness

5. Study Procedures and duration

If you agree to partake in the study, you will be asked open-ended questions about mental illness, mental illness stigma, and experiences of living with mental illness or caring for those living with a mental illness. The interview guide will be given to you during the interview so you know the questions to be asked. The in-depth interview will take approximately 45-60 minutes to complete and will be audio recorded per your consent for transcription after the interview.

You will also complete a short socio-demographic information such as age, gender, race and ethnicity, marital status, occupation, and level of education to allow us to further describe our research.

6. Possible Risks and Harms

There are no physical risks related to participation in the study. However, issues regarding mental illness stigma may arouse negative emotions. Therefore, there is the potential of some emotional and psychological discomforts occurring while sharing your experiences during the interview.

7. Possible Benefits

Sharing your unique lived experiences of familial mental illness stigma provides helpful subjective data to understand what we can do to further reduce stigma. Findings from this study could benefit society more generally through guiding practical policies to reduce familial stigma in our communities.

8. Voluntary Participation

Participation in this study is completely voluntary. It is your own choice to contribute to the study. Participants are at liberty to exit the interview or study at any time without any penalty or consequences. You may also choose to skip any questions that you find uncomfortable to answer.

9. Confidentiality

Through participation you will be providing researchers with personal information such as name, age, occupation, level of education, and email address as well as your signature on the informed consent. Your personal information will not be revealed to anyone outside the research team. All data pertaining to this research will be saved and backed up on an encrypted personal computer and encoded hard drive intended for the study. The data will be kept for seven (7) years in agreement with Western University's policy. Confidentiality and anonymity of all participants will be assured by the researcher and his team. This will be done by asking all who might assist with data management to sign a confidentiality agreement to protect the views of respondents, and no participant's name will be included in any presentations, policy briefs, and publications per the study for the sake of privacy. Participants names will, therefore, be replaced by pseudonyms and unique identification numbers used to conceal your identity. To ensure data security, all information gathered for this study will be kept in a secured, locked room at Western University. All files that pertain to data will be secured using passwords that are known to only the investigators. Hard copy records will be protected in cabinets within the locked room and shredded at the end of the period specified as directed by the university ethics board. With your consent, direct quotes may be used in reporting the study findings. Any information identifying yourself or others will be removed from these quotes.

10. Compensation

Although we do not intend to pay participants for contributing to our study, persons with mental illnesses and family members/close relatives will be given an incentive of $20 CAD as a stipend for their time if they consent to participate in the interview.

11. Rights as a participant

Participation in this study is voluntary. You may decide not to be in this study at any given time.

12. Contacts for Further Information:

If you have further questions regarding this research study please, contact the co-investigator, Joseph Adu at or the Principal Investigator, Prof. Abe Oudshoorn. Furthermore, if you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Research Ethics at (519) 661-3036, 1-844-720-9816, email: ethics@uwo.ca. This office oversees the ethical conduct of research studies and is not part of the study team. Everything that you discuss will be kept confidential.

13. Consent form

Q1. After reading the letter of information on the study, have you understood the scope of the study and agreed to participate?

[ ] YES [ ] NO

Q2. From the information letter, have all questions been answered to your satisfaction?

[ ] YES [ ] NO

Q3. Do you agree that your responses be audio-recorded in this study?

[ ] YES [ ] NO

Q4. Do you agree to the use of anonymous quotes obtained during the study in communicating our findings?

[ ] YES [ ] NO

I consent that I have understood the study and I am willing to participate in the research.

Participant signature: My signature indicates my informed consent to participate in the research study

Print name of participant	Signature	Date (DD-MM-YYYY)
Print name of person obtaining consent	Signature	Date (DD-MM-YYYY)

This letter is yours to keep for future reference.

Appendix C: Participants Recruitment Script

Research Participants Wanted

Participate in a study exploring familial mental illness stigma

Are you a person living with a mental illness(es)? Do you have a close family member living with a mental illness(es)? We would like to invite you to participate in a virtual research interview to discuss your experiences.

Participation Criteria:

1) A resident of London-Middlesex
2) Have a close family member who has a mental illness
3) Or self-identify as an individual living with a mental illness (es)
4) 24 years of age or older

What you will do:

1) One 45–60 minutes interview
2) Exploring mental illness stigma, particularly one perpetrated within the family
3) On Zoom (virtual platform) at a date/time of your choosing
4) All participation is voluntary
5) You will be compensated for your time

For more information or to participate contact:

This project is supervised by Dr. Abe Oudshoorn, School of Nursing, Western University

Joseph Adu, PhD Candidate

May 2022

Appendix D: Interview Guide for Persons with Mental Illnesses

Demographic

Participants unique identification numbers
Age
Gender
Race and ethnicity
Marital status
Occupation
Residing in owned home, rented accommodation, no fixed address – living alone or with others – if yes, whom
Diagnosis
Level of education

Interview questions

1. You've been invited to participate as a person who has experienced a mental illness. Can you tell me a bit about the history of your mental health?
    a. When did you first feel that maybe your mental health wasn't as good as it could be?
    b. When did you first seek help?
    c. Did others ever comment on your mental health?
2. [If diagnosis and hospitalization were separate events] When did you first receive a diagnosis?
    a. How did you feel at this time?
    b. What supports did you receive
3. Tell me about the process of being hospitalized?
    a. Were you in favour of going to hospital?
    b. Did you have supports from family while in hospital?
4. Thinking more about the experience of living with a mental illness, what has it been like for you?

   (a) Have you ever felt discriminated against because of your mental illness?
   (b) Have you ever experienced discrimination from a family member in particular? [If yes] Can you tell me more about how that has felt?
   (c) [If yes] In your own view why do family members discriminate against their relatives with mental illnesses? [If no] Not with your experience in particular, but why do you think in other cases family members might discriminate against their loved one with a mental illness?
   (d) Overall, how supportive have your family members been toward your care since your diagnosis and/or your hospitalization? What kind of activities do your family members help you with? How do you feel about the help they give you?
5. In terms of how you feel about yourself, do you feel different from other members of your family? How is it like?
   (a) Do your family members involve you in family decision-making? Do your family members seek your opinion on issues that relate to the well-being of all family members? How often do they seek your opinion on important matters that need attention from all family members?
   (b) Could you describe how you feel about your involvement in family matters; before and after your diagnosis of a mental illness?
6. Do you tell others outside your family about your mental illness?
   a. Have family members or professionals ever encouraged you to speak publicly or not to speak publicly about your mental health?
7. Tell me about your relationship with your friends? Do your friends know about your diagnosis? [If yes] How do they behave towards you after knowing about your diagnosis?

8. Do you have any close siblings? [If yes] How is your relationship with your siblings? How do they behave towards you after your diagnosis?
9. Are you currently in a romantic relationship? [If yes] How has your partner reacted to your diagnosis?
10. Do you receive any ongoing support for your health and well-being on a daily basis? [If yes] Do you feel like you have sufficient decision-making authority in your daily care?
11. [If they noted in the demographics, they live with family members] Is living with family members your ideal living arrangement? How do you see your relationship with your family moving forward?
12. Thinking over the long term, in your own opinion, what role do you think family members play in your ongoing mental health recovery?
13. What do you think can be done to reduce negative behaviours and beliefs towards people with mental illness? What do you expect policymakers and civil society organization to do to prevent negative behaviour towards persons with mental illness from happening in our communities?
14. Do you have any questions or comments for me?

Appendix E: Interview Guide for Family Members (Close Relatives) of Persons with Mental Illnesses

Demographic

Participants unique identification numbers
Age
Gender
Race and ethnicity
Marital status
Occupation
Level of education

1. So, before we get into specifics, I want you to talk about mental illness stigma more generally. What kind of mental illness stigma do you think people experience in Canada today?
2. Do you think stigma has gotten any better in recent years?
3. What do you think causes mental illness stigma?
4. You've been invited to this study because of being the family member of a person diagnosed with a mental illness. Can you tell me a bit about your family member who lives with a mental illness?
    a. How long have they been living with a diagnosis?
    b. What kind of supports do they receive?
    c. How often do you see them?
5. How would you describe your experiences of having a family member who lives with a mental illness?
    a. What have been the most important things you have learned through this?
    b. What have been the largest challenges they have faced?
    c. What have been the largest challenges for you, personally?
6. Has this experience changed how you understand mental illness?
    a. [If yes] How so?
7. Now let's talk specifically about stigma. Do you believe your [family member] experiences of stigma is because of their illness?
    a. What kinds of stigma do they experience?

   b. Have you ever been present when you saw them being discriminated against because of their illness? What was that like?

8. In this study we hypothesize that family members themselves might stigmatize their loved ones with a mental illness. Personally, do you feel like anyone in your family has acted in ways that are discriminatory towards your loved one with a mental illness?

(a) How supportive have your family members been toward the care of your relative through their illness?

   a. [If you provide a lot of direct support yourselves] What kind of activities do your family members help you with?

   b. How do you feel about the help they give you?

9. Thinking honestly about your experiences through this all, do you think your attitude towards your loved one has changed since they started experiencing symptoms of mental illnesses?

   a. How was your relationship with your relative before their diagnosis?

   b. How close are the two of you now?

10. If you were ever to notice family members treating your loved one poorly because of their mental illness, how do you think you would address these negative behaviours?

    a. Is [family member] involved in family decision-making? If so, how often do you seek their opinion on important matters that need attention from all family members?

11. What is your opinion about other extended family and friends knowing about the diagnosis of your relative?

    a. Do you ever [yourself] feel embarrassed about their illness?

12. Has your relative’s diagnosis had any impact on you in terms of your relationships with others? How comfortable are you discussing your relative’s diagnosis with close friends?

13. In conclusion, what do you think can be done to reduce negative behaviours towards people with mental illnesses?

14. Do you have any questions or comments for me?

Curriculum Vitae

Name: Joseph Adu

EDUCATION

Western University, London, ON, Canada	
Ph.D. Candidate, Health & Rehabilitation Sciences	2018 – Present
Memorial University of Newfoundland, St. John's, NL, Canada	
MSc, Community Health	2014 – 2017
University of Ghana, Ghana	
MPhil, Business Administration (Health Services)	2011 - 2013
University of Ghana, Ghana	
BA, Psychology & Sociology	2004 - 2007
Sekondi Nurses' College, Ghana	
Certificate, State Registered Nurse	1998 – 2001

PROFESSIONAL EXPERIENCE

Middlesex-London Health Unit, London, ON, Canada	
Program Assistant	Jan 2022- April 2022
Western University, London, ON, Canada	
Graduate Teaching Assistant and Research Assistant	2018– Present
Memorial University of Newfoundland, St. John's, NL, Canada	
Research Assistant	2014 – 2016
CareGivers- Bluesky Family Care Service, St. John's, NL, Canada	2015 – 2018
Child and Youth Care Worker	
Mamprobi Polyclinic-Ghana Health Services, Accra, Ghana	Jan 2014 –Aug 2014
Acting Health Services Administrator	
Accra School Hygiene- Ministry of Health, Accra, Ghana	2009 –2014
Senior Health Tutor	
Korle-bu Teaching Hospital, Accra, Ghana	2008 – 2009
HIV/AIDS Counsellor	
Sefwi-Juaboso Health Directorate –Ghana Health Services	2001–2008
Registered Nurse	

PUBLICATIONS (Peer-Reviewed Journals)

1. **Adu, J.** Oudshoorn, A., Anderson, K. K., Marshall, C. A., & Stuart, H. (2022). Experiences of Familial Stigma among Individuals Living with Mental Illnesses: A Meta-Synthesis of Qualitative Literature from High-Income Countries. *Journal of Psychiatric and Mental Health Nursing*. https://doi.org/10.1111/jpm.12869
2. Martin-Yeboah, E., Gyamfi, S., **Adu, J.**, & Owusu, F. M. (2022). Reconciling Primary Healthcare Delivery with Social Media: A case study of Cape Coast, Ghana. *International Journal of Africa Nursing Sciences*. https://doi.org/10.1016/j.ijans.2022.100395

3. **Adu, J**., Oudshoorn, A., Van Berkum, A., Pervez, R., Norman, R., Canas, E., Virdee, M., Yosieph, L. & MacDougall, A.G. (2022). System transformation to enhance transitional age youth mental health – A scoping review. *Child and Adolescent Mental Health*. https://doi.org/10.1111/camh.12592
4. **Adu, J.,** Owusu, F. M., Gyamfi, S., Pino, L., & Yeboah, E.M. (2022). A Discussion of some controversies in Mixed Methods Research for Emerging Researchers. *Methodological Innovations*.
5. **Adu, J**., & Oudshoorn, A. (2022). Social Contact: A human approach to mental illness stigma. *Behavioural Public Policy – Blog. https://bppblog.com/2022/07/21/social-contact-a-human-approach-to-mental-illness-stigma/*
6. **Adu, J.,** Yeboah, E.M., Gyamfi, S., & Owusu, F. M. (2022). How can we support evidence-informed policy-making on the African continent? http://www.evidenceandpolicyblog.co.uk/
7. Pino, L., & **Adu, J**. (2022). Critical Narrative Inquiry: An Examination of a Methodological Approach. *International Journal of Qualitative Methods.* https://doi.org/10.1177%2F16094069221081594
8. **Adu, J**., & Monette, E. (2022). Can global health equity gaps be bridged during a pandemic? *Global Health Equity Blog*. https://ghe.uwo.ca/blog/posts/can_global_health_equity_gaps_be_bridged_during_a_pandemic.html
9. **Adu, J.** Oudshoorn, A., Anderson, K. K., Marshall, C. A., Stuart, H., & Stanley, M. (2021). Policies and Interventions to Reduce Familial Mental Illness Stigma: A Scoping Review of Empirical Literature. Issues in Mental Health Nursing. https://doi.org/10.1080/01612840.2021.1936710
10. **Adu, J.** Oudshoorn, A., Anderson, K. K., Marshall, C. A., & Stuart, H. (2022). Social Contact: Next Steps in an Effective Strategy to Mitigate the Stigma of Mental Illness: Commentary. *Issues in Mental Health Nursing*, https://doi.org/10.1080/01612840.2021.1986757
11. **Adu, J**., Gyamfi, S., Yeboah, E.M. (2021). Knowledge translation platforms to support African evidence-informed policies: challenges and progress. *Evidence & Policy Journal*. https://doi.org/10.1332/174426421X16123456824061
12. **Adu, J**. (2020). The Relevance of Feminist Issues: Race, Class, and Sexuality to Maternal Mortality in Ghana. *Women's Health Science Journal, 4*(2). https://doi.org/10.23880/whsj-16000143.
13. **Adu, J**. & Oudshoorn, A. (2020). The Deinstitutionalization of Psychiatric Hospitals in Ghana: An Application of Bronfenbrenner's Social-Ecological Model, *Issues in Mental Health Nursing*, DOI: 10.1080/01612840.2019.1666327. https://doi.org/10.1080/01612840.2019.1666327
14. **Adu, J**., Tenkorang, E.Y., Banchani, E., Allison, J. & Mulay, S. (2018). The effects of individual and community-level factors on maternal health outcomes in Ghana http://dx.plos.org/10.1371/journal.pone.0207942
15. **Adu, J**., Mulay, S., & Owusu, F.M. (2021). Reducing Maternal and Child Mortality in Rural Ghana: Commentary. *Pan African Medical Journal*. https://doi.org/10.11604/pamj.2021.39.263.30593

16. **Adu, J**., Owusu, F. M. & Yeboah, E.M., Ahenkan, A., & Gyamfi, S. (2021). Maternal Health Care in Ghana: Challenges facing the uptake of Services in the Shai Osudoku District. Women's Reproductive Health Journal. https://doi.org/10.1080/23293691.2021.2016187
17. **Adu, J**., Owusu, F. M., Gyamfi, S., Yeboah, E.M. (2021). Assessing the Psycho-socioeconomic impact of COVID-19 on International Students and their Families. Pan African Medical Journal. *One Health. 2021;5:14. [**doi**: 10.11604/pamj-oh.2021.5.14.30044]*Available online at: https://www.one-health.panafrican-med-journal.com/content/article/5/14/full
18. Adu, J. & Owusu, F. M. (2023). How do we improve maternal and child health outcomes in Ghana? *International Journal of Health Planning and Management*. https://doi.org/10.1002/hpm.3639

MANUSCRIPTS UNDER REVIEW

1. **Adu, J.,** Martin-Yeboah, E., Gyamfi, S., & Owusu, F. M. (2022). Analyzing two decades of literature on experiences of familial mental illness stigma in four advanced countries (2000–2020). Manuscript ID: CJMH-2022-0530 - Journal of Mental Health
2. Owusu, F. M., **Adu, J.,** Gyamfi, S., Yeboah, E.M. (2022). Addressing the non-communicable disease policy conundrum: Are African countries up to the challenge? International Journal of Health Planning and Management. Manuscript ID: HPM-22-00727
3. Owusu, F. M., **Adu, J**., & Dortey, A. B. (2022). I tell you, getting data for this is hell'– Exploring the use of evidence for noncommunicable disease policies in Ghana. Plos One Global Public Health. Manuscript ID: PGPH-D-22-01481
4. Owusu, F. M., **Adu, J**., Dortey, A. B., Gyamfi, S., Yeboah, E.M. (2022). Exploring health promotion efforts for NCD prevention and control in Ghana. Health Promotion Practice. HPP-22-0452
5. Gyamfi, S., **Adu, J**., Martin-Yeboah, E., Owusu, F. M., Agyabeng-Fandoh, E., & Attiogbe, A. (2023). Perceived Public Attitudes that Influence Experiences and Perceptions of Stigma among Persons with Mental Illness in a South Saharan Country. International Journal of Africa Nursing Sciences.

MEDIA APPEARANCES

1. (January 26, 2022). Social contact is key to reducing mental health stigma. A New Western-led study offers a promising next step in changing public perceptions. Western News. https://news.westernu.ca/2022/01/social-contact-key-to-reducing-mental-health-stigma/
2. (January 28, 2022). Familial Mental Illness Stigma and Social Contact-based Education. CBC Radio, London Ontario.

SCHOLARLY AWARDS & HONORS

1. The Ying Cao International Community Health Graduate Student Award 2014-15 of the Memorial University of Newfoundland- ($6000)
2. 2014 – 2016 Memorial University of Newfoundland, School of Graduate Studies Masters Fellowship ($12,000)
3. Global MINDS Fellowship 2019 Award. London Ontario, Canada; July 2019- 500 CAD

4. Western University Graduates Scholarship. London Ontario, Canada; Sept 2018-Present ($20000 CAD for four years)
5. The Society of Graduate Students, Western University: Fall 2022 Research Completion Fund-($717 CAD)

ACADEMIC CONFERENCES & PRESENTATIONS

1. **Adu, J.,** Oudshoorn, A., Anderson, K. K., Marshall, C. A., & Stuart, H. (2023). Negotiating familial mental illness stigma: the role of family members of persons living with mental illnesses. Submission of Abstract to Western Research Forum 2023, Western University, London-Ontario
2. **Adu, J.,** Oudshoorn, A., Anderson, K. K., Marshall, C. A., & Stuart, H. (2023). The experiences of familial mental illness stigma among individuals living with mental illnesses. Virtual poster presentation. Parkwood Institute Research Day, April 27, 2023, London Ontario
3. Martin-Yeboah, E., Quan-Haase, A., & **Adu. J.** (2022). Deciphering Ontario Library Association's Health and Well-being Support to Members During covid-19 Pandemic. Ontario Library Association Conference (January 2022).
4. **Adu, J.,** Oudshoorn, A., Anderson, K. K., Marshall, C. A., & Stuart, H. (2021). Exploring the Experiences of Familial Stigma Among Individuals Living with Mental Illnesses. Health and Rehabilitation Sciences conference January 02, 2022, Western University, London-Ontario.
5. **Adu, J.** & Oudshoorn, A. (2021). Policies and Interventions to Reduce Familial Mental Illness Stigma: A Scoping Review of Empirical Literature. Health and Rehabilitation Sciences conference, Western University, London-Ontario.
6. **Adu, J.** & Oudshoorn, A. (2021). Policies and Interventions to Reduce Familial Mental Illness Stigma: A Scoping Review of Empirical Literature. London Research Day, May 2021, London Ontario.
7. Oudshoorn, A., Virdee, M., **Adu, J.,** Norman, R., Canas, E., Pervez, R., & MacDougall, A. (May 7, 2020). A Scoping Review of Promising Structural Reforms to Support Youth Mental Health. Legacy 2020 Research Conference: Honouring our Past, Creating our Future, London, ON.
8. Yeboah, E. M., **Adu, J.,** Owusu, M. F., Gyamfi, S., Obeng, I. N., Toku, C., Macavo, D., Ofori-Amanfo, J., Yankey, E., Nkansah, F., & Agyeman, S. (July 31, 2021). Libraries, Covid-19, and mental health: A scoping review. 2021 Ghana Library Association Conference
9. Oudshoorn, A., MacDougall, A., & **Adu, J.** (May 14, 2019). The Evidence-Based Possibilities of System Transformation to Enhance Transitional Age Youth Mental Health.
10. **Adu, J.** & Oudshoorn, A. (2019). Mental health care delivery in Canada and Ghana: Identifying resources and support networks to enhance community integration of people diagnosed and treated for mental illness. Lawson Health Research Day, London, ON.
11. **Adu, J.,** Tenkorang, E.Y., Banchani, E., Allison, J. & Mulay, S. The effects of individual and community-level factors on maternal health outcomes in Ghana in Toronto, Canada (November 2018). 24th Canadian Conference on Global Health.

PROFESSIONAL ACTIVITIES

Manuscript Reviewer/Academic Editor

1. Academic Editor for Plos One Journal, 2022 – Present
2. Qualitative Health Research, 2020 – Present
3. International Journal of Homelessness-2021-present
4. Health Promotion International Journal-2022
5. Member Western University SOGS' International Graduate Student Issues Committee (IGSIC), May 2021-May 2022
6. Curriculum Development for Achieving Equity and Global [EDI-D-I: Equity, Diversity, Inclusion, Decolonization and Indigeneity] Competence in the Canadian Health Sector Workforce
7. Mentor/ Judge: How to change the World; Fall 2022 at Western University, London Ontario
8. Mentor: How to change the World; Winter 2023 at Western University, London Ontario
9. Judge: IJOH Student's Pre-Conference Symposium; March 02, 2023, at Western University, London Ontario

TEACHING EXPERIENCE (Teaching and Research Assistantship)

1. PT 9133: Physical Therapy CLINICS I (Upper Quadrant), Western University, Summer 2022
2. AHS 9014: Addiction and Substance Use, Western University, Winter 2022
3. AHS 9009: Project Management, Health Sciences, Western University, Fall 2021
4. SODH 1002B: Social Determinants of Health, Health Sciences, Western University, Winter 2021
5. HS2250A: Introduction to Health Promotion, Health Sciences, Western University, Fall 2019
6. AHS 9001A**:** Critical Thinking and Critical Analysis for Health Sciences, Health Sciences, Fall 2018
7. Mental Health Structural Reforms research project, Western University, Winter 2019- Fall 2020
8. Criminalization and Housing research project, Western University, Summer 2020- Winter 2021
9. Designing Canada's long-term affordable housing approach research project, Western University, Fall 2022-Present

COURSES TAUGHT (Accra School of Hygiene/J-Prompt Institute Ghana, Sept 2009-2014)

1. Health Sociology
2. Health Psychology
3. Community Mental Health
4. Health Sociology and Anthropology

PROFESSIONAL MEMBERSHIP

1. Member: Canadian College of Health Leaders; Sept 2022-Present
2. Member: Nurses' and Midwives Council for Ghana
3. Member: Ghana Registered Nurses Association (GRNA)/Ghana Association of Health Tutors
4. Member: Health Educators Group Ghana