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The experiences of familial mental illness stigma among individuals living with mental illnesses

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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 the following: 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

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, programmes, 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).

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., labelling, stereotyping, separation, status loss, and discrimination) in the context of social power. Stigma can involve labelling – 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, and tuberculosis). 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 and 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 and Jones, 2018; Lucas and Phelan, 2012; Mittal *et al.*, 2012).

The stigma of mental illness has been characterized as a complex 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 (PWMIs) 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 PWMIs 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 PWMIs 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 and Whitley, 2015; O'Reilly *et al.*, 2019; Östman and Kjellin, 2002; Paul and 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).

In Canada, mental illnesses have been found to contribute significantly to disability, affecting one in every five people (Centre for Addiction and Mental Health, 2019; Public Health Agency of Canada, 2019). In addition, it is documented that about 11 million (38%) Canadians aged 15 years and above have at least 1 immediate or extended family member who lives with a mental health concern, diagnosed or otherwise (MHCC, 2012; Pearson, 2015; Pearson *et al.*, 2013). Further, of Canadian families with a loved one living with a mental health concern, nearly 71% of them felt that their livelihoods were impeded by their relatives' illness (MHCC, 2012; Pearson, 2015; Pearson *et al.*, 2013). This current study, therefore, 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.

Methods

Design

An interpretive phenomenology design was adopted to understand the lived experiences of familial stigma among PWMIs, 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 analyse 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 and 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 and Willis, 2004). In this study, the phenomenon of familial mental illness stigma is explored with an analysis of 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 the following:

(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).

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. London-Middlesex has several healthcare institutions that handle both physical and mental health conditions. In the area of mental healthcare delivery, the London Health Sciences Centre 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 and 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 (CMHA).

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 24 years or older, recognizing that the experiences of adults differ from those of youth and older adults. The age limit for this study was necessitated by the fact that familial mental illness stigma appears to be a sensitive issue as we sought to explore family members as stigmatizers of their loved ones with mental health problems. Hence, we decided to speak to persons who are independent of their families and willing to share their lived experiences with the research team without fear or intimidation from family members. Recruitment was conducted with the assistance of key connections in the community such as family physician practice clinics, CMHA offices, and community health centres who work directly with the target population. The local organizations that 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. Our sample size was informed by the use of interpretive phenomenology design. According to Creswell (1998) and Morse (1994), the ideal sample size for phenomenological studies should be between 5 and 25. Again, in interpretive phenomenology investigations, researchers intend to recruit a limited number of participants vis-à-vis a larger size to focus deeply on lived experiences to increase the likelihood of thick, rich, and unique stories relative to the phenomenon under study (Laverty, 2003). Inclusion criteria for participants for the in-depth interviews included the following: (1) being 24 years or older, (2) self-identifying as an individual living with mental illnesses, (3) able to speak and understand English; (4) being a current resident in the London-Middlesex area; and (5) being willing to participate in the study for 45–60 minutes. The exclusion criteria for participant recruitment included the following: (1) PWMIs who were not residents of the London-Middlesex area, (2) PWMIs who were less than 24 years of age, (3) unable to communicate in and understand English, and (4) unwilling to participate in the study for 45–60 minutes.

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 was not 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

Data collection

In-depth interviews were conducted with all participants between May and July 2022. In-depth interviews allow for both specificity and content flexibility (DeJonckheere and 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 about 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 at 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).

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. Detailed textual analysis implies in-depth exploration of the language in the text to form concepts and patterns that capture participants' thoughts and lived experiences. The line-by-line analysis of transcripts of each participant allowed us to capture the actual meaning embedded in the text or message. 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 were identified. Identification of themes was an iterative process of reviewing various sets of data with particular attention to how they pull together. To ensure intercoder reliability, we employed an open coding technique that allowed for the inclusion and repetition of important concepts and opinions identified and categorized as codes in all segments of the data relative to the study objectives. Two members of the research team read and coded all transcripts independently. The coding team met regularly to compare codes to maintain consistency in the coding process. Any inconsistency identified in the coding process was resolved through dialogue and consensus. Rigour 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.

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).

The 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.

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 two subthemes: '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:

Table 2. Socio-demographic Characteristics of Study Participants

Participant ID	Age range	Gender	Marital status	Level of education	Race/ ethnicity	Diagnosis
PWMI_2	30–34	F	Married	College	Caucasian	ADHD/neurodevelopmental disorder
PWMI_4	20–24	F	Single	Graduate	Caucasian	Anxiety disorder/PTSD
PWMI_7	25–29	F	Single	College	Caucasian	Borderline personality disorder
PWMI_8	40–44	M	Divorce	College	Caucasian	Bipolar type II disorder
PWMI_9	35–39	F	Common law partner	High school	White Canadian	PTSD/major depression
PWMI_10	40–44	F	Single	College	Caucasian	Major depression
PWMI_12	40–44	F	Common law partner	Graduate	White Canadian	Depression and anxiety
PWMI_16	35–39	F	Married	High school	White Canadian	Depression and anxiety
PWMI_17	40–44	F	Married	College	Canadian	Major depression
PWMI_20	35–39	F	Single	Undergraduate	Caucasian	PTSD/bipolar type II
PWMI_22	30–34	F	Single	Graduate	Caucasian	Clinical depression
PWMI_23	30–34	Non-binary	Single	Graduate	White European	Anxiety/depression and borderline personality disorder
PWMI_27	30–34	M	Married	Graduate	Caucasian	Generalized anxiety disorder
PWMI_28	30–34	M	Separated	College	Caucasian	Depression/bipolar type II disorder
PWMI_31	30–34	F	Married	Undergraduate	Caucasian	Panic disorder and Depression

Key: ID, identification; PWMI, persons with mental illness; ADHD, attention-deficit/hyperactivity disorder; PTSD, post-traumatic stress disorder.

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)

These participants saw a confirmation of their diagnosis from experts as a sigh of relief as it offered them an opportunity to look at options necessary for treatment and possible recovery. Having struggled for many years with poor mental health problems, their diagnosis allowed them to have a plan to improve their mental status and better explain their condition to others.

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 borderline personality disorders 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)

This implies that the misconceptions associated with mental illnesses can lead some family members to question the personal traits of their loved ones with mental illnesses as these families often doubt the capabilities of their relatives and liken them to being reckless. These stereotypes could damage the self-esteem and self-efficacy of affected individuals and prolong their recovery.

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 towards them compared with 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)

The participant feels their dad is biased towards them compared with other family members due to their diagnosis of mental illness. This feeling of insecurity within the participant's environment is not helpful to their mental health recovery due to associated emotional conflicts.

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)

This suggests that PWMIs 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)

The participant's view illustrates that PWMIs may be perceived as different from the rest of their family members. For instance, in this case, they were seen as worthless and mistrusted within their family due to their condition which is demotivating for focusing on recovery.

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)

This participant had a difficult time within their immediate environment just after a diagnosis as they were kept out of information sharing within the family. The feeling of exclusion in family decision-making could negatively impact their already affected mental health.

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 to 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)

These observations reflect that persons living with mental illnesses face many challenges due to the misconceptions connected to mental health problems at both the family and community levels. These challenges may include the breakdown of romantic relationships which, in turn, contribute to low self-efficacy and personal empowerment as well as emotional problems.

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 minds 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)

The participant's opinion indicates that the unpredictability of the symptoms and the false perceptions associated with mental illness make it difficult for persons with mental health problems to keep romantic relationships at times.

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)

Participant's perception of mental illnesses can negatively impact their self-esteem and the ability to keep healthier relationships. The barriers they face to making friends and staying connected with people can result in the internalization of personal issues that under normal circumstances could be shared with their loved ones for support.

Another participant described their opinion on the turn of events within the family post-diagnosis, where they cannot 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 everything under the pretense that they don't want to worry me. (Participant 10)

This participant is not enthused about the family's view on their diagnosis. There seems to be an issue of trust versus mistrust among the affected person and their family which could exacerbate emotional distress that might negatively impact the participant's mental health.

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 disorders until one has lived experience, one may not fully understand it. Also, people don't like to be around individuals who are constantly negative . . . (Participant 7)

That is, 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 PWMIs. 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)

The complex interplay of familial relationships and mental illness stigma could be a reason for the discrimination experienced by these participants within their families, particularly the perceived lack of knowledge about mental health problems.

Familial stigma as societal stigma localized

In considering stigma experienced by 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', 'exclusion from the circle of information within the family', '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)

Family members expressed fear and powerlessness when it comes to handling persons with severe mental illnesses as they at times consider their loved ones as dangerous depending upon the intensity of their symptoms.

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)

This quote reflects the fact that some families victimize their loved ones with a mental illness diagnosis to cover their embarrassment due to the genetic predispositions associated with mental illnesses.

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)

Participant accounts echo the need for familial education on mental illnesses to correct the existing misinformation about mental health issues to avoid needless discrimination against affected persons and rather offer them both practical and emotional support to help improve their mental health.

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 which 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 would allow me a space to do so... (Participant 23)

Um, my family plays a very big role in my recovery. The family continuously observes me and usually keeps 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)

The viewpoints of participants imply that having the full support of family members within one's immediate environment and feeling love without any intimidation and restrictions is key to their mental health recovery. More so, 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).

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 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)

Participants reiterated the need to modify societal knowledge on mental illnesses through contact-based education with intentionality. This will inform members of the general public about the multifaceted nature of mental illnesses and the need to come close to PWMIs to better understand their predicaments and ways to curb stigma towards them. A good example of this is what Bell Let's Talk is doing in Canada. 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 on 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 towards the presentation of mental health problems in the news. Participants questioned why news reporters and presenters often concentrated mostly on the negative aspects of PWMIs 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 is 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)

This participant blames the media for the increase in stigma around mental illnesses, particularly when criminality in media is often tied to a psychiatric diagnosis and highly criminals in various movies are tagged with personality disorders. This, according to the participant, adds to the misconceptions associated with mental illnesses. They, therefore, admonish the media to correct this impression by replacing such negative connotations with positive ones to sanitize the public space and help close the 'we and them' gaps in society.

When it comes to family education in particular, participants noted that 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 PWMIs regarding their capabilities and inabilities. A participant requested society pay more attention to the competencies of PWMIs 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 the 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 part of how they personally confronted stigma. For these participants, disclosure to family members about their mental illnesses offered an 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)

The quotes from these two participants suggest the importance of public disclosure as a good step where affected persons can share their lived experiences of mental illness for social support and coping strategies, especially with people who have gone through similar experiences and with close relatives.

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.

We have proposed five aspects of familial mental illness stigma notable among participants. These included the following: 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 the 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 labelled with mental illnesses to include the potential for loss of social status, poor housing or homelessness, unemployment, social isolation, and poor healthcare and suicidality (Link and 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 towards 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 a 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 PWMIs 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 a very specific stigma related to exclusive conditions such as schizophrenia which are framed as 'dangerous' within public narratives (Ghiasi *et al.*, 2022; Gottfried and 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 one becomes 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 and Corrigan, 2008; Rössler, 2016; Umberson and Karas Montez, 2010).

The recovery of PWMIs is linked to the combined support of family members, social support services, and health professionals (Bjørlykhaug *et al.*, 2021; Larson and 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 a myriad of support 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 and 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, and improve social support and quality of life (Brouwers *et al.*, 2020; Corrigan, 2022; Corrigan and 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 and 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 regarding access to support.

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.

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 towards 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 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.

Limitations

Our study is limited by the age restriction (24 years 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 3 males participated in the study compared with 11 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 coronavirus disease 2019 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.

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 towards 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.

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