BARRIERS TO CARER PARTICIPATION FROM BLACK COMMUNITIES IN FIRST EPISODE PSYCHOSIS FAMILY PSYCHOEDUCATION PROGRAMMING: A QUALITATIVE EXPLORATORY STUDY

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ABSTRACT

Background: First Episode Psychosis (FEP) is a psychiatric condition that typically emerges in late adolescence and early adulthood. *Family psychoeducation* is a facet of early intervention programming for FEP patients that supports the education and empowerment of *carers*, i.e., family members, friends, or spouses that provide physical, emotional, and tangible support (ex. financial support) to patients in recovery. Family psychoeducation is an evidenced-based practice that has been demonstrated to be effective in reducing relapse and re-hospitalization rates, decreasing family burden, and reducing positive symptoms of psychosis. It is therefore an integral part of psychosocial intervention for the treatment of psychosis. Despite the importance of carer participation in family psychoeducation sessions, clinical observations at two prominent FEP clinics in Montréal, Canada have recorded the overall low attendance of carers at the family psychoeducation seminars; especially, those from visible minority communities. Recent clinical observations (2020-2022) from these two programs note that despite 20-25% of the patient population self-identifying as Black, less than 5% of carers who attend the program are Black. Black populations in Canada disproportionately face numerous systemic and structural inequities when accessing and receiving treatment for mental health issues that may impact engagement from carers in Black communities.

Aim: This master's thesis seeks to uncover the barriers that impede the engagement and attendance of Black carers to the quarterly family psychoeducation seminars offered by the First Episode Psychosis Program (FEPP) at the Jewish General Hospital and the Prevention and Early Intervention Program for Psychosis (PEPP) at the Douglas Mental Health University Institute, in Montréal, Canada.

Methods: This qualitative multi-site project consisted of semi-structured interviews with caregivers (n=4), of patients with FEP from Black communities who entered treatment from January 2016 until December 2021, as well as program case managers (n=10) who coordinate and facilitate the family psychoeducation programming to uncover barriers that impair engagement with the program.

Results: Findings were obtained through a thematic analysis, with three main groups of barriers emerging: logistic, systemic, and interpersonal and community barriers. Within these three themes, distrust in the healthcare system due to historical trauma, denial of the diagnosis, isolation, and stigmatization were some of the key barriers identified facing Black carers. The use of virtual modalities for psychosocial services such as family psychoeducation are also discussed.

RÉSUMÉ

Contexte : Le premier épisode psychotique (PEP) est une maladie psychiatrique qui apparaît le plus souvent à la fin de l'adolescence et au début de l'âge adulte. La psychoéducation familiale est une facette des programmes d'intervention précoce pour les patients souffrant d'un premier épisode psychotique qui soutient l'éducation et la responsabilisation des aidants, c'est-à-dire les membres de la famille, les amis ou les conjoints qui apportent un soutien physique, émotionnel et matériel (par exemple, un soutien financier) aux patients en voie de rétablissement. La psychoéducation familiale est une pratique fondée sur des données probantes qui s'est avérée efficace pour réduire les taux de rechute et de réhospitalisation, diminuer le fardeau de la famille et réduire les symptômes positifs de la psychose. Elle fait donc partie intégrante de l'intervention psychosociale pour le traitement de la psychose. Malgré l'importance de la participation des soignants aux séances de psychoéducation familiale, les observations cliniques effectuées dans deux cliniques de premier plan de la FEP à Montréal (Canada) ont permis de constater la faible participation des soignants aux séminaires de psychoéducation familiale, en particulier ceux issus des minorités visibles. Des observations cliniques récentes (2020-2022) réalisées dans le cadre de ces deux programmes montrent que, bien que 20 à 25 % des patients s'identifient comme noirs, moins de 5 % des soignants qui participent au programme sont noirs. Les populations noires du Canada sont confrontées de manière disproportionnée à de nombreuses inégalités systémiques et structurelles lorsqu'elles accèdent à des traitements pour des problèmes de santé mentale et les reçoivent, ce qui peut avoir un impact sur l'engagement des soignants dans les communautés noires.

Objectif : Ce travail de maîtrise cherche à découvrir les barrières qui empêchent l'engagement et la participation des soignants noirs aux séminaires trimestriels de psychoéducation familiale offerts par le Programme du premier épisode psychotique (PPEP) de l'Hôpital général juif et le Programme d'intervention précoce et de prévention des psychoses (PEPP) de l'Institut universitaire en santé mentale Douglas, à Montréal, au Canada.

Méthodes : Ce projet qualitatif multi-site a consisté en des entrevues semi-structurées avec des soignants (n=4), de patients atteints de FEP issus de communautés noires qui ont commencé leur traitement entre janvier 2016 et décembre 2021, ainsi qu'avec des gestionnaires de cas du programme (n=10) qui coordonnent et facilitent la programmation de psychoéducation familiale, afin de découvrir les obstacles qui nuisent à l'engagement dans le programme.

Résultats : Une analyse thématique a permis de dégager trois groupes principaux d'obstacles : les obstacles logistiques, les obstacles systémiques et les obstacles interpersonnels et communautaires. Parmi ces trois thèmes, la méfiance à l'égard du système de santé en raison d'un traumatisme historique, le déni du diagnostic, l'isolement et la stigmatisation sont quelques-uns des principaux obstacles identifiés pour les soignants noirs. L'utilisation de modalités virtuelles pour les services psychosociaux tels que la psychoéducation familiale est également abordée.

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want to be when I grow up. Lindsay Doyle, my friend, and dedicated helper, thank you for cleaning up hours of transcripts and being a ray of sunshine in my life. To my mentor and pseudo mother, Dr Nicole D'souza, whose impact on my personal growth and career is immeasurable. I would not be here without you and am so grateful for you and your beautiful family – Juan and Emmy – who mean the world to me. Nicole, I admire your tenaciousness, intelligence, and compassion, thank you for pushing me to be the best version of myself; I am merely reflecting what I learned from you.

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CONTRIBUTIONS

This thesis is an original work of scholarship. Findings from this study are novel and first authorship is ascribed to the student researcher, Michaela Field.

The study was designed in consultation with my supervisor, Dr G. Eric Jarvis and Advisory Committee members, Drs Sophia Koukoui, Jai Shah, and Charles Gyan, who offered feedback and suggestions on all aspects of the research endeavour. I conducted the interviews with participants, performed the data analysis, and wrote the final manuscript. Dr Jarvis helped guide and edit the final manuscript.

A special thank you to all participants in this study for their contributions. Mental health is a difficult and deeply personal topic to discuss, and I am eternally grateful for the candor and openness of family members, who shared their joy, grief, and hopes for the future with me.

SCHOLARLY REFLECTIONS

In thinking about how to organize this thesis, I realized I needed a few words to reflect upon the successes and challenges of the past three years. I embarked on this master's program in the fall of 2020, merely months into a global pandemic that had me shuttered in my family home, unable to see friends, mentors, or fellow scholars. Starting graduate school from your childhood bedroom is both exciting yet deeply humbling, as you begin a significant academic journey while sitting in your pajamas during online classes and muting yourself over Zoom to yell at family members downstairs to be quieter. It was a strange time, and although now as I write this in 2023 the pandemic feels both like yesterday and ages ago – I am lucky to have had this unique experience to grow academically and personally.

Academically, although my grades did not suffer, I never met any of my classmates in person, and did miss out on the opportunity to make new friendships (coffee chit chats over Zoom are not quite the same). I remain immensely grateful to all my professors who acknowledged the strangeness of the learning situation and did their best to support their students and modify their teaching style to fit the new normal. With my mentors, I attempted my hand at creating a virtual education space and co-organized an online course on community-based and -led mental health interventions that brought hundreds together worldwide. I was also honoured with opportunities to join multiple courses as a teaching assistant later during my master's, discovering a whole new love of teaching. On a personal front, I ended a long-term relationship, moved out from my childhood home, adopted a cat, and truly became the independent person I always wanted to be.

This research endeavour emerged during monumental movements in the zeitgeist outside of the pandemic. Following the murder of George Floyd in May 2020, a social and personal reckoning erupted worldwide, with the Black Lives Matter movement emerging onto the global stage. Whiteness and one’s addiction to it and the structures it upholds, necessitated a long overdue self-reflection for all. As a White settler engaging with Black folks and anti-racist work, I had to constantly challenge and reflect on my positionality, and its impact on those I was trying to work with. I learned that questioning myself and understanding my place and role in a system that privileges some above others, is part of the process towards unpacking both conscious and unconscious biases. It can be uncomfortable and difficult work at times, but necessary if one is committed to disrupting the current structures and offer genuine co-conspiracy allyship – something I am still actively learning how to apply in my everyday life.

I am very grateful for the participants who held space for conversations around race and the reflexivity and connection that our discussions allowed for on both ends. I was entrusted with personal histories and stories from participants and remain ever conscientious of that privilege, treating their narratives with the utmost care. This work is only made possible due to the amazing case managers and family members who so graciously shared their life stories and experiences, and I am immensely grateful to each person for their contributions. Not every part of our conversation made it into this body of work, as some words were meant to just exist between us; however, the aspects most salient to this research endeavour are highlighted.

It has been a remarkable three years of trials and tribulations, as well as wonderful achievements and education. Writing this thesis was incredibly difficult for me, as I am quick to begin new projects but struggle tremendously during the final leg of any journey. This thesis is a labour of determination – not so much love – and is a culmination of everything I have learned over the past few years. There are a million things I could have done differently, and yet I would not actually change a thing. This formative period of my life is ending, and I have no regrets; only looking forward to the future, with this work as a first step. Thank you for reading.

INTRODUCTION

What is Psychosis?

According to the National Institute of Mental Health (NIMH) (2023), the term *psychosis* is used to describe a complex collection of symptoms that results in an individual struggling to discern between what is real and what is not. *First Episode Psychosis* (FEP) refers to the initial break from reality an individual experiences, commonly referred to as a *psychotic episode* (NIMH, 2023). FEP typically emerges during late adolescence into young adulthood, with approximately three out of 100 people experiencing an episode in their lifetime (NIMH, 2023**;** Tsuda et al., 2022). Psychosis is demarcated by the appearance and combination of *positive* and *negative symptoms*. Positive symptoms include *delusions* (holding false beliefs despite what others believe and despite evidence to the contrary) and *hallucinations* (perceiving something that is not actually there), while negative symptoms tend to include flat or blunted affect, social and interpersonal withdrawal, and poverty of speech or thought (Tsuda et al., 2022**).**

Of importance is that psychosis can be a symptom of various mental disorders (e.g., schizophrenia, depression, or bipolar disorder), physical illnesses (e.g., head injury, Parkinson's disease), and other issues such as sleep deprivation and drug and alcohol misuse (NIMH, 2023; Tsuda et al., 2022**).** Due to the variety of instances in which psychosis can emerge, there is no identified specific cause for the disorder, which is thought to be related to biological factors (i.e., dysregulation of the neurotransmitter dopamine, genetic loading in families), environmental factors (i.e., heavy drug use, birth complications, childhood abuse, migration, social adversity), or some combination of both (Badcock & Paulik-White, 2019).

Psychosis in Black Communities

In Canada, schizophrenia and other psychotic disorders are estimated to affect 4% of the population (Lecomte et al., 2021; Perälä et al., 2007). Studies from the US and Canada have shown a disparity between the diagnosis rates of psychotic disorders between racialized and White people, with Black individuals diagnosed at higher rates than other groups (Faber et al., 2023). For example, an epidemiological survey conducted by Cohen and Marino (2013) in the US, observed that Black Americans had the highest lifetime rates of disorders that included psychotic symptoms (15.3%), compared to Latino (13.6%), White (9.7%), and Asian (9.6%) populations. Cénat et al. (2023) highlighted similar racial disparities in a scoping review of psychosis in the Canadian context, noting that Black individuals were more likely to be diagnosed with psychosis compared to those from other ethnic groups.

This disparity in diagnosis necessitates sociocultural contextualization. Historically, mental illness was weaponized against Black people to secure their subjugation; from the early writings of Samuel Cartwright (1851), an American physician, who coined the term *Drapetomania*, which referred to the urge in Black slaves to run away from their masters; to New York psychiatrists Walter Bromberg and Franck Simon (1968), who used the term "protest psychosis", to describe how Black Americans who resisted white oppression risked being labeled insane; and the popularization of schizophrenia during the American Civil Rights movement as a Black mental illness to negate anti-segregation movements and reverse social advancements by Black people (Metzl, 2010). Indeed, the relation between psychosis and Black Americans has been a long and controversial one (Jarvis, 2008), but for the purposes of this study, understanding that historic trauma exists when it comes to psychosis is relevant, as the effects of this systemic violence persist for Black people accessing and receiving mental health care in the US and Canada.

Of note, when attempting to establish a similar historical contextualization of psychosis in Black communities in Canada a paucity of literature emerged. Much of mental health research examining the impacts of racism comes from the US and is often applied to the Canadian context (Williams et al., 2022). Although it is understood across psychosis and mental health research that Black populations in Canada are affected by ongoing social, economic, and political inequities that stem from a history of slavery and colonization, there lacks an in-depth investigation of the history of psychiatry in Canada, and how institutional policies and practices may have impacted Black people (Government of Canada, 2020). This discrepancy in historical data is potentially due to Canada's self-promotion as a multicultural and inclusive nation, allowing for racial trauma to be overlooked within its society. For example, many Canadians are mis/uninformed about the history of slavery in Canada and assert a moral superiority over their American peers, believing if slavery was present in Canada, it was to a lesser degree and not as violent as the American system (Government of Canada, 2020; Williams et al., 2022).

Canadian context. Much of the current literature on psychotic disorders in North American Black populations explore the traumatic pathways to care that this population takes (Anderson & Rodrigues, 2023; Oluwoye et al., 2021), and their increased risk of coercive medical intervention and police violence when doing so (Knight et al., 2022). Findings from a recent scoping review of the Canadian literature identified various disparities related to psychosis in Black populations (Cénat, 2023), and some work has demonstrated the increased likelihood of Black individuals being diagnosed with psychosis (Jarvis et al., 2010). Additionally, when compared to other ethnic groups (Anderson et al., 2012), Black people were most likely to disengage from treatment, calling into question the quality of care and service that this group can access. Black patients were also more likely to have poorer follow-up compared to other patients, as providers may have preconceived expectations about visible minorities, which affects their perception of treatment adherence and outcomes (Nikolitch, Ryder & Jarvis, 2018). Finally, Knight et al. (2021), reported that Black people with first episode psychosis were significantly more likely to be coercively referred to services, often entering psychiatric care through via the police or court ordered evaluation in addition to experiencing excess coercive interventions like involuntary hospital admission, forced community treatment orders, and ongoing contact with the judicial system.

It is worth mentioning that Cénat et al. (2023), noted that all 15 studies included in their review were conducted among first episode psychosis (FEP) patients in just two Canadian provinces, Québec, and Ontario, and that most of the literature came from two teams – one led by G.E. Jarvis in Montreal, and the other led by K.K. Anderson in Toronto. This indicates a significant lack of information on the general experiences of patients with psychosis from Black communities across Canada. Additionally, as most research endeavors treat Black people as a monolithic category, there are few sociocultural nuances to the studies, necessitating further inquiry into a variety of individual factors (ethnicity, social status, migration history, etc.).

A brief note on terminology. It is also important to note that the term *Black*, defines a large racial grouping that differs greatly across ethnic, linguistic, and cultural lines. The term Black is not equivalent to an ethnic group, nor does it imply a collective biological heritage; it is intended to refer to those racialized by North American society, and can include Black-African, Black-Caribbean, and African American people (Faber et al., 2023). For the purposes of this paper, I will be following *Statistics Canada*'s guidelines, which use the term Black as a racial identifier to broadly encompass this heterogeneous community (Maheux & Do, 2019).

Treatment for Psychosis

In Canada, there is a longstanding history of early intervention (EI) services for FEP, which offer specialized services for those in recovery and include pharmacological and psychosocial interventions (Iyer et al., 2015). In Québec, these programs were historically developed and managed by clinicians (Bertulies-Esposito et al., 2022). However, in 2017, due to concerns regarding accessibility and variability in the services offered in Québec, the provincial government developed program standards and allocated specific funding and support for existing and newly founded EI programs province-wide (Bertulies-Esposito et al., 2022). Although this government funding provided better overall access to and quality of EI services for psychosis, there remain questions about fit and fidelity, as these programs may not adapt to the specific needs of their respective catchment area and caseloads, preferring instead to closely follow provincial standards to maintain funding eligibility (Bertulies-Esposito et al., 2022).

In Montréal, there are four established EI programs that offer services for patients and families, two of which were participating sites in this project. As part of their provincially mandated services, these programs offer medical treatment, psychosocial counselling, and interventions tailored for each patient (Gouvernement du Québec, *First Episode Psychosis*). Additional services include the education and support of family members and other carers who are supporting their loved ones toward recovery.

Carer support. Due to the early onset of psychosis, the FEP patient population is quite young (18-35), and family members are almost always involved in their recovery. In some cases, friend, spouses, or other non-blood relative may be present as a carer. Carers are important collaborators and support systems for patients. With a diagnosis of psychosis comes new challenges to the family system, and the world literature reports that the behaviour of carers has a powerful effect on clinical outcomes and the overall wellbeing of the patients (Bighelli et al., 2021). For instance, close family contact can benefit patient engagement in treatment regardless of context (Iyer et al., 2020; Doyle, 2014), reduce relapses (Camacho-Gomez & Castellivi, 2020), and support a better quality of life for patients (Oluwoye et al., 2020b; Kane et al., 2016). However, despite the benefits of family involvement in FEP recovery, carers do face burnout and exhaustion. Onwumere et al. (2018), noted the high levels of emotional exhaustion and increased risk of burnout in first episode psychosis carers, which negatively impacted their appraisals of caregiving and calls for increased early intervention and support of carers. Additionally, shame, guilt/self-blame, and other negative expressed emotions affects this population (Wasserman et al., 2012). Carers also struggle with seeking help themselves and can feel undervalued or unheard by the clinical team (Lavis et al., 2018).

In response to the known impact of carer support on patient outcomes and the benefits for carers, EI programs in Quebec offer *family psychoeducation* sessions*,* an evidenced-based practice that has been demonstrated to be effective in reducing relapse and re-hospitalization rates (McFarlane et al., 2012) and reducing positive symptoms of psychosis (McFarlane, 2014), as well as decreasing family burden (Harvey, 2018; McFarlane et al., 2012; Lincoln, 2007).

Overview of Family Psychoeducation

Family psychoeducation is an integral psychosocial intervention for the treatment of psychosis. The first iteration of family psychoeducation programming emerged in the 1980s (Hogarty, Anderson, and Reiss), with the aim to inform patients and relatives about psychosis and support their ability to cope with the illness (McFarlane, 2016). Family psychoeducation was conceptualized to be more than a simple knowledge transfer about psychosis by decreasing familial stress by engaging them in the treatment and answering their questions, with the aim of reducing patient relapse (Harvey, 2018). The current family psychoeducation model offers an expansion of this initial version with elements from behavioural family therapy and multifamily group therapy, adding cognitive, behavioural, communication, informational, problem solving, and consultative therapeutic elements to the program (McFarlane, 2016; Harvey & O'Hanlon, 2013). What is key about family psychoeducation is that the participants (i.e., the carers) are implementers themselves, such that through this education they are empowered to assist their loved one to recovery (McFarlane, 2016).

Components of family psychoeducation. Although family psychoeducation programs may differ based on context and target population, there are a few key active "ingredients" as described by Harvey (2018) that are common to most family psychoeducation models: (1) the inclusion of single or multiple families; (2) program facilitation by mental health professionals; (3) on average is 12 sessions long, held biweekly for 9-12 months, (4) can be located in the clinic, family home, or community; and, (5) can include the participation of patients in most session. Regarding the content of the program itself, McFarlane (2016) outlines the following topics typically covered during the sessions, such as content about psychosis and its treatment, information about the clinical services available, assistance with family communication and emotional reactions and expressions, knowledge about coping strategies, and crisis management. There are also ongoing efforts to culturally adapt the program to be more accessible by diverse carers by including relevant sociocultural content (Oluwoye et al., 2020a; Maura & Weisman de Mamani, 2017; Hackethal et al., 2012).

Current Concern with Family Psychoeducation

The premise of this study emerged from a Health Canada-funded initiative to culturally adapt family psychoeducation programs at four Montreal-based EI clinics. An emerging concern from initial observations of this research project (2020-2023) was the clear lack of racial diversity amongst the attending carers despite efforts to invite all families to participate. From clinical observations and estimations from staff at both sites included in this master's project, the *First Episode Psychosis Program* (FEPP) at the Jewish General Hospital and the *Prevention and Early Intervention Program for Psychosis* (PEPP) at the Douglas Mental Health University Institute, 20-25% of the patient population identifies as Black. However, in observing and conducting surveys at three psychoeducation sessions at FEPP, held in September 2020, March 2021, and June 2021 respectively, and two sessions at PEPP held in November 2021 and February 2021, less than 5% of the attending carers identified as Black. Hence, there was an attendance gap specific to the family members of Black patients with FEP.

There is limited research examining the specific barriers that carers of FEP patients may encounter that impede their access to the family psychoeducation sessions. Easson et al. (2014) identified barriers to family involvement and showed that organizational culture could limit family engagement, as well as power relations, fear of negative outcomes, and balancing the confidentiality of patient-practitioner relationship; however, these problems can be mitigated by mutually trusting relationships and commitment to family involvement by the clinical teams. Additionally, in an Australian study, Petrakis et al., (2014), noted that barriers of competing commitments (personal and professional), discomfort with sharing emotions, and a belief that some experiences should be kept private impeded family involvement. However, for those that did attend psychoeducation sessions, family group participation reduced feelings of isolation, promoted a sense of collectiveness, decreased shame and stigma, and increased knowledge about the illness and coping skills (Petrakis et al., 2014).

While there is some literature on barriers to family involvement, there is almost no research exploring the barriers to accessing family psychoeducation by Black carers. One of the only intersectional studies in the US found that Black family members were less likely to attend the family psychoeducation sessions despite outreach efforts from providers being significantly higher for Black families versus White ones (Oluwoye et al., 2020c), supporting the clinical impressions of the FEP teams in Montreal. In other research exploring the intersection of race and general mental health care service access and usage in Canada, systemic and structural barriers have been identified. Specific barriers that are known to impact Black populations in Canada, include systemic inequity (socioeconomic status, institutional discrimination, inadequate resource allocation), lack of representation in health provider roles, poor mental health literacy and awareness, myths, misconceptions, and stigma about mental illness (Faber et al., 2023b; Fante-Coleman & Jackson-Best, 2020; Conner & Brown, 2014; Whitley et al., 2006).

Study Rationale

Given the paucity of literature examining the experience of Black carers, and the lack of research examining the access barriers that these carers face for attending family psychoeducation and other psychosocial services, this study aims to document attitudes and expectations toward, and reasons for not attending, family psychoeducation by Black carers.

To investigate the barriers affecting Black carers of FEP patients, carers who *had* and who *had never* attended the family psychoeducation program were invited to participate in an hour-long interview, to discuss what barriers this carer population faces that impacted their service access and usage. In addition to interviews with carers, interviews with case managers from each clinic were also conducted. As part of their clinical work, case managers maintain close contact with carers of patients with FEP, and are the coordinators, recruiters, and facilitators of the psychoeducation sessions. Case managers thus are in a unique position to offer valuable insights about accessibility and service delivery.

These aims and goals led to the following research question: *What barriers exist that impede attendance at family psychoeducation seminars for carers of patients with FEP from Black communities?* Additional research objectives included: (1) uncovering carer and case manager reported barriers to access psychosocial programming, such as family psychoeducation; (2) examining the family psychoeducation coordination and facilitation process, and how additional barriers to access this kind of care may be due to clinical structures, and (3) identifying what adaptations to the family psychoeducation program are required to adequately meet the needs of Black carers of patients with FEP to increase service accessibility and usage.

METHODOLOGY

Study Sites

Two sites in Montréal were included for participant recruitment: (1) the First Episode Psychosis Program (FEPP) at the Jewish General Hospital, and (2), the Prevention and Early Intervention Program for Psychosis (PEPP) at the Douglas Mental Health University Institute. These sites were selected due to pre-existing collaboration on an ongoing Health Canada funded study to culturally adapt family psychoeducation programming (2020-2023). I had previous ties to both FEPP and PEPP, as I was a research assistant to the ongoing, multi-site, Health Canada funded project led by my supervisor, Dr. G. E. Jarvis. As coordinator of the PEPP's arm of the multi-site project, I attended clinical meetings, helped support the family psychoeducation sessions, and was overall familiar with members of the PEPP team.

Site demographics. Both service catchment areas have diverse populations. However, as data from the clinics unevenly noted ethnic or racial information about patients, from clinical observations and interviews with providers during this project, patient populations at both sites were estimated to be 20-25% Black, with a less than 5% attendance rate of Black family members to the family psychoeducation seminars. Additionally, these sites were also selected due to the similarity of their family psychoeducation programs, which each consisted of three sessions, with minor differences in process and content between the locations.

Family psychoeducation sessions. The FEPP and PEPP family psychoeducation programs are ideally offered quarterly at both sites, although in practice occur fewer times annually. The sessions are organized by members of the clinical team, who also recruit carers to the sessions. There are three, two-hour sessions, one offered weekly for three consecutive weeks. Each session covers a different topic: the first session provides information on what psychosis is (i.e., its symptoms, potential causes, etc.), the second session provides information on the available treatments for the illness, and the third is a psychosocial focussed session that offers coping, communication, and problem-solving techniques to carers.

The first two sessions are facilitated jointly by a psychiatrist and case manager from the clinical team, with the last session presented by two of the respective clinic's case managers. The last session also offers real world narratives, with patients and family members further along in the recovery process invited to speak and share their experience. Following each session, all participants receive a copy of the presentation and any additional resources that were presented. Pre-COVID-19, both sites offered the program in person, but have since pivoted to an online session held over *Zoom* or *Teams*. Note, as of June 2023, there has been no return to in-person sessions at either site; however, in my research, as some case managers participated in live session prior to COVID-19, I asked questions regarding barriers to virtual and physical program formats.

Finally, one difference to note between the two programs, is that PEPP offers their family psychoeducation in exclusively French or English sessions; thus, when registering for the program, carers are asked their preferred language and are provided the resources in their language of choice. Both language sessions run simultaneously (same date and time), and the content is the same in both sessions. FEPP prefers a hybrid approach, with presenters alternating between both languages, although English is the dominant language, and the program offers slides in English and French and live translation of participant commentary when requested. Additionally, FEPP and other FEP clinics are invited to PEPP sessions, to offer the opportunity to join an exclusively French or English session.

Research Design

From a philosophical perspective, this research projects best aligns with a *critical theory paradigm*, whereby experiences or events exist within various ever-evolving contexts that are perceived differently by each subject (Doyle et al., 2020; Guba & Lincoln, 2005). Reality is thus subjective and requires naturalistic methods to study said phenomena that are inductive and adaptive but avoids manipulating or influencing the data and research outcomes (Guba & Lincoln, 2005; Sandelowski, 2000). Therefore, for this exploratory project, a *qualitative description design* was selected, as it allows for researchers to describe a phenomena through the generation of data related to the *who*, *what*, and *where* of an event from subjective perspectives (Sandelowski, 2000). Qualitative description is helpful for service usage studies, as it supports the exploration of differences and commonalities in experience of a phenomena (in this case the family psychoeducation service), across a demographically diverse group (Sandelowski, 2000; 2009).

Ethics

This study was approved by the Research Ethics Boards (REB) of the *CIUSSS du Centre Ouest-de-l'Île-de Montréal* and the *CIUSSS du l'Ouest-de-l'Île-de Montréal*, respectively. All participants were assured that their participation would be kept confidential, with all personal identifiers being omitted from the transcript and this final report. All participants were informed of their right to modify or retract statements from their interview or request to be omitted from the final report. Additionally, due to COVID-19 protocols, additional protections for participants were required, including a secure *OneDrive* and *Zoom* account on which interviews could be recorded and saved.

Participants

Carers of FEP patients. Carers for the purposes of this study refer to the individual identified by the patient as their primary contact for emergencies and support. Carers are also invited by case managers to participate in family psychoeducation seminars as per clinical routine. Given the young age of this patient population (many FEP patients are adolescents or in their early twenties), family members are almost always the identified carer. In some cases, a friend or other non-blood relative (i.e., spouse, roommate, neighbour, etc.) may be identified as a carer.

A researcher's note. It is imperative to acknowledge that the Black community in Montréal is a vastly diverse community of people that differ across ethnocultural lines. The unifying factor amongst participating individuals is a shared racial background, which demands careful efforts to avoid generalizations or erasure of specific identities or experiences. Results from this exploratory work are not meant to speak for all carers from Black communities in Montreal but are meant to highlight the experiences of those interviewed during this research project.

*Inclusion criteria***.** Black carers of FEP patients that were accepted into FEPP and PEPP from January 2016 to December 2022 were recruited, who *had* or *had not* attended the family psychoeducation programming. All participants had to be over 18 years of age and there were no limitations regarding migration status. As I am a native Montrealer and bilingual speaker, no language restrictions applied, and I conducted interviews in English or French. If a participant had preferred to speak in a language outside of French and English, I would have organized an interpreter to join our interview session.

Case managers of patients with FEP. At both FEPP and PEPP, case managers play an integral role in the ongoing treatment of FEP patients. Upon entry into the two-year program, each patient is assigned a case manager who is their main contact and support. The educational background varies across case managers, who may be trained as occupational therapists, social workers, psycho-educators, or nurses; however, they all perform similar tasks, including supporting the mental health of FEP patients, performing wellbeing checks and community visits, and evaluating the patient's progress as they work towards achieving their physical, social, professional, and scholastic goals. Case managers are closely linked to the carers of patients with FEP and are often in communication with carers as first points of contact, and thus have intimate knowledge about the carer and their history with the patient. Additionally, case managers at both FEPP and PEPP are the primary recruiters and facilitators of the family psychoeducation seminars and have firsthand accounts as to why some carers do not attend the program.

Inclusion criteria. Any interested case manager from either FEPP or PEPP. There was no limitation as to how long the case manager had been working at either clinic. As with the carer recruitment pool, there was no restriction on languages spoken, with French and English speakers included in the participant pool.

Data Collection

Recruitment: Carers. For this research project, two groups of carers were recruited: (1) those who had attended the family psychoeducation program; and (2) those who had not. Members of the clinical team at both sites identified appropriate carers to contact for recruitment or contacted carers on my behalf. I provided clinical staff with a detailed flyer with information about the project, the relevant inclusion criteria, and my contact information that they could share with carers. Additionally, where possible, I posted flyers in the clinic waiting rooms.

Recruitment: Case managers. Once my study was approved, I requested to join a weekly meeting at each clinic to present my project, asking for case manager help to recruit carers and to invite them to participate in the study as well.

Interview protocol. I developed a semi-structured interview guide for each participant group. The interview guides were exploratory by design and based on the goals of the project, which were to seek the lived experience of the participants, and were supported by literature review findings, and consultations with academics, clinicians, and advisory board members. Each guide was divided into three sections with specific questions related to the theme of each section: (1) sociodemographic information; (2) lived experience as a carer or case manager; and (3) identifying barriers impeding the access of Black carers to the program.

Procedure. To recruit case managers, I sent direct emails through the relevant CIUSSS email networks, inviting them to participate. For carers, as therapeutic relationships with the clinical team are incredibly important to protect, I followed the lead of case managers at each clinic and contacted them first to inquire about family members they considered open to recruitment. With their approval, I would then email or contact the approved carer in their preferred language. After contacting potential participants who accepted to meet, I scheduled a time and date to conduct the interview. Within the confirmation email for the interview, I included a link to the consent form for this project on *SurveyMonkey*. I developed French and English consent forms and sent the appropriate version to the participant based on their language preference.

Most interviews were conducted over Zoom (n=4), or in-person at the clinic (n=7). One interview was conducted over the telephone (n=1), and in two exceptional cases, I had carers prefer for me to meet them in community settings. For these two interviews, I met them at a coffee shop of their choice, where they felt more comfortable.

Before any of the interviews began, I went over the consent form with each participant to ensure they were informed about the research process and their rights as participants. Regarding being audio-recorded, all participants agreed except one. For this individual I took notes and immediately transcribed the material following the interview. As the interviews were semi-structured, I posed open ended questions based on the guide and probed with follow-up questions depending on the themes or specific perspectives that emerged during the interview. *All* participants were provided a virtual 20$ gift card and were able to choose from *Amazon*, *Tim Hortons*, or *Walmart*. Additionally, for carers, I provided a list of resources that I compiled that offer psychosocial and other supports to those helping FEP patients in recovery. This resource list is available in the *Appendix* section.

Study interviews ranged from 50 minutes to 120 minutes and were conducted over the course of 9 months from June 2022 to March 2023. Due to delayed REB approval from one of the participating sites, there were only 4 months to recruit and interview participants. Each interview was transcribed, inputted, and analyzed with *NVivo* (1.7.1.) software throughout the recruitment and interview period.

Data Analysis

A descriptive research approach was implemented using the 14 semi-structured individual interviews (Braun & Clark, 2021). All interviews were transcribed verbatim on *NVivo* (Release 1.7.1.). No one withdrew from this research project and all participants were included in this final report (n=14). Out of 14 interviews, 7 were conducted in French (n=4 case managers; n=3 carers). As I did not want to lose any context due to translation efforts, I maintained the original French transcripts, but coded for themes in English due to my familiarity with both languages.

To conduct an inductive qualitative analysis of the transcribed interviews, I followed Braun and Clarke's (2013) steps of thematic analysis to identify key needs, concerns, facilitators, barriers, and other suggestions for modification to improve the family psychoeducation program. Instead of developing *a priori* codes as in deductive analysis, inductive coding allows for the generation of data-derived codes. Braun and Clarke's process is six-fold and includes the first steps of reviewing all the transcripts and generating initial codes, before collating codes into broader themes and highlighting relevant extracts. These main themes are summarized in the *Results* section.

This method of data analysis is reflexive and encourages the active modification of coding systems and strategies, as the transcripts were simultaneously collected and analyzed throughout the research process. To enhance rigour during the coding process, a constant reappraisal of the fit of codes was necessary with each new input of data and an assessment to ensure that the data was not being made to fit the constructed categories, but that the data defined the categories (Milne & Oberle, 2005).

Researcher Reflexivity

Incorporating reflexivity throughout all stages of the project was integral to ensuring the research's depth and legitimacy. As introduced in my scholarly reflections, I had continuous reflexive work to engage with on a personal level (re. my positionality as a White researcher conducting this type of research), but also in my role as a researcher. As a researcher, I was (understandably) barred as non-essential staff for at least a year into my master's. It was nearly a year and a half into the pandemic that I was allowed onto the premises of the participating sites for my supervisor and my own project, sending our timelines askew and requiring constant adaptation, creativity, and collaboration from the whole research team and our partners to fulfill our goals.

Due to the nature of my research, I was a witness to Montréal's straining healthcare system and saw firsthand how early intervention mental health programs grappled with increasingly challenging barriers, including staff burnout and turnover, unclear and everchanging COVID-19 regulations, and cuts and relocation of resources and services. I heard from both patients, families, and staff alike about how they struggled to remain afloat physically, emotionally, and financially during these times. New concerns about research ethics and the protection of participants were brought to light given the new virtual modalities in which studies were being conducted, as well as philosophical questions about the importance and value of conducting research during a time of survival. I have no answers to these queries, except a more mindful and realistic approach to conducting research. It mainly involves constant self-doubt and asking yourself – Is this needed? – and going beyond the REB approval to ensure your morals and ethics are aligned with those you want to work alongside.

One notable facet of my position was how I navigated my role within clinical teams. Being embedded within these teams granted me access to information about participants that might not have been known or agreed upon by the participants themselves. This presented a unique ethical challenge, as I had to balance the need for comprehensive insights with maintaining participants' privacy and autonomy. This dynamic influenced the thesis in several ways. Firstly, it underscored the importance of acknowledging the potential dissonance between participants' perspectives and the information I had access to. This dissonance highlighted the complexity of representing participant experiences accurately. Secondly, it reinforced the significance of maintaining a critical stance, continually evaluating my own position and potential biases in relation to the data due to any pre-existing personal relationships with clinical members.

In sum, active reflection on my positionality and role in this study was imperative. I maintained a research diary throughout the study to document my evolving thoughts, biases, and preconceptions. Regular discussions with my supervisor, mentors, and fellow students, allowed for an external perspective, enabling me to identify and address any potential biases or assumptions that could influence the research process. Although my embeddedness within clinical teams prompted ethical considerations and shaped how participant information was handled and interpreted, ultimately, they added depth and complexity to the thesis's findings.

RESULTS

In total, for this study, I recruited four family members, two from each site. Of note, I was only able to recruit carers that *had* attended the family psychoeducation program (n=4). Three of the carer participants were mothers, while one was a sibling of a patient. Recruitment was challenging during this project, which is further discussed in the *Discussion* section of this thesis. To protect the anonymity of the case managers, I will not detail which sites they came from but will note that four were recruited from one site, and six from the other, for a total of ten (n=10) participants. *Overall, fourteen participants (n=14) were included in this study.*

The following results are organized by themes based on participant interviews (n=14). This section describes participants' views on barriers to access that carers from Black communities may face when accessing family psychoeducation programming. Additionally, it addresses the current challenges faced in program recruitment and implementation, along with proposed strategies and suggestions to improve carer attendance and engagement. In this study, three types of barriers are generated based on the collation of codes:

(1) *Logistic/practical* barriers, which encompass barriers that are physical in nature. This includes technological barriers, such as the lack of computer literacy or access to technology, language barriers, and logistic barriers related to transportation, employment, and availability.

(2) *Systemic* barriers, which includes organizational challenges, such as staff burnout and turnover and infrastructure concerns, carer and clinical team dynamics, and institutional distrust.

(3) *Interpersonal/community* barriers, which summarizes family dynamics, cultural differences in mental health conceptualization, and carers experiences of grief and denial, as well as community shame and stigma.

Logistic/Practical Barriers

Use of technology. All participants (n=14) engaged in discussions about the implementation of virtual family psychoeducation sessions, which were conducted via platforms like *Zoom* or *Teams* due to pandemic restrictions. Carers and case managers held mixed feelings about virtual meetings. According to some case managers (n=8), the accessibility of virtual platforms has resulted in increased attendance rates to the psychoeducation, despite some of the concerns with technological literacy:

> I know there's been an issue of technology. And I know it's going to get a little more awkward for people to talk on a little more *Zoom* or *Teams*. But it's easier because people then can get home and just participate versus having to come here at 6:00pm. And sometimes they would come late because of traffic. (*Case Manager 4*).

Before the COVID-19 pandemic, the family psychoeducation sessions were held in-person at each clinic. When asked about potential transportation issues impacting access, case managers did identify that transportation could potentially act as a barrier for participants, but only moderately so. Despite the improvements in accessibility due to the use of virtual platforms, study participants noted that they negatively impacted organic conversations and communication between attendees, as participants remain muted throughout the session unless there is an explicit pause or request for questions. Although as one case manager mentioned, the potential for anonymity by joining these virtual sessions, might also be a contributing factor to an increase in attendance and sharing amongst participants; particularly, using the chat function, which allows all attendees to participate. Study participants noted that increasing the opportunities for interaction between family psychoeducation attendees would be helpful for bridging connections and developing support networks:

> [*On the use of virtual platforms for family psychoeducation sessions*] I think it's, in a way, practical for a lot of people. But it is also a barrier, and it also doesn't like foster, the

> same connections, and sense of community, not that these families necessarily then start meeting each other outside, but it sparks the interest. (*Case Manager 5*).

Case managers (n=4) and carers (n=3) suggested that returning to in-person family psychoeducation sessions might be helpful, as it could promote supportive relationships amongst carers, who currently have little opportunity to connect during virtual sessions. However, all carers (n=4) noted that despite the virtual modality, the family psychoeducation sessions were a positive experience and helped them feel less isolated and alone. As one carer noted, "You feel isolated in what you're going through. […] I think seeing other parents who are going through that at the same time… it just made you feel less like an alien. Like no one else knows what I'm going through. But here [*at the family psychoeducation sessions*] were other people going through it too."

Language, logistic, and physical barriers. Logistic barriers regarding carer involvement in patient follow-up and family psychoeducation were articulated by study participants. For instance, participants (n=3) highlighted that carers who worked multiple jobs were unable to make themselves available to join family psychoeducation sessions. This issue was thought to be more prevalent within Black populations and other marginalized groups, which often experienced greater socioeconomic pressures or status instability. These factors had an impact on their ability to make time for this psychosocial programming. One case manager mentioned that during the recruitment process, taking the time to detail the benefits of attending the program and intentionally explaining how it is relevant to the individual carer's situation may improve attendance.

Additional barriers include physical distance, as case managers (n=5) noted that there are carers who are difficult to contact given that they live outside Montréal. Case managers did stipulate that there are efforts made to contact these family members and establish a rapport;

however, for the most part, the clinical team only connects with these physically distant carers if they visit Montréal. Finally, a few case managers (n=3), spoke of language barriers as a potential concern affecting participation in family psychoeducation sessions. One case manager spoke of their caseload having a high number of immigrants, who spoke neither French nor English, and the difficulties they faced in communicating with them. Overall, however, language barriers were not thought of as a significant barrier, as French and English sessions are offered at one clinic, while the other clinic offered simultaneous translation efforts. Additionally, carers from FEPP, are invited to join PEPP's family psychoeducation sessions and can join the all-French sessions based on their preference. Interestingly, as one case manager stated, language barriers were less important than carer support, love, and engagement, which they felt could potentially transcend this concern:

> I think maybe it's a psychological barrier. I don't think it's a reality because I have had a family member, a Dad come in – it was clearly not his first language, English. But he was still present. I felt like they [*the family*] were good, like loving. […] When they were present like showing their support because love is like – it doesn't need language to show it. It doesn't need language to communicate either. And so, the question is more on understanding [*the patient*]? (*Case Manager 8*).

Systemic Barriers

Organizational challenges. Both clinics have faced challenges in the past few years of staff burnout and turnover, increased caseloads, and adaptions to program services due to the COVID-19 pandemic. During COVID-19, patients were unable to physically come to the clinic unless they were in crisis, leaving case managers to follow-up remotely with many clients as best they could. At one clinic, disengagement with service continues to be higher than normal, as a residual impact of these practices. As an example of workload challenges, one case manager noted that according to their guidelines, they should only be managing sixteen cases at a time;

however, each case manager that I interviewed had nearly double or even triple that number of cases to manage.

> We have caseloads that are higher than what is supposed to be in *cadre de reference*[1]. In the *cadre de reference*, it talks about sixteen clients per case manager. At the moment, I have thirty [cases]. That gives you an idea of how high the patient caseload is... especially after COVID-19, there was a surge of patients. (*Case Manager 5*, Translated into English).

Burnout affected carers as well. One participant noted that they were frustrated by constant changes in staff, as each time they would call the clinic to discuss their loved one's progress they were told they were assigned a new case manager. This issue frustrated case managers as well, with some expressing concern over the difficulties in fostering therapeutic alliances with patients and carers who were previously with other team members.

> I think there have been a lot of staff changes. So, I sometimes get frustrated, there's no follow-up. They're not going to tell you that your staff member has left, you have to find out yourself. For example, when I started to see that things were starting to come back – certain problematic behaviors [exhibited by the patient] – I called the same number I had. But I was told that the person wasn't there anymore and given the new person's number to contact. I think there's a lack [of communication] there. (*Carer 2,* Translated into English).

All case managers (n=10) noted the importance of carer support and engagement, seeking to collaborate and remain in close contact with family members as much as possible.

> I see them as like an extension of our team in a way. Like, it's just that very collaborative. It's very important that we hear their perspective and their experience, and we're very open to hearing what they have to say. We like to be accessible as much as possible. And even if the client is opposed to this, we work very hard to try to, to allow for them to be open. So that we can meet with the family. I hope there's a partnership. I'm hoping that they feel comfortable with the team. (*Case Manager 1*).

Case managers understand the significance of carer engagement for clinic outcomes and reflected on the critical role they play in patient's recovery. Case managers praised how involved the carers are and the ways in which they support their loved ones, such as transporting them to

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[1] Refers to provincial guidelines for FEP clinics.

their appointments, providing emotional support and advocating for the patients, and fulfilling financial and basic needs (lodging, food). Additionally, when they connect to carers, it helps support and sustain the therapeutic alliance with the patient.

> Oftentimes patients are living with family members, who help make sure they take their medication and help them remember their appointments. They provide transportation to the appointments, moral support, advocacy – advocating for the family too. It's also really helpful to get another perspective on what's going on, because the client sometimes gives us information strategically or aren't aware of what their behavior is like [which the family can see]. There are many different roles that the family members play. (*Case Manager 2*).

Most case managers mentioned they would like more time to work alongside carers but due to competing demands and too many cases, they have little time to do so. They also see their role as helping carers minimize stress in the family environment and highlight their existing strengths. Case managers mentioned that community visits are slowly being reintroduced as part of the clinic's gold standard of care, thereby increasing time spent with carers and patients in their home environment.

> [On community visits] Yes, [these visits] are where often the richest conversations are. And it really helps with engagement. It's been hard to make time and space for it as much as we would like and now as much as we're supposed to [according to the new gold standard]. (*Case Manager 5*).

Time constraints impacted clinical teams' ability to recruit carers to family psychoeducation sessions, with both teams appreciating the recent help from research teams supporting the recruitment and organization of the family psychoeducation sessions.

Case managers at both sites also mentioned that with the onset of COVID-19 additional services, such as the family psychoeducation sessions, were cancelled to cope with the immediate crisis. A case manager at one clinic, noted that it took some time before pivoting to a virtual platform, which may have affected the organizational culture around family engagement, as it was deprioritized for a time. One participant also noted how their clinical team's morale was affected by COVID-19 and continues to be impacted by distancing measures; for example, their team cannot meet in-person yet for their weekly rounds, and use *Teams* to facilitate their meetings. However, as their network infrastructure cannot support the amount of people joining, everyone meets with their cameras turned off.

Institutional distrust. Nearly all participants (n=12) expressed concerns about distrust in the healthcare system, which they identified as a potential impediment to carer engagement. Carers reflected on the deep-rooted origins of this distrust, including one participant who spoke on the historical trauma that Black people have experienced in healthcare.

> Black people famously have lived, especially those in the diaspora, have lived through experimentation on our bodies, experimentation on our minds. We were used as guinea pigs without consultation, without our consent. You know, let's talk about Tuskegee. Let's talk about, you know, so many other things [...] Who knows what else people have gone through and are still going through and put yourself at risk of being of continuing that trend. (*Carer 1*).

All case managers were well versed and conscious of the persistent inequities facing Black people in the healthcare system. Although few case managers felt that carers were afraid of facing racism or prejudice during the family psychoeducation sessions, they did acknowledge the institutional fear and distrust that exists amongst marginalized people, which could affect their engagement with the clinical team and the program's services.

> I think that there is also, from what I understand, there can be like, a deep-rooted lack of trust in establishments. Whether it be the police, health care, or school, in some of these minority cultures – and maybe not just Black people – there is a history of not being treated as well or being treated differently; it can instill a lack of trust. And then with that lack of trust, they might not see the purpose of being as involved in a treatment plan and the professionals, as they have a history of feeling disrespected. And there is evidence to show, you know, when a Black person shows up at the E.R. with the same picture as a white person who shows up, they are like maybe the Black person will get more PRNs[2], put it in isolation or not be treated as well. (*Case Manager 6*).

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[2] PRN refers to *pro re nata*, or "as needed" medication. It is a term used to describe the administration of psychotropic PRN medications for the rapid management of acutely agitated psychiatric patients in emergency care.

Both case managers and carers noted the feelings of disempowerment and fear of those impacted by systemic injustice have of hospitals and other health institutions, and that part of the family psychoeducation sessions could be spent demystifying the system and making more efforts to address these concerns directly and openly. Carers also highlighted the issue of underrepresentation in clinical settings, where there are often very few Black individuals working. Two carers mentioned that having community members or clinical team members who are Black could potentially increase attendance of Black carers to the program. One carer mentioned that they opted for one first episode psychosis clinic over the other due to having a friend associated with that particular institution. This highlights the potential influence of interpersonal connections with members of the same ethnic community on engagement with clinical services.

With conversations about institutional distrust, came discussions about the legal and law enforcement systems that often play a role in psychiatric settings. Many case managers (n=5), reflected on the fears that carers have expressed to them regarding their loved one's potential or ongoing interactions with the law. Carers were concerned about their loved ones experiencing episodes publicly and becoming victims of police violence. One carer recounted the first episode of psychosis their loved one experienced in a public park before being taken to the hospital by a family friend, and how terrified they were that their son would be found by the police:

> I think about life or death. The cops would have come. They could have tasered him. They could have whatever. I don't know what would have happened. And he would have died, and I would have gotten no answers […] Like he told me he was hiding in the bushes… Like you see a six-foot-tall dark-skinned Black guy with dreadlocks hiding in the bushes. Is he a criminal? Is he planning on hurting someone? There are all these questions. (*Carer 1*).

Another carer spoke to me of a frustrating experience they had with the police. Their son had an emotional outburst that resulted in him breaking the front door and running off late at night. The carer could not find their son and called the police to request support in the search after having no luck themselves. The police that arrived were entirely focussed on whether the carer wanted to press charges against their loved one for breaking the door. The carer was incredibly angry and disappointed in the police's efforts (or lack thereof), as their main concern was to find their son and had hoped for additional support.

Case managers spoke of the examples they have seen of patients having negative experiences with police during their psychotic episodes that have been very detrimental to their recovery due to the prolonged impact of the judicial system. There is an understanding amongst some case managers (n=4) that the interaction with the legal system negatively impacts clinical outcomes.

Interpersonal & Community Barriers

Denial & grief. Denial was noted as a barrier mentioned by both case managers (n=7) and carers (n=4) alike, as they reflected on carers' denial of the diagnosis or current state of their loved one. Many participants remarked on denial as key barrier, as it affected carers' initial buy in and participation in family psychoeducation sessions. According to carer participants, in Black communities, there may be a tendency to reject mental illnesses in favour of alternative diagnoses, possibly due to the negative stigma associated with psychosis in their community.

> We're going to limit who we talk to about this, okay? Because we know how it's seen in the Black community, we know that mental illness isn't something that's easily accepted. We're going to try to find other reasons. We're not going to believe it's mental illness. (*Carer 2,* Translated into English).

In rare cases, secondary issues, such as underlying cognitive problems were openly denied by some family members. In one case mentioned, a Black patient experiencing psychotic symptoms was also diagnosed with an intellectual disability. The family was comfortable with the diagnosis and treatment of psychotic symptoms but refused to acknowledge the intellectual disabilities that the patient was also identified with, insisting that the treatment for psychosis would be sufficient for recovery.

Additionally, participants noted how denial was often tied to feelings of grief, as families were thought to need time to process their new reality and grieve the impact of the illness on their loved one's life and future. Participating carers noted that they were saddened by the turn in their loved one's life; in particular, some mothers noted intense grief when coming to terms with psychotic illness, as their expectations or vision for their child's future had significantly changed.

> There's denial. You know, there was a whole grieving process in terms of dealing with the illness as well. That's what I find often at the beginning, we don't have a lot of families [*at family psychoeducation*]. It might be denial or minimizing of what's happening or not wanting to go there, […] or thinking if they take the medication they'll be back at school. (*Case Manager 1*).

Denial was also thought to impact carer perspectives about medication and treatment, as some participants (n=5) noted that resistance to medication could emerge in carers who refused to accept the diagnosis of psychosis. On the other hand, participants (n=3) noted that some carers were overly reliant on medication as a "cure" and refused to accept the pervasiveness of the illness, anticipating an early end to the illness.

Family conflict. Family dynamics were a potential barrier to family psychoeducation attendance. Case managers (n=5) described complex cases, wherein patients refused contact with family members, as there was a history of interpersonal conflict, rejection, neglect, and in some cases, abuse.

> One of the problems is that sometimes the patient doesn't have a good relationship with the family. So, it's very difficult. We don't talk to each other [*the family*]. The patient is coming to the recovery, he's with the stepfather, they don't talk to each other. The stepfather just brings him because he's under the court order. If I talk to the stepfather, there's nothing to say. No relation at home. Just so disengaged. (*Case Manager 3*).

Additionally, as some case managers noted, in cases with dysfunctional family dynamics, patients often rescind their consent for carers and clinic team members to be in communication with one other. Thus, case managers cannot contact carers to invite them to family psychoeducation sessions.

Cultural conceptualizations of psychosis. Cultural differences in understandings of psychosis may contribute to lack of engagement with family psychoeducation sessions and treatment in general for patients and their families. One case manager recounted a case where the patient had to continue seeking help from the clinic in secret, as the patient's family believed that the prescribed medication was worsening their condition and that prayer should be prioritized to heal them. In reflecting on this case, the participating case manager noted:

> There are some families who have very strong beliefs about medication and mental health and are really hostile to the healthcare system. […] We don't often get cases that are extreme like this, but it's a reminder that we should keep in mind how people understand the symptomatology [of psychosis] in other cultures. (*Case Manager 10,* Translated into English).

Similarly, another case manager noted that being open-minded to different conceptualizations about mental health is necessary; however, they acknowledged that some clinical team members may lack the time and tools to address these differences.

> I think that mental health isn't necessarily understood by everyone. I don't think everyone [clinical team] is going to adapt their language to the family or the person who's in front of them. I also don't think we take enough time to address their [carers] different beliefs and experience. Especially if they're really deep-rooted [beliefs]. (*Case Manager 7,* Translated into English).

Finally, although participating carers in this study did not endorse non-medical ways of thinking about psychosis, and even rejected spiritual, religious, or other cultural conceptualizations of psychosis, they acknowledged that these beliefs are still held by many in their communities.

> You know, I hid it from a lot of my family and friends… Especially those in racial communities, racialized communities. I didn't exactly tell them why I was back…because

> I just wanted to focus on him. I didn't want it to be about, oh, but why didn't you do this? Why didn't you take him to the church? Maybe he needs to get baptized. Maybe he needs to be saved. Maybe he needs some bush tea. I don't know. Like all those bulls**t excuses. (*Carer 1*).

Stigma & shame. Participants reflected on the stigma of mental illnesses, particularly psychosis. Given the understanding of both carers and case managers alike that in some communities mental health problems are misunderstood, stigma and shame were viewed as interconnected concepts. One case manager articulated how they believe some carers understanding mental health issues:

> This is my understanding…but because mental illness affects our thinking, belief systems, and perceptions, we assume we are always in control of that. We can understand that when you have a break in your leg, you're not going to be able to walk on it. Or if your pancreas shuts down, you'll need insulin, medication, whatever... These are concrete [ailments]. People get it. When it comes to… whether its mood or perception of reality, or your belief system, delusions… People feel that it's just a matter of willpower. (*Case Manager 4*).

All carers (n=4) noted that initially when their loved one was at the peak of their illness, they did not share what was happening with anyone in their lives, outside of their immediate family, due to fear of the stigma, blame, or discrimination that they and/or their loved one would face. One carer mentioned that they continue to peel the labels of their loved one's medication bottles off before throwing them out, to ensure that no one would find out that someone in the building was taking anti-psychotic medication. Stigma can be crippling, and can disrupt family relations, as one case manager articulated:

> What she said is that mental health is extremely stigmatized in her country. And when she first had her initial kind of "breakdown", in her words, her family was involved because it happened when she was visiting for all siblings in New York. At the time she was in touch with her family, and she said it went terribly – you know, her sister has called her crazy, they didn't understand. (*Case Manager 9*).

Three out of four carers noted that the experience of their loved one getting diagnosed with first episode psychosis caused them to reflect on their family histories, and members who were "the odd ones out". By having conversations with other family members, they learned more about these familial outliers, realizing that they could have been suffering with the same or similar mental illness as their loved one. One carer even took it upon herself, with her new knowledge about psychosis, to help an elderly family member in Senegal receive proper medication and care for her mental illness. Unfortunately, they were distraught to learn that access to newer anti-psychotics with fewer side effects were nearly impossible to access and unaffordable for most.

DISCUSSION

This study is among the first to explore barriers affecting carer participation in family psychoeducation sessions for the family members of Black patients with first episode psychosis (FEP). The study helped identify logistic, systemic, and interpersonal barriers affecting this population. Although separated into three main themes, these barriers do not exist in a vacuum and intersect and influence one another.

The study's findings regarding technology-related logistic and practical barriers corroborated with current and ongoing research into the access and use of technology in healthcare settings. The mixed results describing the pros and cons of using virtual modalities for these psychosocial programs highlight similar practicalities and downsides to its usage in other settings (Mueser, 2022). This aspect presents a promising avenue for future research, as there is very little literature about the use of virtual platforms for this type of programming. Organizational concerns, such as staff burnout and turnover, and their impact on quality of care and therapeutic alliances have been reported in other recent research findings (Meyer-Kalos et al., 2023). The instability of these clinics due to the COVID-19 pandemic, amongst other issues, was felt by carers and patients alike, and requires time and resources to ensure that programs have the resources to provide high quality care. Consistent communication and collaboration with carers will also contribute to strengthening therapeutic alliances and ensuring participation in services, such as family psychoeducation (Meyer-Kalos et al., 2023).

Linguistic barriers can have implications for clinical care, even if participants in the study viewed them as only a moderate barrier. A recent study conducted by Nweze et al. (2022), observed that English-speaking Black Quebecers are at increased risk of discrimination and barriers when accessing healthcare. According to Nweze et al. (2022), Quebec's English-speaking Black community finds itself at the intersection between two levels of marginalization, linguistic and racial, resulting in more barriers to accessing healthcare and lower mental health than their French-speaking counterparts. Additionally, although the access to family psychoeducation services offered in English and French is undoubtedly beneficial for those who are proficient in these languages, the presence of linguistic barriers remains a concern for non-anglophone and francophone speakers (Gyan et al., 2023). Previous research has shown that when patients and carers are unable to communicate effectively in their native language during clinical interactions, it can hinder the accurate understanding and exchange of information, leading to misunderstandings, misinterpretation of symptoms or treatment instructions, and potential misdiagnoses (Arpin-Gemme et al., 2023; Gyan et al., 2023; Brisset et al., 2013). It can also impede the establishment of trust and rapport between patients, carers, and the clinical team, as individuals may feel uncomfortable or vulnerable when expression themselves in a language that they are not fluent in (Thomson et al., 2015). Language barriers can hinder the active participation in family psychoeducation sessions, preventing carers from fully benefiting from the program.

A notable theme from this study was carer *denial*, and how it was often related to grief. It is interesting to note that several individuals identified grief as the originator of the emotional and behavioural experience of denial. Denial is a well-known component of grief often preceding coping and acceptance; therefore, a better understanding of denial in carers supporting FEP would be relevant as it was considered a significant barrier to carer engagement. There are very few studies examining carer denial of psychosis directly, although in literature examining the coping behaviours of FEP patient carers, denial is often mentioned (Gerson et al., 2011). Smith et al. (2014), is one of the few to examine denial across racial lines and found that due to community stigma, African American family members reported greater levels of denial than White family members. However, despite having increased avoidant coping behaviours of denial, African American family members included in this study still sought help from an available program similar to family psychoeducation. Furthermore, although limited in number, previous studies examine loss and grief from both the patient (Ridenour et al., 2023) and carer perspective (Rachamin et al., 2022). Rachamin et al. (2022), found high incidence rates of *complicated grief* in carers of those living with chronic psychotic disorders, which is a type of unrelenting grief that offers after the death of a loved one; additionally, those with complicated grief had a higher prevalence of posttraumatic and depressive symptoms, and overall worse physical health.

A more practical application of this finding could be to hold space for specific discussions about denial and grief during family psychoeducation sessions. It could spark meaningful connections and conversations with other carers and prepare the way for discussion with case managers. It is possible that many carers do not even realize that they are in denial, which could yet be another meaningful research topic; however, as some case managers noted in this study, many carers are waiting for the medication to address all the issues with the patient in the hopes of their lives returning to how things were before the onset of the illness. For many patients, this will not be possible; thus, perhaps further inquiry into patient and carer understandings about psychosis and their expectations from treatment and the clinical team is necessary. This could potentially improve relations among clinical teams, patients, and their families, as setting expectations and understanding the limitations of the clinical team and interventions could help (1) ensure the quality of care is met, and (2) alleviate any frustrations based on assumptions about what is possible in terms of treatment and recovery.

As already mentioned, carers from Black communities may have difficulty being open about mental illness due to stigma and fear of judgement (Cénat et al., 2023). However, although mentioned anecdotally to me during the interviews, carers benefitted from shared experience and knowledge once they began talking to members of their family and inquired about other potential illnesses in their family tree. Perhaps, this is an opportunity for willing community champions and carers to take part in clinical settings, as through leading by example can inspire and motivate others to share about their experiences as well. Furthermore, as an emergent concern was carer isolation, this increased community representation, as well as facilitating opportunities for connection between all carers could help address these feelings of isolation (Gibbs et al., 2022). The family psychoeducation sessions could be adapted to allow for more engagement between participants, even offering support group sessions. Increasing opportunities to educate people about psychosis and foster relationships with other carers could also help negate fears of stigmatization and feelings of shame. On the other hand, opening conversations about stigma in communities could leave individuals vulnerable to culturally unsafe discussions; thus, they would require careful moderation and expert facilitation to ensure such topics are navigated safely (D'souza et al., under review).

Additionally, carers who participated in this study prioritized biomedical explanations over cultural or religious understandings of mental health care and treatment. This may be why these carers were engaged with clinic and attended the family psychoeducation programming, as they articulated to me their rejection of traditional or religious beliefs. However, carer participants did acknowledge that others within their communities may hold other beliefs about psychosis, which could impact their engagement in the program. According to Gibbs et al. (2022), institutionally led community outreach efforts to increase the awareness and education of psychosis and other mental health illnesses could help foster engagement. Additionally, hosting family psychoeducation sessions outside of the institutional space and in communities themselves could improve the accessibility of the program. However, regardless of locale, finding community champions and ensuring community representation at the institutional level would be important for facilitating this outreach, as well as fostering community connections with local leaders, such as religious heads or local community organizations, to support community buy-in and acceptance (Gibbs et al., 2022).

Finally, institutional distrust was a key finding that deserves to be articulated clearly within the current context of Québec. In my introduction, I briefly reviewed the history of psychosis and the trauma that Black people have faced within healthcare settings. However, in October 2021, the Premier of Québec, François Legault, staunchly claimed that there was no systemic racism in Québec in the wake of an official report regarding the treatment of an Indigenous woman, Joyce Echaquan, who was a victim of racism and prejudice before her death (Bruemmer, 2021). During this research study, I heard firsthand from carers about the persistent distrust in healthcare institutions and other systems, such as justice and law enforcement that their community holds. Case managers were also cognizant of these existing systemic boundaries and have noticed the impact on patient outcomes and their own relationships and engagement with carers.

The impact of system distrust on the mental health of Black communities in Canada is not a new revelation (Faber et al., 2023b; Cénat, 2023; Fante-Coleman & Jackson-Best, 2020; Nikolitch, Ryder & Jarvis, 2018). Outside of mental health, during the COVID-19 pandemic, Cénat et al., (2023b) observed that Black communities in Canada were disproportionately affected by infection and mortality rates when compared to the general population and had the highest rates of vaccine mistrust. Upon investigation into phenomenon, Cénat et al. (2023b), despite in those having high rates of health literacy, if individuals had experience racial discrimination when interacting with health services, they were more likely to develop vaccine mistrust. Addressing systemic racism is a crucial and urgent responsibility that demands collective effort and commitment at both provincial and institutional levels. It requires a comprehensive approach to dismantle discriminatory practices and promote inclusivity and equality. Acknowledgement of the persistent distrust in institutions by Black communities is merely the first step towards an antiracist approach in mental health care service provision, as family psychoeducation is but one of many interventions underutilized by Black people in Canada.

Limitations

This was a first attempt to identify barriers to access family psychoeducation sessions for Black carers and is limited in its generalizability of results. One of the main challenges of this study, was the inability to reach family members who *had not* attended the family psychoeducation sessions. Below are some trends I found when trying to recruit participants, as I believe these ethnographic notes may be interesting to other researchers and contribute to explanations about low engagement with carers from Black communities in the family psychoeducation program.

I worked hard without success to reach this group of carers, which could be for a variety of reasons. Firstly, when trying to recruit participants, I found that many could not be contacted. In working with the research team and clinic members who had access to carer information, I discovered many dead phone numbers in case files, email addresses that would bounce back, or in some cases, simply did not have any contact information for carers. This could reflect institutional inconsistencies in reporting, but also the instability that some marginalized individuals face regarding access to consistent communication methods and service access. Secondly, as mentioned in the *Results* section, many carers from Black communities were not in Montréal. Many young Black patients had relocated from the Caribbean or Africa, (particularly from French speaking West Africa) to Montréal for school and had little social support available locally; if they did have someone available, it was often a sibling in the primary caregiver role. Some of the more disengaged patients were also of refugee or other non-resident status, and often did not have carer contact information noted in the file.

I also wanted to remark upon the documentation of participant characteristics. Due to missing clinical data on the ethnic background of patients and family members, it was difficult to be more specific in terms of recruitment and study focus, i.e., Black-Caribbean vs. Black African, or even more specific ethnicities, Nigerian, Senegalese, Jamaican, etc. However, when possible, in the summary of carer participants, their nationalities were noted (see *Appendix*). This issue speaks to some of the systemic and organizational issues affecting clinics, and how increased attention to collecting data on ethnicity and race would be helpful for future research efforts examining service usage and engagement. Canada has long been hesitant to collect race-based data, despite evidence that this limits the ability to ensure the applicability of evidence in healthcare research, provide patient-centred care, and address knowledge gaps in specific marginalized populations (Sheikh et al., 2023). Currently, there are calls for the development of a framework for systematically collecting, maintaining, and reporting ethnic data that will be informed and guided by Indigenous, Black, and other marginalized communities (Sheikh et al., 2023).

Additionally, as I was reliant on clinical staff support for carer recruitment and followed their recommendations regarding who would be appropriate for this project, it is possible that their own perceptions and relationships with carers had an impact on the study. For instance, specific carers may have been recommended to me over others due to pre-existing relationships that are viewed positively by clinical team members; moreover, carers that are perceived by case managers as being more receptive to research endeavours or are overall “easier” carers to interact and work with may have also been favoured. Thus, carers that are more critical of clinical services or have conflictual relationships with case managers may have been omitted from this study due to the recruitment procedure.

Finally, I wanted to address my own positionality during this project. I am a young White female researcher conducting a study on a highly sensitive topic. It may have been challenging for potential participants to feel comfortable speaking to me about a subject that was not only deeply personal, but potentially taboo for some. Furthermore, as hospitals and those affiliated with them are part of an institutional system with a history of discrimination toward Black people, there may have been some resistance or distrust in me and my intentions. Systemic racism is pervasive in psychiatric practice and research, and it is possible that some people were understandably disinterested in engaging with these systems beyond what was necessary.

Future Directions

This research is an attempt to engage with those that are disengaged from the family psychoeducation programming and the first episode psychosis clinics in general. These findings regarding the type of barriers that exist offer future avenues of research and suggestions for family psychoeducation modifications to improve access and attendance of carers from Black communities. Examples include identifying carer understandings of feelings and experiences of grief and its relationship to denial, addressing systemic mistrust, and assessing the impact of organizational culture on therapeutic outcome. All topics of future research would require an intersectional approach and should examine these concerns across ethnoracial, socioeconomic, and gender lines. Additionally, developing strategies to incorporate and promote community representation at an institutional level and further outreach to disengaged carers should be prioritized. Finally, as evidenced through this study, given the challenges reaching carers who are disengaged, more time would be required to complete such a project in the future – more than a master’s project could allow, especially when considering the context of the COVID-19 pandemic and physical distancing measures.

CONCLUSION

This exploratory study identified barriers impeding carer engagement from members of Black communities to family psychoeducation programs at two first episode psychosis clinics in Montréal. Core emergent themes included logistic, systemic, and interpersonal and community barriers. Relevant subthemes, such as distrust in the healthcare system due to historical trauma, denial of the diagnosis, isolation, and stigmatization were some of the key barriers identified facing Black carers. Additional research objectives in this study were met, including examining the organizational culture and structure of the clinic which hosts the family psychoeducation, and reflecting on the impact of the pandemic on the quality of care and service. While some challenges can be addressed by the clinical team, including more interactions and connections with carers, some issues reflect ongoing struggles in Québec's healthcare infrastructure and may require provincial level changes and support.

Another objective of this research was to identify adaptations to improve the attendance of Black carers of patients with first episode psychosis. Adaptations included advertising the family psychoeducation appropriately and clearly communicating the relevance of the content to carers' everyday challenges, while ensuring that at the clinic level and during program sessions there is community representation, and a holding space for more connections and discussions amongst carers in attendance to alleviate sentiments of isolation. These findings also speak to the implications of virtual modalities to conduct future family psychoeducation sessions and whether their accessibility and convenience impact the potential therapeutic benefits of the sessions. Additional avenues of research include further examination of the experience of denial and grief by carers, as well as how institutional structures can improve relationships with marginalized communities. Future research endeavours should strive to improve outreach efforts, such as community visits, to the most disengaged carers to understand their lived experience and potential additional barriers that this population faces.

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APPENDIX

Tables: Sociodemographic Information

Table 1

Sociodemographic Characteristics of Case Managers

Characteristics	Respondents *n*
Gender	
Female	8
Male	2
Country of Birth	
Canada	7
Iran	1
Cameroon	1
USA	1
Ethnic background	
Canadian/Quebecois	6
Cameroonian	1
Jewish	2
Persian	1
Mother tongue	
English	5
French	4
Other	1
Highest education level	
University	6
Post-graduate degree	4

Table 2

Sociodemographic Characteristics of Participants

Carer	Age	Gender	Country of Birth	Ethnic Background	Languages spoken	Highest education level	Relationship to patient
C1	58	Female	Senegal	Senegalese	French	University	Mother
C2	52	Female	Haiti	Haitian	English, French, Creole	Postgraduate	Mother
C3	46	Female	Canada	Barbadian	English	University	Mother
C4	34	Male	Congo	Congolese	French, Kiswahili	Postgraduate	Brother

Resources for Carer Participants

RESSOURCES DE SOUTIEN FAMILIAL | FAMILIAL SUPPORT RESOURCES

L'Accolade Santé mentale

450-699-7059 | 1-866-699-7059

127 boulevard Saint-Jean-Baptiste,
Châteauguay, QC, J6K 3B1

Link | Lien
https://www.accoladesantementale.org/en/

Amis de la santé mentale | Friends for Mental Health

514-636-6885

186 Place Sutton, Beaconsfield, QC, H9W 5S3
- Suite 121

Link | Lien
https://www.asmfmh.org/en/

Association des parents et amis de la personne atteinte de maladie mentale Rive-Sud (APAMM-RS)

450-766-0524

10, boulevard Churchill, suite 206
Greenfield Park, Québec
J4V 2L7

Link | Lien
http://apammrs.org/

AMI-Quebec

514-486-1448

5800, boul. Decarie, Montreal, Quebec H3X
2J5

Link | Lien
https://amiquebec.org/

Association de parents pour la santé mentale de Saint-Laurent-Bordeaux-Cartierville (APSM)

514-847-0787

55, avenue du Mont-Royal Ouest, bureau 602
Montréal (Québec) H2T 2S6

Link | Lien
https://racorsm.org/

Association lavalloise de parents pour le bien-être mental (ALPABEM)

450-688-0541 | 1-888-688-0541

645 boulevard des Laurentides, Laval,
Quebec, H7G 2V8

Link | Lien
https://alpabem.qc.ca/

RESSOURCES DE SOUTIEN FAMILIAL | FAMILIAL SUPPORT RESOURCES

Association québécoise des parents et amis de la personne atteinte de maladie mentale (AQPAMM)

514-368-4824

1260, rue Sainte Catherine Est, bureau 208
Montréal (Qc) H2L 2H2

Link | Lien
https://aqpamm.ca/contact/

Centre de soutien en santé mentale Montérégie

450.486-1609

2046 boul. Édouard, Saint-Hubert, Québec,
J4T 1Z7

Link | Lien
https://www.cssm-m.com/

Parents et amis du bien-être mental du sud-ouest de Montréal (PABEMSOM)

514-636-6885

881 de l'Eglise, Verdun, Quebec H4G 2N4

Link | Lien
https://www.pabemsom.org/

La Parentrie

514-385-6786

10780 rue Laverdure, Local 203, Montréal,
QC, H3L 2L9

Link | Lien
https://www.laparentrie.org/accueil

Société Québécoise de la Schizophrénie

514-251-4125 | 1-866 888-2323

7401, rue Hochelaga, Montréal, Québec, H1N
3M5

Link | Lien
https://www.schizophrenie.qc.ca/accueil