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Understanding the information needs of clients and caregivers regarding early psychosis: A conventional content analysis

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A thesis submitted in partial fulfillment of the requirements for the Master of Health Information Science degree in Health Information Science

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Abstract

A first episode of psychosis is defined by the first presentation of psychotic symptoms that have gone untreated, characterized by a loss of contact with reality and significant declines in functioning. Low psychosis literacy among clients and caregivers can result in a delay in receiving treatment. This study sought to understand the information needs of clients and caregivers regarding early psychosis. Using a conventional content analysis, we conducted a secondary analysis of 64 transcripts from clients, caregivers, family physicians, and early psychosis intervention clinicians. Clients and caregivers often described having difficulties recognizing symptoms of early psychosis until they became overt and disturbing. The results suggest there should be greater awareness of the symptoms of psychosis, more information regarding the causes of psychosis, and information on services for psychosis for clients and caregivers. Educational initiatives aimed at increasing psychosis literacy may increase the perceived need for support and promote help-seeking behaviours.

Keywords

First-episode psychosis, early psychosis intervention, mental health problems, psychoeducation, psychosis literacy, mental health literacy, public education

Summary for Lay Audience

A first episode of psychosis occurs when a person loses contact with reality, which can lead to a decrease in their daily functioning. Psychosis literacy is knowing what psychosis is, what symptoms it can look like, and what are treatment options. Low psychosis literacy can cause a delay in knowing when to get help. The purpose of this study was to understand the information needs of clients and caregivers regarding early psychosis. Using a conventional content analysis, we conducted a secondary analysis of 64 transcripts from clients, caregivers, family physicians, and early psychosis intervention clinicians. Clients and caregivers shared they usually have a hard time recognizing the symptoms of early psychosis from normal behaviour. The results also suggest that there should be more information about what psychosis can look like and where to find the right support. Public education programs can help people know when they may be experiencing symptoms of psychosis and when they should get help from professionals.

Co-Authorship Statement

Tanvin Juneja completed this thesis project under the supervision of Dr. Kelly K. Anderson and under the advisement of Dr. Richard Booth. Tanvin Juneja was involved in the development and design of the thesis, in the data cleaning and conducting a conventional content analysis of the data, and in writing the first drafts of the paper and revising the subsequent drafts. Dr. Kelly K. Anderson was involved in informing the design of the study, in the conventional content analysis plan, in the interpretation of data, and in providing valuable insights during the critical revisions of the article for intellectual integrity. Dr. Richard Booth was involved in the qualitative interpretation of data and in the critical revision of the article for intellectual integrity.

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Chapter 1

1 Introduction and Background

1.1 Thesis Overview

Mental disorders are one of the leading causes of disability (Rehm & Shield, 2019). If left untreated, symptoms of mental disorders can worsen, causing distress and disruption in daily functioning. Severe psychiatric symptoms can result in a crisis and even suicide (COVID-19 Mental Disorders Collaborators, 2021). Research indicates that family members and caregivers play a vital role in motivating the individual to seek treatment (Goulding et al., 2008). Mental disorders can also negatively impact family members and caregivers. Taking care of and supporting a person with a mental disorder can take a significant toll on family members' mental health, employment, income, and social relationships, and can restrict their daily activities and personal life (Del Vecchio et al., 2015; Moudatsou et al., 2021; Selick et al., 2017)

Psychotic disorders, such as schizophrenia, are one type of mental disorder that impacts typical brain activity and function by altering a person's perceptions, thoughts, and beliefs. As a result, people who experience psychotic disorders can have trouble separating their perceptions and experiences from reality due to hallucinations, delusions, and disorganized thoughts and behaviours (DSM-5, American Psychiatric Association, 2013). A first episode of psychosis (FEP) is defined by the first presentation of psychosis symptoms that have gone untreated with antipsychotic medication in which there is a significant decline in daily functioning (Breitborde et al., 2009; McGorry et al., 2008; Perkins et al., 2005).

Although there are numerous evidence-based treatments available for psychotic disorders, clients and their family members face several barriers when seeking services and treatment, resulting in a prolonged duration of untreated psychosis (DUP). There is robust evidence from systematic reviews and meta-analyses that indicate a longer DUP is associated with poorer recovery and treatment outcomes, lower quality of life, and heightened distress for family members and caregivers (Marshall et al., 2005; Penttilä et al., 2014; Selick et al., 2017). One widely reported barrier to help-seeking is a lack of mental health literacy regarding

psychosis, known as psychosis literacy, which is the knowledge and awareness of psychosis, attribution to illness, and ability to navigate professional services (Addington et al., 2012; Jorm, 2000; López et al., 2018). A review of the literature suggests that the general population has low levels of psychosis literacy (Addington et al., 2012; López et al., 2018; Sutton et al., 2018).

It has been shown that increasing psychosis literacy through health promotion interventions and educational campaigns targeted toward the general population can increase awareness of psychosis and promote early intervention, thus shortening the DUP (Calderon et al., 2015; Casas et al., 2014; Hastrup et al., 2018; López et al., 2018; Selick et al., 2017). In order to decrease the barriers to help-seeking, it is important to educate the individual and their family members and caregivers regarding psychosis. This requires understanding what information is needed so effective educational interventions can be created (Addington et al., 2012).

The goal of the current study was to understand the information needs of people with a first episode of psychosis and their caregivers in Ontario, Canada. A secondary analysis (conventional content analysis) was conducted of qualitative interviews from a larger project focused on the role of primary care in early psychosis intervention that included the perspectives of patients, caregivers, and service providers.

1.2 Mental Disorders

Mental disorders are defined by a change in behaviour, thinking, or emotion (DSM-5, American Psychiatric Association, 2013). A mental disorder can cause distress or problems when completing daily tasks and responsibilities. This involves problems functioning in one's work, social, or family activities. Mental disorders can impact any person regardless of gender, age, race, ethnicity, sexual orientation, social status, or cultural identity (DSM-5, American Psychiatric Association, 2013; Jorm, 2000). Mental disorders are considered to be "chronic diseases of the young" (McGorry, 2005). A systematic review of the World Health Organization mental health surveys by Kessler et al. (2007) found that mental disorders that present in adulthood usually had their onset during childhood or late adolescence.

1.3 Psychotic Disorders

Psychotic disorders – such as schizophrenia and bipolar disorder with psychotic features – are a category of mental disorders that impact typical brain activity and function by altering a person’s perceptions, thoughts, and beliefs (DSM-5, American Psychiatric Association, 2013). As a result, people who experience psychotic disorders can have trouble separating their perceptions and experiences from reality (DSM-5, American Psychiatric Association, 2013). The exact causes of psychosis remain uncertain. Research indicates that vulnerability to a psychotic disorder may be related to environmental and genetic factors that influence early brain development (Perkins et al., 2005). Some examples of psychotic disorders include schizoid disorder, delusional disorder, bipolar disorder, and schizophrenia (DSM-5, American Psychiatric Association, 2013; Keshavan et al., 2020). In 2021, it was reported that the prevalence of schizophrenia and other psychotic disorders in the Canadian population was 4% – this is equivalent to over 1.5 million Canadians who are directly impacted by psychotic disorders, and even more family members or caregivers who are indirectly impacted (Lecomte et al., 2022).

1.4 Psychosis Symptoms

A first episode of psychosis (FEP) is defined by the first presentation of psychosis symptoms that have gone untreated with antipsychotic medication and significantly interferes with daily functioning (Breitborde et al., 2009; McGorry et al., 2008; Perkins et al., 2005). Psychotic symptoms – such as delusions, hallucinations, and disorganized thought and behaviour patterns – are debilitating and usually require psychiatric treatment (DSM-5; American Psychiatric Association, 2013). The symptoms of a psychotic disorder can present gradually or suddenly (McGorry et al., 2007; Välimäki et al., 2008). Psychosis can have a substantial influence on a person’s life, including their educational, social, and career development (DSM-5; American Psychiatric Association, 2013; Norman et al., 2005; Reed, 2008). In addition, psychosis can also have a profound impact indirectly on the lives of family members or caregivers as they navigate how to care for the person that is presenting symptoms of psychosis (Arora & Khoo, 2020; Gronholm et al., 2017; Lu et al., 2021; McGorry et al., 2008; Mueser et

al., 2020; Thomson et al., 2015). This typically includes balancing feelings of burden, guilt, exhaustion, and sometimes even embarrassment and shame due to the stigma associated with psychotic disorders (Burke et al., 2016; Compton et al., 2008; Jansen et al., 2015; Kumar et al., 2019; McGorry et al., 2008).

People with psychosis typically experience a range of symptoms that are categorized as “positive” or “negative” (DSM-5, American Psychiatric Association, 2013). The positive symptoms are added to a person’s experience, such as hearing or seeing things, and the presence of delusions. Negative symptoms of psychosis are symptoms that are reduced or removed from a person’s experience, such as social withdrawal and a reduction of emotion or motivation (DSM-5, American Psychiatric Association, 2013; Franz et al., 2010; McGorry et al., 2010).

1.5 Impact of Psychosis on the Individual

Psychosis typically develops during late adolescence or early adulthood, which is a sensitive developmental period in a person’s life (McGorry et al., 2007). It is during this time that people begin to form their peer networks, transition from family dependence to independence, develop their personality, explore sexual behaviours and interests, and figure out their role in the world (*Adolescent Health*, n.d.; McGorry et al., 2008; Reed, 2008). The onset of psychosis during this already vulnerable and difficult time creates a new set of challenges for the person to navigate (Perkins et al., 2005). Oftentimes, the symptoms of psychosis can disrupt the process of maintaining their social networks, developing their career, and advancing their education, which can lead to a person experiencing significant distress and social isolation (McGorry et al., 2008; Reed, 2008).

1.5.1 Warning Signs, Prodromal Phase, and Acute Phase of Psychosis

Prior to the insidious onset of a FEP, a person can show changes in their behaviour. For adolescents, this can include a sudden drop in their grades or job performance and difficulty thinking clearly or concentrating (Hardy et al., 2018; Mueser et al., 2020; Reed, 2008). Some

people may become more irritable, talk about their paranoid thoughts, or have difficulty telling reality from fantasy (Burke et al., 2016; Ferrara et al., 2021; Reed, 2008). Other common warning signs may include social withdrawal, a decline in self-care or personal hygiene, or displaying inappropriate emotions. There also may be an unusual sensitivity to stimuli, reduced speech, increased memory problems, and significant personality changes (Ahmed et al., 2020; Casas et al., 2014; López et al., 2018; McGorry et al., 2008; Mishra et al., 2021; Reed, 2008; Yarborough et al., 2019; Yeo et al., 2006). Prior research shows that several of these warning signs typically appear in the prodromal phase of psychosis. This is the period when most behavioural symptoms are displayed (Ahmed et al., 2020; Dutta et al., 2019; Hasan & Musleh, 2017; Jansen et al., 2015; Reed, 2008; Välimäki et al., 2008; Yeo et al., 2006).

During the acute phase of psychosis, the individual often has difficulty making sense of their experience, and this can lead to significant confusion, fear, and a sense of losing control of themselves. Symptoms that are characteristic of psychosis are typically displayed during the onset of the acute stage (Compton et al., 2008; Hasan & Musleh, 2017; Mishra et al., 2021; Nishii et al., 2010; Reed, 2008; Yarborough et al., 2019). This includes the following:

Hallucinations: a hallucination is a false or misleading perception of an event or object that involves any one of the following senses: visual, auditory, olfactory, tactile, and gustatory. For an individual experiencing a hallucination, the false perspective may seem real even though it is not. Hallucinations can be caused by substance use or chemical imbalances in the brain (Ahmed et al., 2020; Casas et al., 2014; López et al., 2009, 2018).

Delusions: a delusion is a firmly held and unshakeable belief about something that is not true. Even with proof of truth or reality, a person experiencing a delusion is often unable to change their belief (Ahmed et al., 2020; Casas et al., 2014; López et al., 2009, 2018).

Disorganized symptoms, such as thought disorder (ex. disorganized speech) and disorganized behaviour, can also be characteristic of psychosis.

Thought disorder: this can be characterized by disorganized thoughts, speech, or behaviour that can lead to abnormal ways of expressing oneself. A person experiencing a thought disorder may exhibit behaviours or talk about things that do not align with their environment or

situation (Ahmed et al., 2020; Casas et al., 2014; López et al., 2009, 2018).

Disorganized behaviour: this can be categorized by odd or bizarre behaviours that can be purposeless or random, and can involve ambivalent movements or unpredictable agitation. A person displaying disorganized behaviour may dress inappropriately (ex. wearing clothes that don't match the weather) or display inappropriate emotional responses. A person may also present catatonic symptoms that indicate a motor disturbance which can involve decreased motor activity or excessive motor activity (DSM-5, American Psychiatric Association, 2013).

These symptoms can become severe if they are not appropriately addressed and can threaten the person's ability to reason. It can also alter their self-concept. As a result, these experiences are often very distressing. The onset of the acute phase of psychosis can disrupt the individual's plans for their education, career, and social goals (Jansen et al., 2015; McGorry et al., 2010; McGorry et al., 2008; Reed, 2008; Välimäki et al., 2008; Yarborough et al., 2019).

1.5.2 Disruption of Career Development and Social Networks

Other impacts that psychosis can have on the individual is a disruption of career development and social networks. A person's erratic or aggressive behaviour, paired with the negative and stigmatizing attitudes associated with psychotic disorders, can cause family, friends, colleagues, and peers to distance themselves from the person, often because they are afraid or unsure of how they may act (Ahmed et al., 2020; Burke et al., 2016; Chong et al., 2005; Franz et al., 2010; Gronholm et al., 2017; He et al., 2020; Kular et al., 2019). The symptoms of psychosis can also make it hard to maintain close or intimate friendships or may lead to a decrease in job performance. This disturbance in the individual's social life can often lead to feelings of embarrassment, being stigmatized, loneliness, and increased isolation. This results in an overall decrease in social relationships and the desire to participate in social or work activities, further fuelling social withdrawal (Compton et al., 2008; Dutta et al., 2019; Goulding et al., 2008; Yeo et al., 2006). People experiencing these symptoms tend to feel a range of emotions such as shame and fear of not being in control. Many of these feelings can lead to the development of depression, especially as the person begins to understand the gravity of their

diagnosis, and this can result in feelings of loss for their life, career, dreams, and goals (Burke et al., 2016; Hasan & Musleh, 2017; Mueser et al., 2020; Nishii et al., 2010; Reed, 2008; Yeo et al., 2006). People with FEP are at a significantly higher risk of suicide ideation, attempt, and death (Anderson et al., 2018b; McGorry et al., 2010; Nanda et al., 2016; Reed, 2008; Välimäki et al., 2008).

1.6 Impact on Family Members

The symptoms of psychosis can have a profound impact on a person's family or caregiver, especially during a first episode of psychosis (Del Vecchio et al., 2015; Kumar et al., 2019; Moudatsou et al., 2021). A caregiver is any person who provides support to a patient or person in need, and can be an immediate family member, a relative, a friend, or a neighbour (Moudatsou et al., 2021). Taking care of and supporting a person with psychosis can take a significant toll on family members' mental health, employment, income, and social relationships, and can restrict their daily activities and personal life (Del Vecchio et al., 2015; Moudatsou et al., 2021; Selick et al., 2017). Typically after a first episode of psychosis, the emotional and physical burden of support and care is the responsibility of family members or caregivers. This can add to existing feelings of anxiety and stress, especially as they try to navigate their own feelings (Moudatsou et al., 2021; Selick et al., 2017). The unpredictable nature and severity of hallucinations, delusions, or disorganized thoughts and behaviours can also result in feelings of fear for their own safety (Del Vecchio et al., 2015; Selick et al., 2017).

Many family members express feelings of loss and grief for the person's future and goals that they feel will likely not be achieved. Parents may grieve the future that they hoped their child will have and change their expectations regarding their career, education, and marriage (Ahmed et al., 2020; Burke et al., 2016; Reed, 2008; Selick et al., 2017; Yeo et al., 2006). People who experience psychosis in early adulthood can make aging parents feel like they are taking on the parenting role again, and increase feelings of worry about what will happen to their child if they are unable to care for them (Yarborough et al., 2019). Partners and spouses also feel similar emotions, but may also want to distance themselves emotionally or physically from the person experiencing symptoms (Jansen et al., 2015). Overall, this can increase despair and hopelessness

for family members and caregivers. Consequently, these emotions can negatively influence their attitudes toward the person with psychosis, resulting in a decrease in moral support and motivation for them (Goulding et al., 2008; Kumar et al., 2019; Reed, 2008).

Many family members also experience feelings of shame and embarrassment within their social networks as a result of the stigma and misconceptions surrounding psychosis. Family members experience high levels of stigma and negative attitudes that can cause them to withdraw from their social networks (Ahmed et al., 2020; Del Vecchio et al., 2015; Gronholm et al., 2017; Kular et al., 2019; Moudatsou et al., 2021; Selick et al., 2017).

Family members often attribute the early warning signs of psychosis to normal developmental behaviours (Franz et al., 2010; Jansen et al., 2015; Kumar et al., 2019; Yarborough et al., 2019). This increases feelings of frustration towards the person with psychosis and decreases empathetic attitudes (Hasan & Musleh, 2017). Once the early symptoms begin to transition into more acute symptoms of psychosis, family members describe an increased perceived need for support which can facilitate help-seeking behaviours. This can add to the burden of guilt family members experience as they blame themselves for not recognizing the signs earlier (Hasan & Musleh, 2017; Kular et al., 2019; Mishra et al., 2021; Nishii et al., 2010).

It is crucial to also provide support and services to the family members and caregivers of people with psychosis, especially educational interventions that increase psychosis literacy (Moudatsou et al., 2021; Selick et al., 2017). Educational support and interventions regarding stress management, coping strategies, tools for empowerment, types of services available, as well as information on psychotic disorders, has been shown to benefit family members, leading to improvements in quality of life and increased empathy for the person with psychosis (Selick et al., 2017). For instance, Del Vecchio et al. (2015) found that preventative educational interventions can reduce the DUP by enabling family members to recognize deviations of an individual from their typical behaviour. This can increase their perceived need for support (Del Vecchio et al., 2015). Because family members are often key players that are involved in help-seeking for the person experiencing symptoms of psychosis, it is crucial that they are well-informed (Archie et al., 2010; Del Vecchio et al., 2015; Kumar et al., 2019; Yeo et al., 2006). Thus, to ensure that family members feel supported and to reduce their suffering, educational

interventions should be more targeted toward their needs (Selick et al., 2017).

1.7 Duration of Untreated Psychosis

The delay between the onset of symptoms of psychosis and the beginning of appropriate treatment is referred to as the duration of untreated psychosis (DUP) (Marshall et al., 2005). On average, this DUP typically lasts between 6 months and 2 years (Marshall et al., 2005). Some determinants of DUP include demographic factors, mode of onset of symptoms, family-level factors, coping capacity, and health service delays (Akçay Oruç & Gültekin, 2018; Compton et al., 2008, 2008; Hastrup et al., 2018; Perkins et al., 2005).

One contributing factor to treatment delays is the individual, or their family members, not seeking help (Akçay Oruç & Gültekin, 2018; Compton et al., 2008; Franz et al., 2010; Hastrup et al., 2018; Perkins et al., 2005). There are several reasons, and most are associated with low psychosis literacy, which refers to the ability to recognize symptoms of psychosis and the knowledge of services and treatment options available. One factor that impacts the general public's level of psychosis literacy is stigma. Many studies found that stigma creates a considerable barrier because people have limited understanding of their condition and desire to be perceived as normal (Compton et al., 2008; Del Vecchio et al., 2015; Dutta et al., 2019; Franz et al., 2010; Gronholm et al., 2017; Hasan & Musleh, 2017; He et al., 2020; Jansen et al., 2015; Kular et al., 2019; Mueser et al., 2020). Another reason is that people recognize symptoms as unproblematic and interpret them as normal developmental changes. For instance, sleep disturbances, depression, and withdrawal from social settings are typically perceived as normal adolescent behaviour (Ahmed et al., 2020; Bignall et al., 2015; Caplan, 2019; Ghali et al., 2013; Memon et al., 2016; S. Y. Park et al., 2013). Another cause for delay is a lack of support or motivation from family and friends to seek services and support (Hasan & Musleh, 2017; Kumar et al., 2019). Acute positive symptoms are often a strong motivator for treatment, as the symptoms become too severe to ignore, such as full-blown hallucinations and delusions that impair the ability to complete daily tasks (Chong et al., 2005; Kular et al., 2019; Mishra et al., 2021; Nishii et al., 2010).

Several studies suggest that a shorter DUP is associated with better recovery and

treatment outcomes. For instance, Fusar-Poli et al. (2017) and Valmaggia et al. (2015) found that treatment during the very early stages of psychosis, also known as the prodromal phase, is associated with high patient satisfaction, increased engagement with treatment, improved personal well-being and self-image, and better relations with their social networks. These findings were also confirmed in a systematic review and meta-analysis by Penttilä et al. (2014) and a critical review and meta-analysis by Perkins et al. (2005). These outcomes often resulted in a decreased perceived burden to the family, increased quality of life for the individual, and increased functioning in daily activities, such as work or school (Mishra et al., 2021). Many researchers have also found that a longer DUP may be associated with neurotoxicity, worsening of symptoms, poor quality of life, and negative treatment outcomes (Apeldoorn et al., 2014; Dutta et al., 2019; Franz et al., 2010; Hasan & Musleh, 2017; Hastrup et al., 2018; Marshall et al., 2005; McGorry et al., 2007, 2008, 2010; Mishra et al., 2021; Mueser et al., 2020; Norman et al., 2005; Perkins et al., 2005; Reed, 2008; Ruggeri et al., 2015).

Early psychosis intervention (EPI) programs have been developed to recognize and treat symptoms of psychosis when they are in their early stages, with an aim of reducing the DUP. (Marshall et al., 2005; McGorry et al., 2007; Norman et al., 2005; Perkins et al., 2005). The components of EPI include pharmacotherapy, psychotherapy, case management, and family educational interventions and support (McGorry et al., 2008, 2010; Mishra et al., 2021; Schoer et al., 2021). In London Ontario (Canada), the Prevention and Early Intervention Program for Psychoses (PEPP) is the model used to provide clients with comprehensive and coordinated treatment (Norman & Manchanda, 2016). In order to promote help-seeking behaviours and facilitate early interventions by people with psychosis and their caregivers, educational interventions that help with early detection and symptom recognition are needed at the community level (Norman & Manchanda, 2016; Selick et al., 2017).

1.8 Pathways to Care

A pathway to care is the means by which an individual can access help from services and support for their health-related problems (Jansen et al., 2015). As the name implies, it is the series of help-seeking contacts taken to receive appropriate care (Anderson et al., 2010, 2018a; Jansen et al., 2015). Pathways to care are defined as steps of contacts with individuals and

organizations that are initiated by an individual experiencing distress, and by family members or caregivers to seek help and support (Rogler & Cortes, 1993). The components of a pathway to care involve understanding the help-seeking behaviours of service users, accessibility of health services, recognition of symptoms of psychosis, and the appropriate responses to symptoms (Anderson et al., 2010, 2018a; Jansen et al., 2015). Canadian research suggests that many people with FEP face barriers when trying to access specialized treatment programs that are targeted to treat psychosis (Anderson et al., 2010). Since early detection and the reduction of DUP are associated with better outcomes for people experiencing FEP, there is an emphasis to understand the best route to access and receive appropriate treatment (Anderson et al., 2010, 2018a).

Chapter 2

2 Literature Review

The topic for this thesis involves understanding the information needs of clients and caregivers regarding early psychosis. This chapter will review prior literature on the current state of mental health literacy for psychosis, also known as psychosis literacy. The chapter is divided into three sections: knowledge and recognition of psychosis symptoms, barriers of help-seeking behaviours associated with psychosis literacy, and enablers of help-seeking behaviours. This literature review outlines the role of information in the appropriate and timely recognition of psychosis symptoms.

2.1 Mental Health Literacy

To facilitate the early identification of psychosis and help-seeking, the barriers that underpin help-seeking behaviours must be investigated (Akçay Oruç & Gültekin, 2018; Gronholm et al., 2017). It has been well-documented that a lack of recognition of symptoms of psychosis and a lack of knowledge of how to receive support are significant factors that can prolong the DUP (Akçay Oruç & Gültekin, 2018; Anderson et al., 2010; Ferrara et al., 2021; Goulding et al., 2008; Hasan & Musleh, 2017; Lloyd-Evans et al., 2011; Mueser et al., 2020; Reed, 2008; Souaiby et al., 2019). This acts as a barrier for both the individual and their friends, family members, and caregivers. The knowledge and recognition of symptoms and treatment options are referred to as mental health literacy (Jorm, 2000). One widely accepted definition of mental health literacy is by Jorm et al. (2000) which defines it as the “knowledge and beliefs about mental disorders which aid their recognition, management, or prevention” (p.396). Thus, mental health literacy is threefold and a lack of knowledge in any category can act as a barrier to help-seeking behaviours (Jorm, 2012). Mental health literacy for psychosis, also referred to as psychosis literacy, would be similarly defined as the ability to recognize symptoms of psychosis, understand appropriate coping management skills, and seek timely treatment when needed (Addington et al., 2012; López et al., 2018). Recent research over the past decade reveals that the

general population has low levels of psychosis literacy and high levels of stigmatizing beliefs regarding psychotic disorders that are not consistent with current medical models (Ahmed et al., 2020; Calderon et al., 2015; Franz et al., 2010; He et al., 2020; Jansen et al., 2015). Several studies have also found that one of the most common reasons for treatment delays involve low psychosis literacy, such as the unawareness of illness and high perceived stigma (Ahmed et al., 2020; Del Vecchio et al., 2015; Dutta et al., 2019; He et al., 2020; Kular et al., 2019). Low levels of psychosis literacy can lead a person to feel embarrassed when they experience symptoms of psychosis, consequently decreasing their self-confidence and self-image (Burke et al., 2016).

To facilitate help-seeking behaviours, the barriers that are associated with the recognition of psychosis symptoms and treatment-seeking must be investigated. Current efforts to increase psychosis literacy in the general population include public mental health promotion and educational campaigns that strive to promote the need for positive mental health (Calderon et al., 2015; Casas et al., 2014; Fusar-Poli et al., 2017; López et al., 2018; Selick et al., 2017; Yeo et al., 2006). For instance, they outline the importance of resilience, psychological well-being, and competence (Fusar-Poli et al., 2017). As a result, public mental health promotion and educational campaigns are a type of preventive intervention targeted toward the general public. Their primary objective is to raise awareness of psychosis and other mental disorders among the general population, specifically those who may be at risk of developing a psychotic disorder (Calderon et al., 2015; Casas et al., 2014; Fusar-Poli et al., 2017). One example of a community campaign is “La CLAVE” (translation: “The Clue”), which is a psychoeducational tool targeted toward the Spanish-speaking population to increase their psychosis literacy across 4 domains: knowledge of psychosis, identification of psychosis symptoms, attributions to mental illness, and professional help-seeking (López et al., 2009)

It is known that family members and caregivers are crucial in providing support and motivation to seek treatment (Compton et al., 2008; Del Vecchio et al., 2015; Goulding et al., 2008; Kumar et al., 2019; Moudatsou et al., 2021). The person experiencing psychosis may be unaware of the deviations in their own behaviour, thus family members, friends, and caregivers may be more likely to recognize behavioural changes and promote help-seeking (Compton et al., 2008; Goulding et al., 2008; Selick et al., 2017). By understanding the gaps in psychosis literacy in families and social communities that act as barriers to help-seeking behaviours and deter

people from accessing treatment, better public health promotion and educational campaigns can be developed to educate the general population (Selick et al., 2017).

Literature regarding the current state of psychosis literacy amongst the general population suggests that there are varying perspectives on mental disorders and psychosis, and people experience numerous barriers to accessing services (Hasan & Musleh, 2017; He et al., 2020; O'Connell et al., 2022; Torres Stone et al., 2020a).

2.2 Knowledge and Beliefs about Psychotic Disorders

2.2.1 Lack of Knowledge and Recognition

One of the most common reasons for the delay in seeking treatment or support for psychotic symptoms is the lack of knowledge or a poor understanding of mental disorders, including psychotic disorders. To begin, participants from several studies shared that they initially thought the symptoms of psychosis were linked to a somatic illness, such as a seizure, fever, or jaundice (Dutta et al., 2019; Hasan & Musleh, 2017; Jansen et al., 2015; Mishra et al., 2021). The misconceptions regarding psychosis symptoms can significantly impact one's beliefs and attitudes toward those who display these symptoms and thus the need for timely and appropriate medical treatment (Chong et al., 2005; O'Connell et al., 2022; Reed, 2008; Yarborough et al., 2019). As symptoms become more difficult to handle, individuals tend to isolate themselves from their family and friends because they do not understand what they are experiencing (Yarborough et al., 2019). Although people notice a deviation in their normal behaviour, a significant proportion of people with psychotic disorders do not attribute their symptoms to a mental disorder, especially not a psychotic disorder (Anderson et al., 2013a; Calderon et al., 2022; Yarborough et al., 2019). Consequently, they did not perceive the need to seek treatment for their symptoms (Anderson et al., 2013a; Calderon et al., 2022; Yarborough et al., 2019). This causes a significant delay in treatment-seeking because they do not associate their symptoms of psychosis as a psychiatric or psychological problem that requires medical treatment (Berger et al., 2006; Nkire et al., 2015; Torres Stone et al., 2020). Manifestations of early psychosis tend to be normalized in adolescence, such as being labelled as mood swings and

irritability. Parents often attributed their child's anxiety, depression, and social withdrawal a result of academic stresses or changes due to puberty (Dixon De Silva et al. (2020) and C. Park et al. (2022)). It is especially common among ethnic minority families to not recognize the early symptoms of psychosis as requiring medical treatment (Ahmed et al., 2020; Bignall et al., 2015; Caplan, 2019; Ghali et al., 2013; Memon et al., 2016; Park et al., 2013). In fact, Caplan (2019), Dixon De Silva et al. (2020), and Memon et al. (2016) found that many ethnic minority parents expressed that feelings of anxiety and depression were not considered to be real problems within their cultures. These results suggest that symptoms of psychosis are not generally identified among people with psychosis and their family members. Many studies also found that people often considered that mental health services are specifically for those who are "crazy" or experience severe symptoms (Arora & Khoo, 2020; Kular et al., 2019; Reed, 2008).

2.2.2 Culture-Specific Beliefs of Mental Disorders and Causes

Consistent with several previous findings, the general population's perceptions regarding the causes of mental disorders are in some cases assumed to be a result of spiritual or supernatural events. In the context of receiving a formal diagnosis and medical treatment based on the Western model for psychotic disorders, the different understandings and beliefs of psychotic disorders with ethnic cultures can sometimes be seen as a barrier. For instance, research studies conducted with participants from Mexico, United States, Malaysia, Singapore, India, China, and Korea found that a majority of participants perceived that symptoms of psychosis are due to supernatural events, such as being possessed by demons, a result of black magic, evil spirits, or wrong-doing of ancestors (Chong et al., 2005; Dutta et al., 2019; Franz et al., 2010; Hasan & Musleh, 2017; Mishra et al., 2021). These strongly-held beliefs regarding supernatural causes for psychosis were a significant barrier in medical treatment-seeking (Nishii et al., 2010). Instead, several individuals and their families first sought treatment and support from faith-based or traditional healers. This results in a further delay in receiving a formal diagnosis and seeking appropriate evidence-based treatment that aligns with the Western medical model (Chong et al., 2005; Hasan & Musleh, 2017; Moudatsou et al., 2021). Several studies also found that many immigrant populations, such as Latinos, Chinese, Malay, and Indians,

considered that the positive symptoms of psychosis were due to the individual losing their soul, a punishment from god, or a lack of religiosity (Caplan, 2019; Chong et al., 2016; Dixon De Silva et al., 2020). These findings reveal the lack of psychosis literacy among the general population and the need to enhance the understanding of the causes of psychosis.

2.2.3 Perceived Weakness Associated with Psychosis

In some populations, psychotic disorders were associated with weakness and laziness (Chong et al., 2016; Tieu et al., 2010; Yu et al., 2015). Patients, families, and caregivers who do not understand how mental disorders can manifest believed they should be able to manage the symptoms of psychosis on their own without formal treatment. Many studies found that participants attributed symptoms of psychosis as laziness, a weak mind, or a weakness in character (Arora & Khoo, 2020; Park et al., 2013; Salami et al., 2019; Wang et al., 2019). Thus, several ethnic populations do not recognize psychosis as a medical problem.

2.3 Barriers to Help-Seek Behaviours

Overall, prior findings suggest that common barriers for seeking mental health services include misleading assumptions of treatment, low perceived need for support, stigma of psychosis, and a lack of social support from friends and family.

2.3.1 Misleading Assumptions of Treatment

Several researchers report that the general population has misleading assumptions due to a lack of information regarding treatment for psychosis. As a result, this can lead to a delay in seeking treatment because of the associated negative attitudes (Ahmed et al., 2020; Burke et al., 2016; Franz et al., 2010; He et al., 2020; Kular et al., 2019). For instance, populations with low levels of psychosis literacy are skeptical of mental health professionals and believe that psychotherapy services are not effective. In some cases, people agreed that there may be some

benefits to seeking proper treatment, but did not believe that full recovery was possible (Nishii et al., 2010). Many ethnic minority groups, such as South East Asians (SEA), Hispanics, black minority ethnicities (BME) and Chinese, were found to have lower levels of psychosis literacy and many assumed that treatment for psychosis only involved pharmacological options, which was a deterrent to seeking support (Bignall et al., 2015; Dixon De Silva et al., 2020; Ghali et al., 2013; Memon et al., 2016; Saasa et al., 2021). This was also supported by Kumar et al. (2019), who found that patients and families who were receiving medication treatment were provided with little explanation or information as to the treatment protocol and how the medication would be helpful. Some findings also suggest that people are under the assumption that mental health support is only necessary when symptoms become severe or burdening (Hastrup et al., 2018; He et al., 2020).

2.3.2 Low Perceived Need for Support

A low perceived need for support was reported to be a barrier to seeking treatment for symptoms of psychosis. Several studies reported comparable findings that people often underestimated their symptoms and considered them to be a passing phase (Dutta et al., 2019; Hasan & Musleh, 2017; Mishra et al., 2021; Souaiby et al., 2019). Unfortunately, in the early stages, symptoms of psychosis can be confusing, unclear, and difficult to separate from usual developmental challenges (Jansen et al., 2015). Oftentimes, the negative symptoms of psychosis, such as social withdrawal, anxiety, and depression were less likely to be attributed to a mental disorder (Dutta et al., 2019; Hasan & Musleh, 2017; Mishra et al., 2021; Souaiby et al., 2019). Due to a lack of insight, individuals were unable to identify their symptoms of psychosis as requiring medical treatment which resulted in lower self-initiated help-seeking since they did not perceive a need for support (Mishra et al., 2021). They were convinced that their distressing experiences were not disturbing enough to require medical treatment, or could be resolved on their own (Jansen et al., 2015; Kumar et al., 2019; Nishii et al., 2010). After the onset of psychotic symptoms, help-seeking was predominantly initiated by family members and friends (Jansen et al., 2015).

Many parents and caregivers also do not perceive their child's early psychotic symptoms

as those needing attention (Del Vecchio et al., 2015; Jansen et al., 2015; Yarborough et al., 2019). Parents and caregivers often attributed the symptoms to typical adolescent behaviour which led to treatment delays (Jansen et al., 2015; Yarborough et al., 2019). Sometimes, symptoms of psychosis were misattributed to adolescent substance use, such as being under the influence of drugs or alcohol. Due to this, the severity of the symptoms is often underestimated and treatment was not perceived as being important (Franz et al., 2010; Jansen et al., 2015).

2.3.3 Fear of Stigma/Prejudiced Beliefs

Stigma, prejudiced beliefs, and negative attitudes regarding mental disorders was also noted to be a barrier to help-seeking behaviours (Kular et al., 2019). Several studies have consistently shown that the general population is often unable to recognize symptoms of psychosis and or understand what causes them. By lacking knowledge related to psychotic disorders and their manifestations, further negative and stigmatizing perspectives of psychosis and service use are promoted because the common belief is that mental health services are only for individuals that have extreme mental disorders. As a result, people with psychosis face several barriers when seeking treatment and the delay in treatment can lead to detrimental effects on their psychological functioning (Anderson et al., 2013a; Compton et al., 2008; Del Vecchio et al., 2015; Dutta et al., 2019; Franz et al., 2010; Gronholm et al., 2017; Hasan & Musleh, 2017; He et al., 2020; Jansen et al., 2015; Kular et al., 2019; Mueser et al., 2020).

Broadly, stigma is defined as the presence of negative emotional reactions, labelling, stereotyping, and discriminating attitudes towards a population (Anderson et al., 2018a; Compton et al., 2008; Mueser et al., 2020)

Negative, stigmatizing beliefs and attitudes about psychosis are not only held by family members, friends, and the community, but also the individual. People with psychosis typically experience severe perceived stigma and fear of being labelled as “crazy.” This can be due to the false stereotypical beliefs surrounding psychotic disorders, discriminatory behaviours, and display of negative affective reactions. A diagnosis of a psychotic disorder is often perceived to make the individual unpredictable, dangerous, and aggressive (Ahmed et al., 2020; Burke et al.,

2016; Franz et al., 2010; Jansen et al., 2015; Kular et al., 2019). These perspectives negatively influence people with psychosis to withdraw from their social networks. Several studies suggest that individuals with high stigmatizing attitudes towards psychosis often have a longer DUP (Ahmed et al., 2020; Compton et al., 2008; Dutta et al., 2019; Franz et al., 2010, 2010; Gronholm et al., 2017; Jansen et al., 2015; Kular et al., 2019; Mishra et al., 2021). This may be because symptoms of psychosis are ignored or normalized due to the fear of embarrassment or being labelled, until symptoms become pronounced and disrupt the individual's daily functioning (Jansen et al., 2015). Mueser et al. (2020) and Compton et al.'s (2008) findings indicate that high levels of stigmatizing attitudes among individuals with psychosis were typically associated with more severe symptoms of psychosis, decreased recovery, and an overall lower subjective well-being. It was also found that people had a negative self-image, lower levels of self-confidence, increased sense of being different from others, and increased feelings of shame, anger, worry, and depression (Gronholm et al., 2017; He et al., 2020; Kular et al., 2019).

Families often experience social stigma as well if their family member begins displaying symptoms of psychosis. Many families believe that the presence of a mental disorder within their home will bring their family shame in the community. Due to this, many families were reluctant to openly discuss their family member's symptoms (Compton et al., 2008; Goulding et al., 2008; López et al., 2009; Selick et al., 2017). Many individuals hid their symptoms from their families as well because they were afraid of being labelled (Franz et al., 2010; Hasan & Musleh, 2017). Several researchers have also found that seeking mental health services for children with symptoms of psychosis was significantly looked down upon within one's community, potentially jeopardizing the family's integrity and status (Dixon De Silva et al., 2020; Hasan & Musleh, 2017; Hastrup et al., 2018; Herrera et al., 2023; Nishii et al., 2010). To prevent feeling judged or discriminated against, individuals and their families avoided treatment (Dixon De Silva et al., 2020; He et al., 2020; Kular et al., 2019; Memon et al., 2016; Torres Stone et al., 2020b). In summary, lower levels of psychosis literacy were often associated with higher levels of negative and stigmatizing attitudes.

2.3.4 Lack of Supportive Social Networks

Social networks can act as a barrier to help-seeking if they are unsupportive, as they do not empower the individual to seek the appropriate services for their symptoms of psychosis (Goulding et al., 2008; Selick et al., 2017). There are several reasons why an individual's social network may be unsupportive or reluctant to accept there is a concern, such as culture-specific beliefs and negative attitudes toward mental disorders (Hasan & Musleh, 2017). For instance, families and friends may be unsupportive due to the fear of being labelled or stigmatizing societal beliefs regarding psychosis (Burke et al., 2016; Hasan & Musleh, 2017). In addition, some families do not believe that treatment for psychosis and other mental disorders is effective, thus they do not support their family member seeking it, further resulting in a delay (Hasan & Musleh, 2017; Kumar et al., 2019). Hasan and Musleh (2017) found that many people felt that they had to convince their family that they required treatment before they could seek help, and if this was not possible, many people hid their symptoms. Studies also found that individuals were worried that their family members and friends would treat them differently if they sought out mental health services for their symptoms (Ahmed et al., 2020; Burke et al., 2016; Goulding et al., 2008; He et al., 2020).

Several studies found that parents and significant others with lower levels of psychosis literacy were demeaning or uncaring toward the individual with symptoms of psychosis (Hasan & Musleh, 2017; Jansen et al., 2015). This supports the notion that a poor understanding of psychosis results in unsupportive social networks because they are not aware of psychotic disorders and are unsure how to respond to the symptoms. People who are unaware of how psychosis symptoms can manifest often considered symptoms as passing phases (Jansen et al., 2015). As a result, some participants agreed that their social network's unsupportive attitudes and behaviours are not due to bad or malicious intent, rather it was likely a lack of knowledge regarding psychosis and the efficacy of treatment (Jansen et al., 2015).

2.3.5 Other Barriers

An additional barrier to help-seeking for psychosis is being unable to effectively

communicate with professionals and explain symptoms. This can be due to language barriers or lack of knowledge regarding how to articulate their problems (Arora & Khoo, 2020; Torres Stone et al., 2020b). Many studies also indicated that logistical barriers, such as geographical challenges or lack of transportation, negatively impacted help-seeking behaviours (Dixon De Silva et al., 2020; Isaacs et al., 2010). Another common barrier is financial burdens. Many families from low socioeconomic conditions could not afford treatment or were unable to take time off from work to attend their appointments. Some people expressed that childcare options were also limited for them or that they could not afford treatments that were not covered under health insurance plans (Arora & Khoo, 2020; Lu et al., 2021; Thomson et al., 2015). Collectively, these factors acted as additional barriers to help-seeking.

2.4 Enablers of Seeking Treatment for Psychosis

2.4.1 Higher Psychosis Literacy

Several studies have shown the positive impact of educational training and campaigns in aiding early symptom recognition and decreasing negative, stigmatizing attitudes and beliefs regarding psychotic disorders and their treatment. It was found that individuals with higher levels of psychosis literacy were more likely to consider psychosis a medical problem that requires early interventions and medical support, thus it was also associated with a shorter DUP (Fusar-Poli et al., 2017; Hasan & Musleh, 2017; López et al., 2018; Myaba et al., 2021). The effectiveness of mental health promotion campaigns to increase the general public's knowledge and awareness of psychosis and shorten DUP has been studied globally. Several studies report that targeted informational campaigns and early detection can reduce DUP for people with FEP and aid in the navigation of psychosis treatment (Hastrup et al., 2018; Lloyd-Evans et al., 2011; McGorry et al., 2007). Abdel-Fadeel et al. (2013) explored the effectiveness of a large population-wide community-based programme named Treatment and Intervention in Psychosis (TIPS) and found that the implementation of this program also shortened DUP. Lopez et al. (2008) conducted a study with the "La CLAVE" psychoeducational program with Spanish-speaking participants and found that all participants reported an increase in knowledge in all four domains (knowledge of psychosis, identification of psychosis symptoms, attributions to mental

illness, and professional help-seeking). In addition, after the intervention, participants reported that they were less likely to seek non-medical sources of support, such as traditional healers, and more likely to seek professional services for psychotic disorders, (López et al., 2018). These findings were further supported by Calderon et al. (2022) who conducted a follow-up study using the “La CLAVE” psychoeducational program and found that an increase in psychosis literacy was associated with a reduction in DUP. In Ireland, Sutton et al. (2018) investigated the feasibility of a psychosis educational campaign to increase psychosis literacy among professional groups and also found that the intervention significantly enhanced psychosis literacy. Hui et al. (2019) also aimed to evaluate the effectiveness of a school-based intervention program, The School Tour, to increase psychosis literacy amongst students and reported that it significantly improved their knowledge of psychosis and attitudes towards seeking support. A study by Chong et al. (2016) broadly investigated the ability of participants to recognize mental disorders from vignettes and found that depression, dementia, and alcohol abuse were more accurately recognized in comparison to schizophrenia and OCD. The researchers suggested that this may be due to extensive public intervention initiatives that exist to educate the population regarding symptoms of depression, alcohol problems, and dementia (Chong et al., 2016). This indicates that the normalization of mental disorders through educational interventions can have positive impacts on the recognition of symptoms. Thus, to increase the public’s psychosis literacy, more efforts should be made to create targeted educational campaigns. This recommendation was supported by Caplan et al.’s (2019) findings that education interventions and exposure to mental disorders decreased stigmatizing attitudes and increased help-seeking behaviours.

2.4.2 High Perceived Need

One important factor that promoted help-seeking behaviours for psychosis was the perceived need for support, which often was associated with mild and severe symptoms resulting in an emergency or crisis. Many studies have found that when symptoms became severe and unmanageable, individuals were more likely to seek treatment and support, especially if they were experiencing positive symptoms in the acute phase of psychosis (Anderson et al., 2018a; Hasan & Musleh, 2017; Kular et al., 2019; Mishra et al., 2021; Nishii et al., 2010). Specifically

for the case of psychosis, the type of onset of symptoms typically determined help-seeking behaviour. An acute mode of onset was identified as an enabler for help-seeking behaviours because the symptoms became burdensome and disrupted daily functioning, such as causing a loss in work-productivity (Hasan & Musleh, 2017; Mishra et al., 2021; Nishii et al., 2010). Other research also suggests that individuals will seek treatment if their symptoms present as somatic problems or externalizing disruptions rather than psychological problems (Franz et al., 2010; Gronholm et al., 2017). A study done by Schoer et al. (2021) indicates that individuals with psychosis were more likely to access primary care services over the six year period before their first diagnosis of psychosis, relative to an age- and sex-matched comparison group. This suggests that people recognize a need for support (Anderson et al., 2018a; Schoer et al., 2021).

2.4.3 Presence of Social Support

The presence of support from an individual's social networks has been outlined as a critical component in psychosis interventions (Selick et al., 2017). Family members, significant others, relatives, and close friends are crucial players that can facilitate help-seeking behaviours and help encourage the individual to receive the appropriate specialized medical care they need (Del Vecchio et al., 2015; Hastrup et al., 2018; Jansen et al., 2015; Selick et al., 2017; Souaiby et al., 2019). In many instances, family members and caregivers were the primary source of support for an individual with psychosis (Jansen et al., 2015). As a result, if a social network is supportive and empathetic, it can act as an enabler for seeking and staying in treatment, thus shortening the DUP (Hasan & Musleh, 2017). The individual feels empowered to seek the appropriate treatment when families and friends create a comfortable and safe environment in which they can discuss their distressing experiences and symptoms of psychosis (Hasan & Musleh, 2017). Social networks were considered to be supportive and empowering in help-seeking for treatment when they acknowledged that psychosis is a medical problem rather than a sign of weakness. In a study by Goulding et al. (2008), they found that when family members and friends accepted the individual with psychosis and reported lower stigma, this often resulted in a shorter DUP. Similarly, Hasan and Musleh (2017) found that strong family relations and bonds were associated with a shorter DUP. Morgan et al. (2006) found that the DUP decreased

from an average of 12 weeks to an average of 5 weeks when there was family involvement in seeking treatment.

2.5 Study Rationale and Objectives

Presently, there are several studies that explore the information gaps in the knowledge of service providers and professionals to understand how these gaps can be bridged (Berger et al., 2006; Lester et al., 2005; Moudatsou et al., 2021; Reed, 2008; Schoer et al., 2021; Sin et al., 2014). It is important to note that patients and family members are also responsible for recognizing symptoms of psychosis and realizing when they should seek treatment. This requires understanding their specific information needs. Valimaki et al. (2008) interviewed 50 participants in Finland to investigate the problems related to psychosis literacy and reported five areas of information where education is needed: illness, treatment, well-being, daily activities, and patient rights. One study conducted by Pallaveshi et al. (2014) aimed to understand the perceived barriers of immigrants in Canada with psychosis by asking healthcare providers. This study, however, did not consider the barriers experienced by family members/caregivers nor what information is needed to increase caregiver psychosis literacy. Moudatsou et al. (2011) conducted a qualitative study to investigate the needs of families and caregivers of patients with psychosis from the perspective of mental health professionals and found that caregivers could benefit from increased information regarding disease management, knowledge of coping strategies, and services for themselves. This study, however, did not explore the information needs of patients. Hasan and Musleh (2017) interviewed 27 family members of people with psychosis in Saudi Arabia and found that perceived stigma and the fear of being labelled were the primary barriers associated with seeking appropriate treatment and also noted that participants misattributed the cause and symptoms of mental illness. This study also did not explore the information needs of patients.

Presently, to the author's knowledge, there are no studies within Ontario, Canada that explore what patients and their family members and caregivers already know about psychosis and what they should know. The current project is unique because it incorporates the perspectives of clients, family members/caregivers, and service providers. The overall objective

of this thesis is to conduct a secondary analysis (conventional content analysis) of interviews to understand the information needs of clients and caregivers in Ontario from the perspective of patients, caregivers, and service providers. This project builds on Anderson et al.'s (2018) study.

Chapter 3

3 Methods

3.1 Situating the Current Study

This study is a secondary analysis of interview data from a larger mixed-methods project focused on the role of family physicians in early psychosis intervention (Anderson et al., 2018). As part of this study, clients, caregivers, and service providers were interviewed regarding help-seeking and service use for a first episode of psychosis. Throughout these interviews, many participants provided insight into the gaps in knowledge for clients and caregivers regarding early psychosis and what people should know, such as symptom awareness and knowledge of services available, which was the focus of the secondary analysis conducted for the current study.

Before conducting the secondary analysis, the project coordinator reviewed the interview data from the parent study and determined that it provided sufficient depth of information to explore the information needs of clients and caregivers. Also, two of the authors from the parent study were on the supervisory committee for this secondary analysis, which ensured that the transcript data were not taken out of context.

Ethics approval was obtained for the primary study from the Western University Health Sciences Research Ethics Board (#114507), as well as from research ethics boards that are affiliated with the participant recruitment sites, where required (Hamilton, Toronto, Ottawa, Thorold, Thunder Bay).

3.2 Study Design

A conventional content analysis, informed by the work of Hsieh and Shannon (2005) and based in the natural interpretive paradigm, was used to analyze the transcripts. The natural interpretive paradigm allows for theory generation and gaining insight of a phenomenon. It assumes that there are multiple realities, and that meaning is socially constructed and

subjectively interpreted (Moschkovich, 2019). Conventional content analysis is an inductive approach used to describe a phenomenon for which there is limited theory or literature. This typology of content analysis was chosen for the current study because it involved a secondary analysis of transcripts from semi-structured interviews, and the research question did not align with an existing theory. This method allows for the categories to be derived directly from the transcripts and the findings are based on the data being analyzed. In conventional content analysis, the researcher reviews the transcripts several times to become familiar with the data and then reads it word by word to derive codes. The emerging codes can then be sorted into categories and sub-categories. This process continues until the categories and sub-categories have stabilized and the categories are clearly defined (Hsieh & Shannon, 2005).

3.3 Sample Recruitment

Clients and caregivers were recruited from seven EPI programs in the province of Ontario (London, Hamilton, Toronto, Ottawa, Thorold, Kirkland Lake, and Thunder Bay), which were selected to achieve representation from rural and remote areas, as well as a mix of academic and community-based programs (Anderson et al., 2018). All of the sites were EPI clinics, with the exception of Thunder Bay, which was a child and adolescent psychiatry clinic in Thunder Bay Hospital that provided care to clients with a first episode of psychosis. A purposive sampling technique was used to recruit clients and caregivers (Anderson et al., 2018). For Thorold, Kirkland Lake, and Thunder Bay sites, nurses and case managers at each of the sites introduced the study to clients and caregivers during their appointments. Clients and caregivers who were interested in participating received a referral form to complete and send to the research coordinator. For the London site, the research coordinator was on-site for one day. The clinicians of the program identified interested clients and caregivers during their appointments and referred them to meet with the research assistant in person after the appointment. For the Ottawa site, the local psychiatrist PI sent the research coordinator referrals on behalf of the clients and caregivers who were interested in participating. For the Hamilton site, their dedicated research coordinator contacted clients and caregivers from a registry of people who consented to be contacted about research studies. The interested clients and caregivers filled out a referral form and sent it to the project research coordinator. The research coordinator followed up with the interested clients and

caregivers to confirm their participation and schedule an interview. For the Toronto site, the clinicians handled the recruitment and interview process based on their internal protocols.

Family physicians were recruited for the interviews using a combined approach of in-person and mail-based methods. In-person recruitment was done using a booth at the Ontario College of Family Physicians Annual Scientific Assembly Meeting in November 2019. Mail-based recruitment was targeted to 1000 physicians who were randomly sampled from a list from the Canadian Medical Directory and received a postal package that included a recruitment letter, and a \$5 Tim Horton's gift card as an unconditional token incentive. Family physicians who were interested in participating in an interview completed a form and returned it to the research team. The research team followed up with the interested family physicians and scheduled an interview.

Clinicians from early psychosis intervention (EPI) programs were recruited by email from participating sites. A contact person from each site distributed the emails internally among staff and shared a recruitment poster.

3.4 Data Collection

For the qualitative interviews, the primary study recruited first-episode psychosis clients, caregivers, family physicians, and Early Psychosis Intervention (EPI) clinicians. To be eligible for participation, clients must have been between 16 and 35 years of age, have experienced a first episode of psychosis, been within three years of enrolment in EPI services, and had stable symptoms as assessed by the case manager. Caregivers were included if they were part of a patient's social network and were involved in the patient's mental health help-seeking prior to and during their psychotic episode (Anderson et al., 2018). A total of 24 clients and 14 caregivers were interviewed across the seven sites. The interviews were semi-structured and ranged from 30-60 minutes. The interviews were audio-recorded, with permission of the participant. All clients and caregivers received an honorarium for their participation.

A total of 20 family physicians were interviewed. The interviews were semi-structured and approximately 30 minutes in length. All the family physicians received an honorarium for

their participation (Anderson et al., 2018). One focus group interview was conducted with EPI clinicians at each participating site. EPI staff who were interested in participating contacted the project coordinator. One focus group was conducted by telephone, one was held in-person, and the rest were conducted by video conferencing. A total of six focus groups were conducted with EPI staff. A focus group guide was used to facilitate the focus group interviews. All interviews and focus groups were audio-recorded, transcribed, de-identified, and verified for accuracy.

3.5 Data Analysis

The de-identified transcript data from the clients, caregivers, and service providers were imported into the qualitative analytical software NVivo 12. The data were reviewed several times to become familiarized and immersed. Several notes of first impressions and thoughts were made. After the first few reviews of the data, the transcripts were read again line by line to derive codes, and exact phrases were highlighted to capture key concepts. Anything related to information or knowledge for clients and caregivers was coded, including what they currently know about services and symptoms, and what they did not know when they were searching for support, or what people think others should know. After the initial coding, eight categories were derived with several subcategories that were given preliminary definitions. These categories were discussed with the supervisory committee and revised to ensure they aligned with the scope of the research question. This resulted in the eight categories being collapsed to four categories, with further consolidation into three categories that were saturated and stabilized with codes. Each category was then clearly defined.

3.6 Rigor and Self-Reflexivity

Tracy (2010) describes credibility as a key criterion for qualitative research, and defines it as the trustworthiness of the research findings. This study achieves credibility through triangulation, multivocality, and sincerity (Tracy, 2010). For a conventional content analysis, Hsieh and Shannon (2005) noted that the failure to develop an accurate understanding of the data and its content is a key challenge. To maintain credibility, the first author discussed the findings with the supervisory committee. Because the members of the supervisory committee were investigators from the parent study, this ensured that the data were not taken out of context and

that the findings were an accurate representation of the data. The triangulation of codes and categories with the supervisory committee also ensured that the findings remained within the scope of the project and key categories were appropriately identified (Tracy, 2010). Another measure of credibility as described by Tracy (2010) is *multivocality*, which ensures multiple and varied voices are represented throughout the analyses. The current study achieves multivocality through the inclusion of quotes from various clients, caregivers, family doctors, and EPI clinicians. This enhances the results and increases the credibility of the findings.

Tracy (2010) also describes *sincerity* as an additional criterion for qualitative research. Sincerity is characterized through transparency and honesty of the researcher's methods and biases. The biases of the first author were recognized and noted through a reflexive journal. The following is a summary of my biases:

Over the last few years, I have realized the neglect in attention towards child and adolescent mental health, especially in immigrant and conservative households. I experienced this first-hand growing up in a semi-conservative Indian household in which feelings and symptoms of anxiety and depression are all said to be in your head and the solution is to just "get over it." In addition, I have also directly experienced the confusion and stress related to navigating services for a family member who is experiencing symptoms of a mental disorder. As a result, I have slowly gained a passion for mental health literacy and educating the population so they can better recognize the symptoms of mental disorders before they become distressing. This also involves recognizing the culture-specific beliefs of mental disorders to better understand how to develop targeted health promotion for ethnic minority populations. When given the opportunity to explore psychosis literacy in more detail, I was excited to learn about a specific component of mental health literacy.

Up to this point, I have explored several paradigms theoretically but would have to admit that I see myself sitting between the post-positivist and interpretivist paradigm. I have been passionate about adolescent mental health awareness and immigrant mental health literacy for a few years now. Most of my previous work focused on treatment-resistant depression, post-traumatic stress disorder, and mental health literacy of immigrants

globally. Although I've briefly studied psychosis in passing throughout the past few years, it was a relatively new topic for me to explore in detail. I have worked on a project related to methamphetamine use and have come across substance-induced psychosis, however I have not directly studied psychosis until this study. After familiarizing myself with prominent studies in the field related to my topic, I was able to develop a better understanding of psychosis and this allowed for me to dig deeper within the field of psychosis literacy with the guidance of my supervisory committee.

I have spent the last year working on a project in methamphetamine research as a Knowledge Mobilization Specialist within London-Middlesex. Through this, I've had the opportunity to interview people who use substances and explore the impacts of substance-induced psychosis. I believe my professional experience has prepared me to become more sensitive toward symptoms of psychosis and the experiences that people may have as a result of substance-induced psychosis.

By acknowledging and recognizing personal biases and how they can impact the study, the first author strives for sincerity in this study (Tracy, 2010).

Chapter 4

4 Results

Of the respondents interviewed, the majority of the sample were clients and caregivers (n=38). For this study, family physicians and early psychosis intervention (EPI) clinicians are categorized as service providers (n=26). The quotations from clients, caregivers, and service providers will be included below in the specific sections. See Table 1 for interviewee demographics.

Table 1

Interviewee Demographics

| | Gender | Age | Ethnic background | Education | Area of living (rural vs. urban) |
|--------------------------|--------------------------------|--|--|--|---|
| Clients (n=24) | Female = 58% Male = 42% | The age range is 16-33, median age is 25 | White = 45.8% African/ Jamaican = 8.3% Other = 29.7% Mixed = 8.3% | Highschool completion = 45.83% Post-secondary school completion = 50% | Urban = 91.7% Rural = 8.3% |
| Caregivers (n=14) | Female = 78.5% Male = 21.5% | The age range is 46-64, mean age is 58 | White = 85.7% Indian = 14.3% | Post-secondary school completion = 100% Master's program completion = 14.3% | Urban = 85.7% Rural = 14.3% |

| | Gender | Area of practice (rural vs. urban) | Country of medical school graduation |
|------------------------------|----------------------------|---|--|
| Family Doctors (n=20) | Female = 60% Male = 40% | Urban = 15% Rural = 15% | Graduated from a Canadian Medical School = 70% Graduated from a non-Canadian Medical School = 30% |

Three main content categories were derived from the conventional content analysis: (a) *current knowledge of where to seek health services and information*; (b) *symptom awareness and recognition of FEP*; and (c) *information people wish they knew about psychosis or think the general public should know*.

4.1 Current Knowledge of Where to Seek Health Services and Information

Clients and caregivers exhibited a range of help-seeking behaviours based on their perceived need for support for psychosis-related symptoms. Most clients and caregivers expressed that they ended up waiting until symptoms were overt and disturbing to initiate help-seeking. This was particularly true when clients exhibited positive symptoms of psychosis, such as hallucinations and delusions. At this point, clients and caregivers often resorted to seeking support from emergency services, such as police and hospital support. For instance, Client 1 stressed how positive psychosis symptoms lead them to seek support from parents and eventually the hospital system:

I started having psychotic delusions for about a few weeks, and for - started slowly, and I lost my job, and then I was out of work for about a month and a half. And I was having psychotic delusions. Nature, I guess we might get into later. But to focus on the question, I am seeking help from my parents. I told them, I was so much somewhat suicidal. And so they decided to bring me to the hospital. [Client, 1]

During the early symptoms of psychosis, some clients and caregivers recognized that something was wrong but were unsure why. This typically occurred when clients experienced some of the more non-specific and insidious symptoms of psychosis, such as sleep disturbance and mood swings. During this time, clients and caregivers typically sought support from their family doctor if the symptoms began to disrupt their daily functioning.

I think for me it was like in the beginning there were some signs, but my parents didn't fully understand what was going on. So for a long time I was kind of like going to like family doctors.[Client 2]

Well, first I had this job at [Restaurant] and like I was experiencing symptoms. And like took a doctor's note and like I got help from my family doctor and then she recommended me to go to [EPI Program]. [Client 3]

I didn't know I was – Like I knew I was hearing voices, but I thought they were like something else. I didn't know it was psychosis or anything like that. So I didn't seek any help. [Client 4]

Caregivers expressed their uncertainty in finding services for themselves while supporting their family member with psychosis and managing the changes. This lack of knowledge and awareness of services made it difficult to ensure the appropriate services were accessed in a timely manner. According to Caregiver 1, they outlined how they became overwhelmed and found it difficult to locate services:

And with the pandemic it made everything much worse. So we didn't really know what to do. We weren't even part of the early intervention program at the time, when he was hospitalized when it first happened. So there was nobody to really reach out to. So it was very scary, very overwhelming and I can't even – I wouldn't wish this on nobody.

[Caregiver, 1]

Clients and caregivers received information regarding psychosis from several sources, most commonly it was from the hospital or their family doctor. Family doctors were described as an important resource for information.

When he was in hospital in [City] they gave him a lot of information about schizophrenia. And I've still got that and he's gone all through it and marked things up and how his mom did this and his dad did this to him. [Caregiver 2]

No, I think she [family doctor] does a very good job about supporting me, yeah. If I ever need anything she's like oh, like here's, you know, many different cards. You can go call this person, call that person, you know, and she's very helpful that way. [Client 5]

Family doctors and EPI clinicians also mentioned that they would provide their clients with additional psychosis-related information during sessions to ensure they better understood their diagnosis.

I will explain to them, you know, what's the diagnosis of psychosis and some of them it's just they accept it or they are happy that there is a diagnosis. Others might, you know, not accept it but I explain to them and I go through the DSM-V diagnosis with them and we'll talk about the prognosis and the treatment and so on. [Family Doctor 1]

Some caregivers mentioned that they turned to the internet to seek psychosis-related information.

but at the time we're just – we don't know anything about psychosis. We're starting to read about it [online] and try to learn about it ..and I remember printing off that, what do they call that, the DSM or the DS – yeah and looking at oh, yeah, oh yeah, I can see why that happened. He was – like he was just textbook, like every delusion he had it, yeah.

[Caregiver 2]

4.2 Knowledge of Symptoms and Recognition of FEP

Clients and caregivers expressed that symptoms that were overt and disturbing were often recognized as requiring medical treatment, with an increased perceived need for support. In most

instances, clients and caregivers were not aware that the client was experiencing symptoms related to a psychotic disorder; however, they still acknowledged that there was a problem that required support. For example, Caregiver 3 and Client 6 outlined how they noticed some of the behaviour exhibited was abnormal.

And then this went on to, he went to college and when he went to college for three years, he's very, he succeeds very well academically so he was top of his class. But socially very, very reclusive and also exhibiting some very aggressive behaviour at home towards his brother mostly and then towards us as well. And so I repeated, too many times, told my family doctor, "We need help, like we don't know what to do" [Caregiver 3]

Because I guess like there's like a difference between having like a balanced view towards religion and then becoming just like so completely consumed with fear to the point where it's just like, it's negatively affecting your ability to function. And I feel like that's where I got to a point where I was like having like, just irrational fears of death of like, the afterlife of like, of everything that was unknown to me. I don't know if that makes any sense. [Client 6]

It was noted that when clients experienced early symptoms of psychosis that were mostly internalized, clients and caregivers often did not recognize them as requiring medical treatment or associated with a mental illness. Client 6 and Caregiver 4 expressed overlooking their symptoms until they gradually became worse.

So my psychosis was a gradual kind of occurrence. It wasn't kind of like an overnight thing. I was going through a lot of like personal issues at the time, and I was very like unsatisfied with my life and like I was becoming more and more depressed. And basically, my depression just got worse and worse and worse and worse. I had long periods of time where I was like severely sleep deprived and I think it was the intense sleep deprivation that caused like the major chunk of the psychosis that I had was like sleep deprivation... Like I could no longer experience like pleasure from like things that I used to experience pleasure from, whether it was music or watching a TV show or reading a book like stories and like the beauty of humanity just like diminish.

[Client 6]

But he was in psychosis for a while before we realized he was having his – he was in psychosis where I wasn't aware. There was [sic] weird things happening, but I wasn't aware that it was psychosis until he had his complete break. [Caregiver 4]

Parents also often attributed their child's early symptoms of psychosis to normal life changes.

And then in Grade 10 we weren't aware, but there was some very severe bullying going on in the school bus. In fact it took months for parents to find out and when it was found out it really impacted the children on the bus. ... So after that G. [client] started misbehaving, he quit all of his sports teams, he withdrew from the class involvement as president and all that. And I just thought that at that point that maybe he was just going through teenage years and possibly maybe a little bit of a depression. [Caregiver 3]

Well as you know, a lot of the behaviours that can be leading up to this, are very hard to distinguish from pretty typical adolescent behaviours, you know or immature young adult behaviours – risk taking, impulsivity, what's, what's the word – you know constantly pushing back, arguing, not accepting help. I mean that's just on a spectrum of behaviours, it's not abnormal. [Caregiver 5]

When he was a teenager he almost – he had just vanished. Like he had learned – like yeah, all – and he was, he never acted out, he was very quiet, introverted, just he played golf with his dad. He took - he's got a second degree black belt in karate. He never really had many friends. [Caregiver 2]

The most commonly cited reason for not acknowledging the early symptoms of psychosis as requiring medical treatment and delaying seeking treatment is due to negative and stigmatizing perceptions of mental health problems. Clients felt embarrassed and were afraid to be labelled with a mental illness.

Like when I was younger and I first had my psychotic relapse, I was like embarrassed and I didn't trust doctors. I didn't know if they were going to put me in like a strait jacket

or something which I don't know... I was very scared to go to get help because I didn't want them to like lock me up in a psych ward. It's not an unpleasant experience, but it's not necessarily a pleasant experience. Or people have jobs and families, they don't want to leave and stuff like that. [Client 7]

So I didn't want to share what was really bothering me with my counsellor because I felt that I had to like upkeep like the image of my religious community. Like I didn't want to make my religious community look bad or to make myself look bad. ... especially in the Muslim community, if anyone's dealing with this, there's a big stigma in general, but I feel like sometimes there can be a greater stigma even in the Muslim like Arab community around mental health and there's a lot of superstitious beliefs and things like that.

And people don't want to be labelled as psychos, or something – something similar to that. [Client 6]

It's the taboo factor. Like I think we did a great job with depression and anxiety in terms of removing that taboo factor, where people will come forward and talk about their mental health and get treatment for it. The next step is the psychosis factor of it. A lot of people are afraid of coming forward when they're hearing voices, seeing things, having grandiosity, tangentiality or tangential speech. [Family Doctor 2]

4.3 Information People Wish They Knew/People Should Know About Psychosis

It was noted by clients and service providers that clients and caregivers wished they knew more about psychosis when the client first started exhibiting symptoms. Most commonly, it was expressed that there should be more awareness of the symptoms of psychosis and how psychosis can manifest.

I think just the diagnoses or the diagnosis, there needs to be more information shared with families and patients in regard to what their diagnosis is... There needs to be knowledge and shared with a patient specifically, what is this illness? What does this

mean? What does it mean to you? How is it impacting your life? And what changes do you need to make as well? So I think there needs to be more information shared on actual diagnosis and the actual symptoms. And then this will segue into a conversation of early symptoms or triggers that can cause another relapse. So education and awareness.

[Client 8]

I mean, everybody definitely pays attention to the positive symptoms but, you know, ... the increase in isolation, the decrease in being social, all these little things that, you know, we see on top of like the positive symptoms of hearing voices and that kind of stuff which is kind of like oh yeah for sure this is psychosis, it's the other path of the symptoms that is probably is what's getting missed. And it could just be that, you know, they don't have the, like enough education, I think, to spot them out. [EPI 1]

It was also expressed that there should be more information and awareness regarding the causes of psychosis, especially the influence of trauma and substance-use. For instance, Family Doctor 3 and Caregiver 5 outlined the importance of considering the impact of previous trauma and substance use and it may contribute to psychotic episodes.

So I have patients who – I have a lot of sexual abuse in my practice. I have a lot of incest in my practice. I have a lot of people that were beaten in residential schools, in foster care, sexually abused in all of those places. So trying to see what are elements that are related to the, you know, previous trauma. I find that's another difficult thing to assess.

[Family Doctor 3]

I also think there's some ignorance about the severity of marijuana. Like, I mean my kid is now in – very sadly – his second state of psychosis. And he has, he is terribly addicted to marijuana now. [Caregiver 5]

Family doctors and EPI clinicians particularly emphasized that substance-induced psychosis has become very common, and they are often unsure whether the psychosis symptoms are due to a psychiatric disorder or a side effect of substances. As a result, they expressed that clients and caregivers should be educated on substance-induced psychosis.

Yeah so, for pre-psychosis, I think the critical things are psycho-education; [do not touch] marijuana. Stay away from marijuana. Now it's legal, which is even worse. Stay away from marijuana. [Family Doctor 4]

So I have had a lot of people that present as you know, is it schizoaffective, is it bipolar, is it drug induced psychosis, because I have a lot of drug use in the practice as well. And often the differential is difficult at that point, like, it could be, you know, induced by methamphetamine, it could have been induced by marijuana, whatever... I think it's the fact that there's a lot of my patients using drugs and it's – trying to distinguish between drug-induced psychosis or a primary mental illness. [Family Doctor 3]

Caregivers, family doctors, and EPI clinicians also expressed that family members and caregivers should know more about psychosis so they can better support and advocate for their family member with psychosis.

it would be easier if they have family members that are supportive. So I try to also when I see them get their family members coming in as well. Cause I'm seeing them maybe once every few weeks or even few months depending on how acute a situation is... So they might have that initial push from me but then they might need constant support through their family. So having the family onboard I think that's very helpful... But I find that in situations where the patient maybe isolated or don't have any family members that would be willing to help or supportive, that makes it very challenging. A lot of times I find that patient might have been hard to follow up until they're in crisis. [Family Doctor 5]

The reason why I'm getting involved is because I think families are really important. As I said, they see the individual and what's, normal for them. And then what goes beyond that and how they change. And see a significant change can be very scary. Once families get education on it, they can handle it much better. So education is a big piece, too. If I hadn't gotten the education that I had, I'm not sure how our family life would be now. I'm definitely a lot calmer. [Caregiver 6]

It was noted that there was a lack of knowledge and awareness of services for psychosis among clients and caregivers. Clients and caregivers expressed wanting more information about services for clients and a better understanding of the process of receiving support.

Yeah. I mean, the doctor maybe can refer you to a psychiatrist or an intervention program. I wasn't referred to any intervention programs. ... But it would be nice for future to help mental health patients to go to the family doctor and then have the doctor recommending like classes there, where there's all mental patients. [Client 9]

Sometimes I think they may not understand fully all of the options that they have available for them for support for mental health services locally. [EPI 2]

When I finally got in to [community mental health program] with the crisis intervention program she felt that something could have been offered to us before, at least support for us, to know how to protect ourselves and how to do stuff. But that wasn't offered to us and frankly I didn't know that I could have had access to that. I thought that I was waiting for a crisis, for a serious, I was waiting for the really bad thing. [Caregiver 3]

The importance of support for caregivers was also mentioned. Caregivers expressed wanting more awareness of available supports and services for them as they support their loved one and service providers echoed this. It was important to feel supported and know how to navigate psychosis in the family.

It's just, you know, you need more than that kind of – you need some support, and so does the family. The family needs support for that. It's a devastating diagnosis if it does turn out to be schizophrenia, then it's really a devastating diagnosis. [Family Doctor 6]

But the helplessness, the fear, the terror that a parent feels when they have a child in this state and they realize the hospital isn't going to take them, like, you know and fix them. They're going to say, "He's yours. Come back in a week." And you have no tools. You have no tools. None. That is – that to me, is a critical, critical, critical point. And that is a critical point for outreach and help to the family member who is trying to embrace this person who is suffering and get them back into the system. That's why youth get lost. [Caregiver 5]

Chapter 5

5 Discussion

5.1 Summary of Findings

The findings of the current study highlight that FEP clients and caregivers have the following information needs: where to seek services and supports for clients experiencing symptoms of psychosis; where to seek supports for family members and caregivers to learn how to support and cope with having a family member with psychosis; how to differentiate early symptoms of psychosis from normal changes; and psychosis-related information such as what it is, the causes of psychosis and how symptoms of psychosis can manifest in different people.

5.1.1 Knowledge of Services and Supports

The findings from the current study suggest that clients and caregivers had some knowledge of services and supports available when people are experiencing early signs and symptoms of psychosis. The most commonly used services were emergency services, such as hospitals or police, and family doctors. It was found that clients and caregivers often sought support from emergency services when the client was experiencing the positive symptoms of psychosis or when the symptoms had become severely disruptive to their daily functioning. The current study's insights align with Hasan and Musleh's (2017) study, in which they found that when clients exhibited noticeable symptoms of psychosis, these individuals were likely to seek help, commonly from emergency services that also provide mental health support. The current study highlights that clients and caregivers were more likely to visit their family doctor for non-specific and insidious symptoms of psychosis causing mild impacts on the client's life, such as sleep disturbance, mood swings, or social withdrawal. Schoer et al.'s (2021) findings also suggest that people who experience symptoms of psychosis visit family doctors at a higher frequency during the 6 years before their first diagnosis, compared to the general population, with visit frequency increasing 10 months prior to diagnosis. However, Schoer et al.'s (2021) study was unable to identify whether visits were for prodromal symptoms or active symptoms of psychosis. Martin et al. (2018), Del Vecchio et al. (2015), and Bhui, Ullrich, and Coid (2010)

reported similar findings, indicating that primary care was a common point of first contact for clients. This highlights that although clients and caregivers are unaware that the client's symptoms may be associated with psychosis or a mental health problem, there is still a perceived need for support and some recognition that there may be something wrong.

Even though clients and caregivers were aware of where to seek support for symptoms of psychosis, the current findings suggest that caregivers lack knowledge of supports and services available for them as they care for their family member with psychosis. This finding from the current study is similar to the results of several previous studies that indicate that family members and caregivers struggled to find services for themselves to cope with the changes related to their family member's illness (Kumar et al., 2019; Moudastou et al., 2021). The findings of the current study commonly indicated that caregivers experienced feelings of fear, frustration, confusion, and experienced family dysfunction as a result of a family member having psychosis. Moudatsou et al. (2021) previously interviewed 12 mental health professionals to understand the needs of caregivers of family members with psychosis and further noted that caregivers experienced increased responsibilities, which can add to professional and financial burdens, social constraints, and their personal psychological deterioration. Providing caregivers with support such as psychoeducation can improve the care they provide to their family member with psychosis (Cheng et al., 2020; Martin et al., 2018).

The current study's findings also suggest that clients and caregivers lacked knowledge of psychosis prior to the client experiencing symptoms of psychosis. It was found that the most common sources of psychosis-related information after the onset of symptoms included the hospital and family doctor. The results of the current study highlight that family doctors were aware that they are typically a family's first source of psychosis-related information, and described the efforts they made to ensure they provide the family with sufficient information. This outlines the importance of the family doctor's role in psychosis treatment and education, which has been studied in several studies and is the focus of the parent study (Anderson et al., 2018a; Reed, 2008). Some caregivers also mentioned seeking additional information from the internet to learn more about psychosis. This insight aligns with results from other studies that found that clients and caregivers often use the internet as either their first source of psychosis-related information or for supplementary information (Aref-Adib et al., 2016; Birnbaum et al.,

2016; Cheng et al., 2020; Jansen et al., 2015; Onwumere & Kuipers, 2018). Further work will be required to explore how perceived stigma of psychiatric disorders affects information seeking of caregivers and others in the larger circle of care.

5.1.2 Associating Symptoms with a Psychotic Disorder

The findings from the current study suggest that although clients and caregivers were able to recognize the overt and positive symptoms of psychosis as requiring medical treatment, they were often unaware the symptoms were a sign of psychosis. This aligns with previous literature that indicates that the positive symptoms of psychosis are more easily recognized because they cause an obvious disruption in the client's daily functioning (Franz et al., 2010; Hasan & Musleh, 2017; Martin et al., 2018; Mishra et al., 2021; Nishii et al., 2010). When symptoms are recognized as requiring medical treatment, clients and caregivers exhibited a higher perceived need for support, which was usually when they accessed support from emergency services because the client's needs escalate. Similar to the results from previous research (Mishra et al., 2021; Nishii et al., 2010), the current study found that clients and caregivers typically sought support after their symptoms worsened or escalated into the active phase of psychosis. The current study's results suggest that clients and caregivers commonly missed the early prodromal symptoms of psychosis, and did not associate them with FEP or another mental illness. Family doctors and EPI clinicians described that the early symptoms of psychosis are often overlooked and attributed to typical adolescent behaviours and changes. This insight from the current study has been highlighted in previous research and supports the notion that the early signs and symptoms of psychosis are difficult to recognize, and that the general public has low levels of psychosis literacy (Franz et al., 2010; Hasan & Musleh, 2017; Hastrup et al., 2018; Jansen et al., 2015; Kumar et al., 2019; McGorry et al., 2008; Perkins et al., 2005; Rietdijk et al., 2011; Yarborough et al., 2019). As a result, there is a low perceived need for support during this period, and clients tend to not seek support until symptoms worsen. The results of the current study suggest that symptoms of psychosis are likely to be recognized as a psychotic disorder when clients and caregivers have previous family experience with psychosis. This finding is similar to the results from Chen et al. (2005) and Lloyd-Evans et al. (2011), who identified that personal and previous family experience with psychosis can positively influence symptom recognition and help-seeking behaviour. This may be because clients and caregivers

are more aware of how symptoms of psychosis can manifest given their prior experience with it and as a result, are better informed to seek appropriate services in a timely manner (Lloyd-Evans et al., 2011; Yu-Hai Chen et al., 2005).

Another barrier to recognizing the symptoms of psychosis and seeking help was stigma. Clients and caregivers tended to hold negative, stigmatizing perceptions of psychotic disorders and mental disorders. The impact of psychosis stigma has been widely studied globally and is recognized as a barrier to help-seeking and symptom recognition (Addington et al., 2012; Ahmed et al., 2020; Apeldoorn et al., 2014; Burke et al., 2016; Franz et al., 2010; Gronholm et al., 2017; Hasan & Musleh, 2017; Hui et al., 2019; Kular et al., 2019; Moudatsou et al., 2021). It is possible that the perceived stigma and misconceptions that clients and caregivers internalize may have been responsible for the rhetorical comments and inappropriate humour present during the interviews, such as clients referring to themselves as being “crazy.” This prevents clients and caregivers from seeking appropriate services in a timely manner because they fear being labelled with a psychiatric disorder and are embarrassed. This insight is similar to several previous studies (Addington et al., 2012; Ahmed et al., 2020; Gronholm et al., 2017; Martin et al., 2018). It is essential to remove the taboo factor through increased public education and awareness of psychosis.

5.1.3 Information Needs

The findings from the current study emphasize that there should be more information regarding symptoms, manifestations, causes, and prognosis of psychosis. This aligns with several previous studies (Calderon et al., 2015; Del Vecchio et al., 2015; Hasan & Musleh, 2017; Joa et al., 2007; Kumar et al., 2019; Sutton et al., 2018). Specifically, it was expressed that clients and caregivers wanted more information related to the causes and prognosis of psychosis, symptoms of early psychosis, particularly the negative symptoms, and how psychosis can manifest for different people. Several studies report that targeted informational campaigns and early detection can improve psychosis symptom recognition and promote timely treatment (Hastrup et al., 2018; Lloyd-Evans et al., 2011; McGorry et al., 2007). Family doctors and EPI clinicians also emphasized that clients and caregivers should know about the increasing prevalence of substance-induced psychosis and how it may influence future psychotic episodes. A meta-analysis conducted by Lecomte et al. (2018) suggests that substance-induced psychosis is

becoming a common cause of psychosis, and echoes the concerns of various service providers interviewed for the current study that cannabis use can trigger psychosis symptoms. The results of the meta-analysis also highlight that there should be an increased focus on family education for psychosis (Lecomte et al., 2018). Family doctors and EPI clinicians in the current study outlined the importance of family education and the family's role in supporting and advocating for their family member experiencing psychosis. This can result in the client feeling supported as they seek services and treatment. This insight aligns with several previous findings that suggest that family support when seeking psychosis services can act as a facilitator for treatment seeking and treatment retention. (Del Vecchio et al., 2015; Goulding et al., 2008; Hasan & Musleh, 2017; Martin et al., 2018; Morgan et al., 2006; Selick et al., 2017). The current findings also suggest that there is insufficient information available regarding services for clients experiencing symptoms of psychosis. Clients, caregivers, and service providers expressed the difficulties they faced when navigating services for psychosis, and how a lack of knowledge delays timely treatment. Several studies support the conclusion that clients and caregivers are unsure of the processes to receive treatment and often experience frustration when they are not supported by services (Cheng et al., 2020; Hasan & Musleh, 2017; Martin et al., 2018). The findings from the current study outline that clients felt they should have been provided with appropriate referrals and services earlier. This highlights that increased efforts in educating the general public regarding what services are available for clients and when they should access them when they suspect a client is experiencing symptoms of psychosis may be beneficial. The lack of knowledge on available supports for caregivers is a barrier and can lead to the caregiver experiencing several negative emotions, which is also described by Kumar et al. (2019).

5.1.4 Contributions to Future Research

The findings from the current study add to the knowledge of how to improve the early recognition of psychosis, and what information clients and caregivers need as they manage a psychosis diagnosis. Although the current findings were derived from a conventional content analysis and are limited in theory development, they align with several recent studies, thus promoting the theoretical and practical significance.

Although there are several recent studies citing the importance of client and caregiver education globally, this study adds to the specific context of psychosis service navigation in

Ontario, of factors influencing help-seeking behaviours and early psychosis treatment, and the importance of educating clients and caregivers early in the course of illness to enhance and improve treatment outcomes. Another important factor is that this study aimed to understand the information needs of clients and caregivers based on the perspectives of clients, caregivers, family doctors, and EPI clinicians. To the author's knowledge, these diverse perspectives have not been integrated into a single study before.

Future research could explore the implementation of targeted educational campaigns within Ontario that focus on the early recognition of symptoms of psychosis by clients and caregivers, and the impacts on perceived stigma. Another research direction is to develop a better understanding of where clients are most likely to receive their mental health information and how to make those sources more effective. EPI programs should continue to provide psychoeducation for clients and families regarding what psychosis. This includes a strong understanding of early psychosis symptoms, knowledge of services available for both clients and caregivers, and referrals for services to facilitate service seeking for clients and caregivers.

5.2 Limitations

There are several limitations to this study, given that it is a conventional content analysis of secondary interview data. Typically, secondary data analyses can lead to concerns related to the credibility of the data based on how the primary data were collected (Tripathy, 2013). To ensure trustworthiness of data, the first author confirmed all recruitment and data collection procedures with the project coordinator of the parent study. In addition, further confirmation was received from the supervisory committee, as they were also involved in the parent study. Another limitation of a secondary data analysis is that the data collected may be limited in relevance for the scope of the secondary study (Tripathy, 2013). This is because the interview guide of the parent study is often not related to the research questions guiding the secondary analysis. As a result, the data may not contain relevant information. The interview guide for the qualitative portion of the mixed methods parent study was developed based on the quantitative findings of the parent study (Anderson et al., 2018a). Due to this, the interview guide was focused specifically on the family doctor's role in the recognition and diagnosis of psychosis and their ability to co-manage clients with specialized services. Clients and caregivers were mostly asked

questions related to their experience with seeking services and the amount of support they received from their family doctor. Considering this, any narratives related to the current study's research questions were in response to other questions. This shows that even indirectly, educating clients and caregivers and supporting service navigation were prevalent concerns among clients, caregivers, and clinicians involved in early psychosis intervention. Thus, the secondary analysis had sufficient information to saturate and stabilize categories. In addition, prior to confirming the research question, the project coordinator, who has been immersed and familiarized with the data, confirmed that the topic of this study was feasible with the interview data (Tracy, 2010).

Because this study analyzed interview data, it is important to recognize the limitations associated with interviews as well. Interviews can have response bias in which interviewees only participate because they have something to say, thus it may not be representative of the entire population (Tripathy, 2013). Although this is a conventional content analysis based in the natural interpretive paradigm, and therefore the sample is not required to achieve representativeness, it would have been beneficial if more caregiver voices were included (Tracy, 2010). Because this was a secondary analysis, this cannot be controlled for the current study. The first author attempted to reconceptualize the data as much as possible by reviewing background literature about the parent study as well as analyzing beyond what the clients, caregivers, and service providers were saying to also consider what they were not mentioning and why. The inclusion of rich, detailed, and descriptive quotes promotes transferability of results for readers to relate with them with their own lives, allowing for resonance to be achieved (Tracy, 2010).

One limitation regarding implications for the credibility of the current results is that the first author was not able to conduct member reflections to confirm the findings with the interviewees to ensure the themes adequately portray their experiences and perspectives (Tracy, 2010). The results were reviewed by the supervisory committee.

Conventional content analyses are also limited for theory development and determining theoretical relationships between concepts. It only allows for the development of concepts (Hsieh & Shannon, 2005). A conventional content analysis was the best analytic approach for the current study because it was a secondary data analysis that aimed to describe a phenomenon that

did not conform to a pre-existing theory and had limited literature. To draw further conclusions, the implicit, tacit knowledge based on what was not said during interviews was also considered (Tracy, 2010). This allowed for appropriate concept development, which is the primary outcome of a conventional content analysis (Hsieh & Shannon, 2005).

5.3 Conclusion

The current study draws attention to the information needs of clients and caregivers that the participants considered to be important for accessing treatment and services related to early psychosis. Clients, caregivers, family doctors, and EPI clinicians shared several similar thoughts in regard to what clients and caregivers should know about early psychosis, which includes how symptoms can manifest, when and where to seek treatment, and how caregivers can support themselves. Targeted psychosis-related education for the general public may impact the low levels of psychosis literacy.

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