Narratives of South Asian women with first episode psychosis: a qualitative study

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Table of Contents

Table of Contents 2

Acknowledgements 3

Contribution of Authors 4

Abstract 5-6

Résumé 6-7

Introduction 8-9

  Literature Review 9-23

Research Objectives 23-24

Methods 24-43

Results 43-70

Discussion 70-89

Conclusion 89-90

References 91-111

Tables 112

Figures 113

Appendix 114-123

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Contribution of Authors

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Abstract

Psychotic disorders are serious mental illnesses that affect 2-3% of the population and carry potentially long-term health and mental health consequences for those affected. In high-income countries, women tend to develop psychosis later than men, which means that there tend to be fewer women in FEP programs. This may explain the dearth of studies about the lived experience of women with first episode psychosis (FEP), and this issue is even more serious for women from ethnic minority groups for whom less is known about the cultural factors impacting their treatment and recovery process. Despite the fact that South Asian women (SAW) belong to the largest ethnic group in Canada, there is a lack of studies about their lived experience with FEP, as well as their needs. Using an exploratory qualitative research design, this study sought to examine the lived experience of SAW with FEP, their real-life needs, the challenges they face, as well as the cultural strengths and resources they utilize to overcome some of the difficulties they face because of psychosis. A sample of five English-speaking female patients, who self-identify as South Asian, were recruited from three FEP clinics in Montreal, Canada. Participants took part in an individual semi-structured interview. Data analysis was performed using Interpretative Phenomenological Analysis. *Predicaments, Treatment Experience and Help-Seeking Efforts,* as well as *Cultural Knowledge* were the three key themes that emerged from the interviews. The findings of this study demonstrate the needs and challenges SAW face from the onset of psychosis through the treatment and recovery phases, some of which remain unaddressed because treatment teams may lack the necessary cultural information to serve SAW. Furthermore, the results of this study support the notion that culture should not be viewed as merely an obstacle to treatment and recovery, but should be seen as an integral component of it. Taking advantage of the strengths that exist in South Asian cultures, the treatment team can develop services tailored to the needs of SAW. Hence, the findings of this study can be used to inform clinical interventions.

Résumé

Les troubles psychotiques sont des maladies mentales graves qui touchent de 2 à 3 % de la population et qui peuvent avoir des conséquences à long terme sur la santé physique et mentale des personnes concernées. Dans les pays à revenu élevé, les femmes ont tendance à développer une psychose plus tard que les hommes, ce qui signifie qu'il y a moins de femmes dans les programmes PEP. Cela peut expliquer le manque d'études sur l'expérience vécue par les femmes souffrant d'un premier épisode psychotique, et ce problème est encore plus grave pour les femmes issues de minorités ethniques, pour lesquelles on connaît moins les facteurs culturels ayant un impact sur leur traitement et leur processus de rétablissement. Bien que les femmes sud-asiatiques (FSA) constituent le groupe ethnique le plus important au Canada, il y a peu d'études sur leur expérience vécue avec un premier épisode psychotique, ainsi que sur leurs besoins. En utilisant un modèle de recherche qualitative exploratoire, cette étude a cherché à examiner l'expérience vécue des femmes sud-asiatiques atteintes d'un PEP, leurs besoins réels, les défis auxquels elles sont confrontées, ainsi que les forces et les ressources culturelles qu'elles utilisent pour surmonter certaines des difficultés auxquelles elles font face sont confrontées en raison de la psychose. Un échantillon de cinq patientes anglophones s'identifiant comme sud-asiatiques a été recruté dans trois cliniques PEP de Montréal, au Canada. Les participantes ont pris part à un entretien individuel semi-structuré. L'analyse des données a été réalisée à l'aide de l'analyse phénoménologique interprétative. La problématique, l'expérience du traitement et les efforts de

recherche d'aide, ainsi que le savoir culturel sont les trois thèmes clés qui ont émergé des entretiens. Les résultats de cette étude démontrent les besoins et les défis auxquels sont confrontées les FSA, depuis l'apparition de la psychose jusqu'aux phases de traitement et de rétablissement, et que si certains ne sont pas pris en compte, c’est parce que les équipes de traitement n'ont pas toujours l’information culturelle nécessaire pour servir les FSA. En outre, les résultats de cette étude confirment que la culture ne doit pas être considérée comme un simple obstacle au traitement et au rétablissement, mais plutôt comme une partie intégrante. En tirant parti des points forts des cultures sud-asiatiques, l'équipe de traitement peut mettre au point des services adaptés aux besoins des FSA. Les résultats de cette étude peuvent donc être utilisés pour éclairer les interventions cliniques.

Introduction

First-episode Psychosis (FEP) is a psychiatric term used to describe individuals who experience psychotic symptoms for the first time or are at the beginning of their illness or treatment (Breitborde et al., 2009). There are a number of symptoms associated with FEP, including hallucinations, delusions, social withdrawal, and cognitive and mood problems which lead to disruption in the individual and social aspects of a person's life resulting in feelings of fear, distress, and isolation (Reed, 2008). Hence, psychosis is not an illness of itself but refers to a cluster of symptoms that may belong to a number of disorders. The most well-known of these is schizophrenia (Schizophrenia Society of Canada, 2018), which is considered among the most disabling mental disorders (Rodrigues et al., 2020). Moreover, some people with FEP develop chronic symptoms and disability, and individuals with FEP are 69% more likely to develop more than one psychiatric condition (Rodrigues et al., 2020). FEP patients face a variety of challenges that impact their social, academic, and vocational functioning (Fusar-Poli et al., 2017). Thus, psychosis not only causes considerable distress for patients but also places an enormous burden on the primary caregivers, which often are their families (Jeppesen et al., 2005). Moreover, those with FEP tend to be more dependent on their families, often living with and relying on their parents until an older age (Nuttall et al., 2019).

This study focuses specifically on SAW – South Asians being the largest visible minority in Canada (Government of Canada, 2017) - to better understand their experiences and needs. This study will examine the cultural factors and structural obstacles (access to mental health services, knowledge about available resources, language barriers, etc.) that shape SAW's experiences of FEP in three clinics in Montreal. Moreover, this study also seeks to demonstrate how SAW employ and benefit from cultural resources to cope with the difficulties associated with FEP. To provide additional perspectives, SAW were asked if their family members could take part in the research project. Conclusions drawn from this study will add to the literature on SAW with FEP in Canada and will provide insight into factors that should be considered when serving these women. Study conclusions also will be of use to primary health care providers in early intervention services and community center workers about how to culturally adapt their interventions to the needs of SAW with FEP.

Literature Review

As previously mentioned, psychosis often touches all aspects of a person's life. Individuals suffering from FEP, for instance, may lack the motivation to engage in social activities, which can adversely affect their social functioning, and their overall quality of life (Moe et al., 2021). Additionally, during the early stages of psychosis, patients often experience difficulties that interfere with their abilities to continue their education, careers and intimate relationships (Addington & Addington, 2005). These effects of FEP imply that treatment and recovery programs should focus on a variety of areas where psychosis may compromise function. The findings of Lal et al. (2014) revealed that youth with psychosis conceptualize recovery based on resuming their functions in seven key areas: (1) psychological well-being defined as retaining cognitive abilities and psychological functioning, (2) physical well-being defined as engaging in healthy behaviours such as exercise and adequate sleep, (3) emotional well-being defined as feeling good and the ability to control one's emotions, (4) moral/virtuous well-being defined as doing the right thing and behaving maturely, (5) financial/material well-being defined as living an independent and stable life, (6) spiritual well-being defined as having a belief in something transcendental, such as God, having hope and faith in the future, and engaging in activities such as yoga, meditation, or prayers to achieve peace and calm, and finally, (7) social well-being defined as involvement in community activities, having a sense of belonging and social acceptance, feeling supported, and being supportive of others. It should be emphasized, however, that recovery experiences are not necessarily the same for all individuals with FEP and they may even experience different forms of recovery. As Davidson and Roe (2007) explain, individuals with serious mental illness may experience what are known as *Recovery From* and *Recovery In*. While the former implies returning to a state that was assumed to be normal before the illness began, the latter refers to the process of living one's life in a dignified and autonomous manner, despite the ongoing presence of an illness and/or relapse risk. As the authors argue these two forms of recovery are not mutually exclusive and both forms may be experienced by an individual. This is particularly relevant as for some patients, symptoms resolve quickly and never reappear, whereas for others it may be a long and slow process (Lally et al., 2017; Warner, 2009). Recovering from FEP would also require a multi-dimensional approach involving various goals such as the decrease or absence of psychotic symptoms, regaining autonomy and independence, restoration of the ability to trust in others, as well as readiness and motivation to return to a fulfilling social life (Eisenstadt et al., 2012). The return to desired level of social functioning for instance, contributes to a reasonably stable life even among patients who have not yet fully recovered from FEP (Albert et al., 2011). This clearly highlights the critical role early interventions play in reducing the severity of illness and alleviating the distress experienced by patients and their families (Reed, 2008).

It is also necessary to look beyond biomedical approaches and to consider psychosocial and spiritual factors as well. In this sense, implementing a holistic approach will not only lead to better clinical outcomes among service users but will prepare practitioners to adapt their practice to benefit people from diverse ethnic backgrounds (Maurya, 2009). A culturally sensitive approach to people with psychotic disorders can provide insight into factors that can either facilitate or hinder treatment, recovery, and service utilization (Jarvis et al., 2020; van der Ven et al., 2020). Gender-related issues are also important since they reflect cultural beliefs and expectations that shed light on how FEP affects men and women differently in terms of the challenges they face and the needs they may have (Bertani et al., 2011; Ferrari et al., 2018). Considering the limited research on women's lived experience with FEP (Ferrara & Srihari, 2020) and the scarcity of research regarding South Asian women (SAW) with FEP in Canada, further research in this area is imperative (Rotenberg et al., 2019).

What can age and gender differences tell us about FEP?

The age at which FEP occurs is crucial for understanding further difficulties and challenges associated with it. Typically, mental disorders begin manifesting themselves in adolescence or young adulthood (Kessler et al., 2007). As youth navigate this critical period, they strive to establish their identity, which is part of transitioning to adulthood (Harrop & Trower, 2001; Malla et al., 2018). Milestones associated with transitioning into adulthood such as educational accomplishments, economic independence, and building positive social relationships are shaped by culture, and will enable youth to be psychologically, financially, and socially prepared to take on the roles and responsibilities associated with adulthood; one should note though, those suffering from mental disorders, may find it daunting to accomplish these goals (Xie et al., 2014). Consequently, individuals with FEP will face two challenges simultaneously: overcoming the difficulties caused by psychosis, as well as the pressures and expectations associated with transitioning to adulthood (Reed, 2008).

FEP occurs most often in late adolescence and early adulthood and evidence shows both sex and gender differences (Häfner et al., 1998; Lewine, 1980; Spauwen et al., 2003; Grossman et al., 2008). For instance, men are mostly diagnosed with FEP in late adolescence from ages 18-25, whereas women are typically diagnosed at older ages from 25-35 years (Ochoa et al., 2012). For men, the incidence of psychotic disorders sharply decreases after 18 to 24 years of age, while the risk reduces more gradually among women until a second small peak between 50 and 54 years of age (Jongsma et al., 2018). FEP programs usually accept patients who are between 18 to 35 years of age (Edwards et al., 2005; Mueser et al., 2015). While FEP services primarily target young adults transitioning into adulthood, this approach may overlook the needs of older women suffering from psychosis (Jongsma et al., 2018). In addition to gender-specific age-of-onset patterns, clinical symptom presentations, pathways to care, gender roles, and sexual and reproductive health are affected differently in men and women with early psychosis (Ferrara & Srihari, 2020). Compared to men, women with FEP tend to have a better prognosis in terms of social function and show better treatment adherence; men with FEP on the other hand are more socially isolated, experience more negative symptoms, and are more likely to engage in substance use (Barajas et al., 2015; Køster et al., 2008). In epidemiological studies, men have a slightly higher risk of developing psychotic disorders compared to women (Aleman et al., 2003; Li et al., 2016). It is pertinent to note though that these findings are mainly from high-income countries (HIC) and the pattern of age at onset and symptoms manifestation among men and women may not be uniform across the world (Morgan et al., 2023); there could even be differences among ethnic groups within the HIC.

Considering the interplay between gender and psychosis, clinical interventions must pay close attention to the different needs associated with men and women to ensure that the interventions are tailored appropriately. Despite this, due to the underrepresentation of women in FEP programs and studies, less is known about what is at stake for them with respect to psychosis (Ferrara & Srihari, 2020). This has put women in a disadvantaged position and, as a result, clinical programs may not engage women as effectively as hoped (Seeman, 2020). It is crucial to note, however, that gender should not be seen as a binary phenomenon. There is, in fact, a glaring gap in the literature regarding gender diversity in psychosis research, leading to most studies discussing gender in binary terms (Barr et al., 2021). Nonetheless, the emphasis here on the difference between male and female patients is due to the fact that the focus of the present study is on women's needs, challenges, and lived experiences.

What is the significance of culture?

Culture refers to knowledge, attitudes and values transmitted from one generation to the next (Sewell, 2004) and is deeply embedded in all aspects of human life. Failing to consider the complexity and multidimensionality of cultural factors when studying mental health will result in an incomplete picture of individuals’ experiences, health behaviours, and challenges (Gregg & Saha, 2006). Meanings and attributions of lived experience rely heavily on the available repertoire of attitudes and beliefs regarding mental health and illness embedded in community and social networks and reported in the public media (Larsen, 2004), such that cultural beliefs and practices influence how patients understand and interpret their psychotic experiences (Kirmayer & Bhugra, 2009). In addition, family beliefs and attitudes are heavily influenced by socio-cultural norms and values and exert a significant impact on treatment and recovery processes (Kalla, 2005). Explanatory models of illness, for instance, reflect a person's perceptions of an illness's causes, as well as their treatment preferences (Bhikha et al., 2012; Kleinman, 1978). Accordingly, psychosis causes may be perceived in a variety of ways by individuals, including beliefs in supernatural/spiritual, psychosocial, or biomedical causes (Subandi et al., 2021). There is a wealth of evidence indicating, however, that most individuals tend to use a combination of different explanatory models to make sense of the causes and symptoms of psychosis (Awan et al., 2017; Bhikha et al., 2012; Bhikha et al., 2015).

The most profound impact of cultural belief systems on psychosis may have to do with individual, family, and community help-seeking behaviours (Sheikh & Furnham, 2000). Consulting family, friends, and relatives, participating in religious or spiritual rituals, and consulting mental health professionals or traditional healers are various ways used by individuals with FEP from ethnic minorities including South Asians to seek help (Rathod et al., 2010; Singh et al., 2015). Furthermore, help-seeking behaviors can influence treatment and medication adherence (Perera & Chang, 2018). By establishing a good relationship with patients and their families, early intervention services can promote engagement with FEP programs and prevent the serious consequences that may be caused by medication non-adherence (Coldham et al., 2002). According to a study conducted by Maraj et al. (2018) in Canada, medication non-adherence is the strongest predictor of service disengagement among immigrants and non-immigrant FEP patients. Being sensitive to cultural aspects and developing a therapeutic relationship can help improve service engagement, understanding of the importance of medication, and adherence to treatment (Gault et al., 2019). The problem though is that some researchers highlight medication non-adherence in ethnic minority groups without attempting to understand its root causes. Relevant questions include why do some patients and families have less favorable view of medication? Do they doubt the effectiveness of medications? Do they prefer non-medical healing methods? Is there a concern about the short- and long-term side effects of medications? Are there culture-specific beliefs that account for these attitudes? Creating an environment where individuals can freely discuss their beliefs about illness, alternative healing practices, and cultural coping can improve the treatment alliance among clinicians, patients, and their families (Rousseau et al., 2005), while fostering recovery goals in harmony with the expectations of family and community (Subandi, 2015).

Strength-based versus deficit-based approach. Notions of health and wellbeing are profoundly affected by culture. When treating patients, clinicians should certainly be sensitive to the cultural beliefs of patients and be prepared to facilitate respectful and open dialogue, especially when differences of opinion emerge (Gregg & Saha, 2006). However, an approach that views culture only through the lens of cultural barriers and challenges would not be able to recognize the value of cultural, religious, and spiritual resources and their contribution to well-being (Rousseau et al., 2005). Hence, by considering culture as an active component of the treatment, the patient and the clinician will be able to develop a treatment plan that is inclusive of cultural strengths and resources that may otherwise be overlooked by the biomedical model (Dubbin et al., 2013). For instance, one of the cultural strengths that is especially relevant to South Asians is the availability of family support and their active involvement in taking care of their loved ones with mental illness (Littlewood & Dein, 2016). Also, it is important to recognize the importance of religion and spirituality. In a study conducted in Quebec with individials with psychosis, Borras et al. (2010) found that most participants viewed religion and spirituality as important coping strategies helping them overcome some of the challenges caused by psychosis; the findings were consistent across all socio-cultural and religious contexts. Interestingly, even though religiosity was important to Quebec clinicians in this study, they failed to give an accurate portrayal of their patients' religious beliefs and activities. There are a number of reasons why, such as perceived lack of skills, insufficient time, a fear of triggering a relapse by discussing religiosity, and regarding religious leaders as the only ones qualified and responsible to deal with spiritual concerns. Nonetheless, by expressing genuine interest and openness to learning about cultural strengths, clinicians can encourage their patients to utilize cultural resources, such as faith and community support, and to engage in cultural rituals that are enjoyable and personally empowering (Maura & Kopelovich, 2020).

The South Asian Population in Canada

South Asian people constitute a sizable minority group in Canada accounting for 25.1% of the visible minority population, and 5.6% of the Canadian population (Government of Canada, 2017). Additionally, South Asians are the fourth largest English-speaking visible minority group in the province of Quebec, representing 1.1% of the total population (World Population Review, 2021). South Asians exhibit a remarkable degree of cultural diversity based on their country of origin (i.e., India, Pakistan, Sri Lanka, Bangladesh, Nepal), spoken language (i.e., Punjabi, Tamil, Urdu, Gujarati, Hindi, Bangali) (Bélanger & Malenfant, 2006; Government of Canada, 2017; Tran et al., 2005; Wasay et al., 2014), and religious affiliation (i.e., Hinduism, Buddhism, Sikhism, Christianity, Islam) (Hefner, 1998; Veer, 2002). Also noteworthy is the variation in immigration history. Indian immigrants who arrived in Canada in the 1960s and later were mostly highly educated engineers, doctors, and IT experts (Raza & Erfani, 2015). Similarly, Pakistani immigrants who came to Canada since the mid-1960s were mostly well-educated (Agrawal, 2013; Raza & Erfani, 2015). As for Sri Lankans, despite the well-educated Tamil and Sinhalese immigrants between 1948 and 1977, the number of unskilled and semi-skilled workers who left the country began to increase in 1977 (Amarasingham, 2008; Raza & Erfani, 2015). Moreover, unlike Indian and Pakistani immigrants, both Sri Lankan and Bangladeshi immigrants arrived in Canada predominantly as refugees, mainly due to the civil war and ethnic conflicts in the 70s and 80s (Amarasingham, 2008; Ghosh, 2007).

In spite of considerable ethnocultural diversity within and between South Asian nations, they share many similarities, such as a collectivist culture characterized by interpersonal interdependence, warmth, strong ties, and extended support which contribute to shaping the cultural identity of South Asian people (Thomas, 2012). South Asians have made substantial contributions to Canadian society and are recognized as an active and prospering community due to their achievements in various fields, including sciences, business, arts, and literature (Naidoo, 1996, as cited in Naidoo, 2003). Moreover, several South Asian community organizations actively provide culturally oriented services to South Asians in Canada (*South Asian Women's Centre* (SAWC, n.d.), *South Asian Women and Immigrants' Services* (SAWIS, n.d.), *the South Asian Women's Community Centre* (SAWCC, n.d.), and *South Asian Women Association of Canada* (SAWAC, n.d.). Through a wide range of programs such as settlement and employment services, community engagement, counseling and mental health services, language classes, support and advocacy for victims of violence, youth services, as well as parenting workshops, these associations attempt to empower SAW and provide support tailored to their needs.

As with people from any ethnic origin, people of South Asian descent are influenced by the culture of the host country and their own culture as well. Accordingly, the first step toward understanding issues facing SAW in Canada is to understand how they maintain a balance between their cultural heritage and the culture of adoption. In line with the *dualistic traditional-contemporary view of life*, Naidoo (2003) explained that SAW's identity is shaped by a establishing a balance between values emphasized in their culture of heritage such as and emphasis on respect, tolerance, helping and sharing, as well as cultural values and aspirations emphasized by western cultures such as educational accomplishments and professional achievements (Naidoo, 2003). Additionally, according to the principles of *dharma*, which refers to doing one's duty, harmony and cooperation are valued particularly by Hindu SAW and may be reflected in their interpersonal behaviours (Naidoo 2003). Another core component of South Asian culture is the value placed on family. Grewal et al. (2005) explained that while there is evidence showing that the traditional roles of SAW have changed because of living in two different cultures, women are still expected to fulfill certain roles and responsibilities, which continue to have a substantial impact on their health and wellbeing. In their study, Grewal et al. (2005) also stressed that although the family is a crucial source of support and assistance, obligations and responsibilities associated with expected roles such as being an obedient wife, a responsible mother, and a selfless caregiver along with a full-time job can detrimentally affect SAW's health, particularly in Canada where women can no longer count on the domestic help provided to them by their extended families. Lastly, Grewal et al. make the point that in patriarchal societies, such as those in the South Asian context, SAW are expected to abide by their roles in order to maintain harmony in the family and preserve family *izzat* (honor and respect); yet, this can also mean that in order to comply with these expectations, women may have to prioritize the needs of their families over their own (Choudhry et al., 2002). In a study conducted in Montreal, Canada, Talbani and Hasanali (2000) investigated the experience of gender role socialization among adolescent females who were of Indian, Pakistani, and Bangladeshi heritage. Their findings showed that although South Asian immigrants often attempt to balance the host and heritage culture, family and community structures give men a superior status. This is evident in the stringent rules regarding female socialization, including the control over social activities and arranged marriages. The *dualistic traditional-contemporary view of life* can also help us understand the challenges SAW face in Canada as a result of living in a society where the host and heritage cultures are inclined to emphasize different values -autonomy and self-reliance versus interdependence-; this, in turn, causes conflicting demands regarding child-rearing, dating, and arranged marriage that can lead to intergenerational conflicts (Naidoo & Davis, 1988). Adolescence and early adulthood are critical periods, in which intergenerational tension can worsen as youth engage in socializing practices that may not be well accepted by their families, leading to conflict between children and parents (Samuel, 2009).

South Asian Women in the Diaspora - Immigration Challenges and Mental Health

The mental health issues facing SAW in the diaspora are important to document and explicate. As mentioned by Ahmad et al. (2005), SAW’s mental health in Canada is adversely affected by numerous factors, including loss of support from extended family members, diminished social activities, a busy and unfamiliar lifestyle that prevents them from fulfilling traditional gender roles, financial difficulties, health care access barriers, and lack of knowledge about available services. The authors provided further details regarding the perception of mental health issues and how SAWs cope with them. Their findings showed that some women may describe mental health issues as physical symptoms such as headaches, fatigue, or back or joint pain, or they may define mental illness as the inadequacy of resources and coping strategies which, in part, is caused by challenges they experienced during the immigration and settlement process. Women in this study also talked about the range of preventative and coping strategies they employed to sustain a healthy balance between mind and body. Their efforts included socialization, regular physical check-ups, yoga and exercise, as well as home remedies and alternative therapies such as Ayurvedic and homeopathy. Moreover, due to barriers such as long wait times, lack of control over the referral system, language barriers, and lack of knowledge about available mental health services in Canada, SAW chose to increase awareness about mental health by educating themselves about mental illness. They also mentioned that the types of mental illness they encountered in Canada differed from those they knew in their home countries. In a similar study done in Canada Hilton et al. (2001) evaluated the traditional health practices used by SAW and found that participants mentioned home remedies, dietary regimens, prayers, and consultations with hakims, veds, babajis, pundits, homeopaths, and jyotshis. In such cases, the practices may either be done daily or episodically and are usually undertaken to deal with relatively minor health issues or when conventional medicine fails to provide relief.

In another study done by Chiu et al. (2005) in Canada, the authors looked at factors influencing the treatment decision-making process among East and South Asian immigrant women with serious mental illnesses including psychosis. Participants spoke about the strength of family connection as being a great source of support, and one South Asian woman mentioned she felt mentally healthy when she returned to her home country and did not even need to take her medication. Nevertheless, due to stigma, many of the women were hesitant to seek help or disclose their mental health issues to their friends and family because mental illness is regarded as a family secret. Interestingly, women employed diverse and innovative strategies to cope with mental illness including humour, taking part in support groups, art/music, writing, reading, exercise, walking in nature, and actively engaging in religious and spiritual activities (i.e., worshipping, prayer, reading sacred texts, revelation, attending church, temple, or a sacred place, meditation, and repeating God's name). Some of those who believed their illness to be supernatural in origin preferred spiritual treatments to medical interventions, which may delay help seeking. Participants who believed that religion and spirituality enhanced their mental health openly talked about religion and spirituality as a source of coping. Notably, a few participants underlined the importance of using conventional medicine and spirituality at the same time. In their view, spirituality reduced their stress and brought them peace, while medication gave rise to quick and effective symptomatic relief. A South Asian woman, for instance, mentioned that, although Ayurveda or homeopathy might be beneficial, it would take longer for the effects to manifest compared to mainstream medications. These findings clearly demonstrated that help-seeking and treatment decision-making patterns of East and South Asian women are profoundly influenced by their sociocultural and religious beliefs.

In a qualitative study from Canada, Kidd et al. (2014) utilized an arts-based approach to examine the challenges of six racialized women with severe mental illnesses, including one South Asian woman. The South Asian participant stated that mental illness adversely affected her sense of identity, causing her to feel helpless and ashamed, as she lost control over her thoughts. She also mentioned that women are confronted with patriarchal pressures to fulfill what male members of the family (i.e., father, husband, son) expected of them, which often results in women forsaking their own needs. Although the participant asserted that her mental illness liberated her from some traditional expectations, such as getting married at an early age, due to the stigma surrounding mental illness, the negative consequences may be more severe given that some families view women with mental illness as unfit for domestic duties or as a source of shame to the family (Virdee et al., 2017). According to Kidd et al. (2014), it is too simplistic to view women as submissive persons who constantly overlook their needs and individuality. Rather, women discussed breaking their silence and refusing to conform to some restrictive cultural expectations. As a result, they felt empowered, which contributed to their mental health and helped them recover. As discussed by these participants, community activity, social support, and spirituality all contributed to their sense of connection and re-establishing confidence. It should be noted, however, that according to the participants, social supports were mainly provided by their clinical teams, friends, and to a lesser extent their families.

South Asian Families and Caregivers

Having an understanding of the family dynamic in South Asian culture is imperative due to the pivotal role played by the family in this context. In a study focusing on South Asian families in the US, Deepak (2005) explained that although South Asian immigrant families struggle to cope with a range of socio-economic challenges, this could likewise be an opportunity to develop new perspectives resulting in stronger parent-child relationships. As Deepak pointed out, the key component is the ability to navigate immigration and negotiate conflicting cultural norms.

Deepak's findings showed that some families set their roles and responsibilities based on South Asian cultural values, yet also adopted decision-making styles, which resemble the ideals of the culture of the host country. Additionally, being away from extended family afforded first-generation South Asian mothers the ability to make parenting decisions independently, resulting in supportive relationships with their daughters. Nevertheless, adapting to the culture of the host country while maintaining their ethnic identity may pose challenges to South Asian youth's mental health (Sharma et al., 2020). A hierarchical family system combined with authoritarian parenting styles, the expectation that children should prioritize the family's goals over their own, as well as parental expectations regarding education, career choice, and marriage can place an immense psychological burden on South Asian youth (Bhattacharya & Schoppelrey, 2004; Deepak, 2005; Sharma et al., 2020). Having an understanding of families' perspectives and reactions to psychosis could also provide further insight into the needs and challenges faced by SAW with FEP. Although the family is a vital source of psychological and financial support (Littlewood & Dein, 2016), due to the stigma associated with psychosis, South Asian patients may avoid talking about their illness with their families, resulting in a sense of internal stigma (Vyas et al., 2021). Moreover, families' beliefs about psychosis' causes ranging from social and religious to medical can have an impact on seeking care for their children (Littlewood & Dein, 2016).

Objectives of the Present Study

There is a dearth of studies on SAW with FEP and the focus of the limited work to date overwhelmingly reports demographic findings, such as the age of onset, and symptom presentation among South Asian female patients (Kirkbride et al., 2012; Morgan et al., 2016;

Naqvi et al., 2010). Many questions remain to be addressed, such as how female South Asian patients report their lived experience of psychosis, what their challenges, barriers to care and unique needs may be, and which socio-cultural issues are of primary importance to South Asian women with FEP. This also highlights the importance of qualitative studies that can tap into lived experience of SAW. As a result, this qualitative study aims to (1) to explore the lived experience SAW with psychosis, (2) cultural challenges they faced during treatment and recovery, (3) and the cultural resources that augment recovery and coping. It is hoped that the findings of this study provide insight into designing culturally sensitive services tailored to needs to SAW in Canada.

Methodology

Ethics

The research protocol and consent forms of this multi-site research study were authorized and approved by the Research Ethics Boards of the CIUSSS du Centre-Ouest-de-l'Île de Montréal (MP-05-2021-2772), the CIUSSS de l'Ouest-de-l'Île de Montréal (MEO-05-2023-631), and Centre Universitaire de Santé McGill (MEO-05-2022-7727).

Research Design Overview

Choice of Methodology. An exploratory qualitative research design was used to study the lived experience of SAW with psychosis, the needs and challenges they encounter, as well as the cultural strengths and resources they draw upon to overcome their illness. Face-to-face semi-structured individual interviews were conducted to study the meaning patients ascribe to their lived experience. A phenomenological approach was utilized to gather in-depth data about how a person engages in meaning-making and reflects upon phenomena of existential importance to them (Smith, 2011; Smith, Flowers, & Larkin 2009). Assuming that the collected data would most likely reveal culturally-informed beliefs, attitudes and explanations, the objective was to understand how cultural factors can shape the lived experience of SAW. Hence, in order to gain a deeper understanding of the lived experience of SAW with psychosis, data analysis was performed using *Interpretative Phenomenological Analysis* (IPA). A detailed description of the IPA's philosophical foundations, as well as how it was applied in this study will be provided later in this chapter.

Sample and Recruitment

Setting. This study took place in collaboration with three first episode psychosis clinics in Montreal over one year. Participants were recruited from the *First Episode Psychosis Program (FEPP) at the Jewish General Hospital*, the *Prevention and Early Intervention Program for Psychosis (PEPP) at the Douglas Mental Health University Institute*, and the *Prevention and Early Intervention Program for Psychosis-MUHC (PEPP-MUHC) at the McGill University Health Center*. Staff at these sites helped recruit the participants. Convenience sampling was used as a method of sampling.

Sample (South Asian Women with FEP). The patients were recruited from referrals to participating FEP clinics. The recruitment was done prospectively based on new referrals to the sites, as well as retrospectively, from patients who had been referred to the clinics since January 2018. Both strategies were implemented to ensure that an adequate number of South Asian women would be recruited. Inclusion criteria included female patients who met the routine clinical criteria for FEP (first psychotic symptoms for more than three days; age 18-40 years; absence of significant substance abuse, intellectual impairment, or medical illness that could account for the psychotic symptoms; and taking antipsychotic medication for less than 30 days). Additionally, participants had to be of South Asian descent (i.e., from India, Pakistan, Sri Lanka, Bangladesh, or Nepal). First- and second-generation immigrants, as well as refugees and asylum seekers, could participate in this study and there was no limitation regarding the length of time since immigration. As for the young patients who were born in Canada, both parents had to be from one of the South Asian countries mentioned above. Hence, this study cannot speak about the experiences of biracial youth with one South Asian parent.

Sample (Family Members). South Asian cultures emphasize the importance of family and family members often wish to take an active role in taking care of their loved ones with psychosis. Therefore, the student researcher decided to include families in this study as their perspective would enable her to better understand the SAW in a culturally appropriate way through family members reflecting on their loved ones' experiences with psychosis and the treatment they received. To recruit families, the consenting study participants (i.e., patients) were asked to identify a family member whom the researcher could contact for their consent. As for the inclusion criteria, family members had to be at least 18 years old to participate. It should be mentioned, however, that among 5 participants, only one authorized the researcher to contact a family member. One participant was initially willing to consent but preferred to first check with her family member and ask if they would be willing to take part in the study; the family member was not interested. The participant who did give consent, wanted the interviewer to contact their mother. In total one family member participated in the study. As this was not a sufficient number, her data was not formally analyzed.

Sample Size. A sample of five English-speaking female-identifying patients, aged 21-40, who self-identified as a South Asian, and were followed up by the participating clinics were recruited to the study.

A qualitative study's sample size is determined primarily by the scientific paradigm under which the study is conducted (Boddy, 2016). In a qualitative study there is no formula to estimate the adequate sample size, and the validity, relevance, and usefulness of the collected data are assessed based on the richness of the gathered data (Dongre et al., 2009). Through qualitative studies, researchers seek to achieve a better understanding of a phenomenon via various methods such as in-depth interviews and hence the focus here is essentially on the adequacy, richness, and depth of the collected data rather than its numerical value (Malterud et al., 2016). Furthermore, saturation can also provide information about how the data collection process has been conducted and whether enough participants have been recruited. In a constructivist and in-depth qualitative study, a smaller sample size will suffice if it provides meaningful information and new insights into the phenomenon under investigation (Boddy, 2016; Malterud et al., 2016). Conversely, a large sample size in qualitative research may result in the overgeneralization of findings when the study involves a highly specific population (Green & Thorogood, 2004). Thus, a sample size of 5-10 SAW was estimated suitable for this study. This is in line with previous studies that showed a sample of 6-10 participants would be adequate for the identification of the codes and themes arising from participants' accounts (Young & Casey, 2018). Moreover, due to the focus of this study on the lived experience of SAW, the Interpretative Phenomenological Analysis (IPA) was chosen as the analytical method. IPA provides an in-depth analysis of each case and is suitable for a small sample size (even a single case) (Eatough & Smith 2017; Smith, 2011). The upcoming sections will provide a full description of IPA and the analytic framework used in this study.

Female Focus. This study focused on the lived experience and needs associated with South Asian women with FEP. As a result, only female-identifying patients were recruited. Two reasons justify the study's exclusive focus on women. First, FEP research does not adequately represent the needs or lived experience of women (Ferrara & Srihari, 2020). When SAW are the focus of investigation, most studies report demographic findings, such as the age of onset, and symptom presentation among South Asian female patients (Kirkbride et al., 2012; Morgan et al., 2016; Naqvi et al., 2010), without adequate attention to lived experience, what their needs may be, and the socio-cultural factors that could impact their treatment and recovery. Second, researchers can conduct an in-depth analysis of a subgroup when a homogeneous sample is available (Patton, 2002). To ensure homogeneity, gender (i.e., female patients), ethnicity (i.e., South Asian), age (i.e., 18-40), and admission to the FEP clinic were taken into consideration in this study.

Data Collection Procedure

Recruitment. The student researcher met members of the FEP clinical teams at three sites to describe the study to them and to explain their role in the recruitment of patients. The patient sample was recruited from referrals to participating FEP clinics. The recruitment consisted of new referrals to the clinics since January 2018. The student researcher attended weekly clinical meetings to ascertain which patients may be suitable for study participation. When participants met the eligibility criteria, the clinicians (i.e., the patient's psychiatrist and case manager) were consulted to make sure that the patient was clinically stable and able to take part in a 1–2-hour interview. Then the case manager approached the patient, explained the study, and asked if they would like to be contacted by the researcher to receive further information about the study. The case manager also informed the patients that they were under no obligation to participate in the study even after they are contacted by the researcher. If the patient gave verbal consent to the case manager, their name and contact information were shared with the student researcher who then contacted the patient by telephone.

Reflexivity. The Researcher's position in relation to the population under study may profoundly affect the data collection and analysis process (Berger, 2015). In a qualitative study, the researcher may even be seen as the *research instrument* as their personal experiences, values, interests, and prejudgments can influence how they approach understand and interpret phenomena (Dodgson, 2019). This brings us to the concept of reflexivity. Reflexivity is an attempt to become cognizant of one's own positionality in terms of social position (e.g., gender, age, race, immigration status, sexual orientation), lived experiences, and personal beliefs

(Berger, 2015). In other words, reflexivity is a vital step in understanding the researcher's role in the type of data collected (Jootun et al., 2009) and, most importantly, to identify biases that may impact data collection and analysis (Palinkas, 2014). In addition, reflexivity would require that the researcher be transparent and honest and be open to sharing their research interests and socio-cultural background with participants, which, in turn, can facilitate the participant-researcher relationship and ensures the richness and credibility of the findings (Patnaik, 2013).

In this study, prior to each interview, the position of the student researcher was transparent. The researcher shared that she identifies as a person of color and that she is an Iranian Canadian woman who immigrated to Canada 7 years ago. The researcher explained that she is completing her masters at McGill University and is working as a research assistant at the Jewish General Hospital. She also informed participants that she is not part of the clinical team and does not provide any clinical services. Moreover, she stressed that as an immigrant and a member of an ethnic minority group, the intersection between culture and mental health is of interest to her and strongly feels the necessity of culturally appropriate mental health services that are sensitive to needs of individual from diverse ethnic groups. Taking into account her cultural background, the researcher also introspected her own personal and cultural beliefs and values. This was done to explore and be cognizant of how these elements of her culture could impact her approach to the topic under study. Nevertheless, the researcher meticulously avoided allowing her assumptions to bias the data collection and interpretation. By closely following the qualitative semi-structured interview protocol, the McGill Illness Narrative Interview (MINI), as well as asking probing and clarification questions -instead of solely relying on her judgment and interpretation- the researcher endeavored to obtain a rich and comprehensive picture of participants' lived experiences.

Procedure. Interviews took place from March 2022 to November 2022. During this time five SAW with lived experience of psychosis were interviewed. Four of the participants were Canadian-born citizens with ancestors from one of the following South Asian countries: India, Pakistan, Sri Lanka, Bangladesh, or Nepal. One participant was born in Pakistan and migrated to Canada for university studies.

Recruitment and Ethical Considerations. To recruit participants, the student researcher first contacted patients receiving care from FEP clinics who consented to sharing their contact information with the researcher. They were told that the purpose of this study is to better understand the lived experience of South Asian women with psychosis, their needs, and treatment and recovery experiences. They were also told that their participation would involve taking part in an online interview during which they will be asked a series of open-ended questions related to their experience with psychosis. In addition to providing patients with detailed information about the study, the student researcher reviewed the consent form with them and answered any questions or concerns they had regarding the study and their participation. Participants were advised that everything mentioned during the interview would be kept strictly confidential. They were, however, told that if new information is uncovered during the research interview that has a bearing on their health, safety or well-being and would require intervention, the researcher would inform the clinical team because they have a responsibility to help and protect patients. Participants were told that they were not obligated to answer the questions if they did not feel comfortable, and if they felt distress at any time, they could tell the researcher, and she would stop the interview. Participants were told that they could withdraw from the study at any time without reason or consequence. If the patient was interested in taking part in the study, she was asked to indicate her consent by filling out and submitting the online consent form (the link to the consent form was emailed to the participant after the phone call). The patient was also asked if they authorize the researcher to contact their family member. If yes, they were asked to indicate the name and contact information of the family member(s) in the online consent form. Then the student researcher coordinated a time and date for the interview that was convenient for the participant. The consent form and Zoom session links were emailed to the participant after the phone call. Because of the pandemic all interviews were conducted online via the video conferencing application, Zoom. The Family member was recruited using the same procedure.

On the day of the interview, prior to beginning the interview, the researcher addressed any questions that the participant had about the consent form or the study. The researcher also reminded the participant that their participation is entirely voluntary, and they can withdraw at any time if they wish to do so. Interviews were conducted remotely and one-on-one between the researcher and the participant in a private setting. It was also advised that participants disclose only information they felt comfortable sharing. The length of interviews varied from one hour and fifteen minutes to two hours and ten minutes and were completed in one session. All participants consented to the session being audio-recorded. At the end of the interview, all participants were given a $20 e-gift card to compensate them for their time.

COVID-19 Considerations. Conducting online interviews during the pandemic required certain precautions to ensure the safety and well-being of the participants. In an in-person interview, if a participant begins to feel distress and discomfort, the interviewer can accompany them to clinical care. This is not possible in an online interview. For this reason, a safety protocol is prepared in advance. In this study all participants were pre-screened by clinic staff for stability and suitability. Additionally, on the day of the interview, prior to initiating the interview, the researcher verified the participant's location to get help if need be. The safety protocol, developed with the student's supervisor, had two sections. In the first section, responses were categorized based on low, medium, and high levels of emotional distress felt by the participant. The second section contained emergency contact information, as well as contact information for the appropriate clinic, so that the researcher could convey an urgent message to the patient's clinical team, if needed.

Instrument

McGill Illness Narrative Interview (MINI). Participants in this study were interviewed using the MINI, a theory-based, semi-structured qualitative interview protocol that explores the lived experience of participants, their modes of reasoning, how they understand and explain their illnesses within a socio-cultural context, and their experience with the treatment (Groleau et al., 2006). The holistic picture derived from participant narratives allows the researcher to gain a better understanding of individual needs, challenges, and cultural resources. The MINI is a relatively long interview and typically it takes 1 to 2 hours to administer. Originally designed to interview patients, the MINI has also been adapted to interview family members and clinicians, and it has been used to explore participant narratives of various illnesses and disorders (Dominicé Dao, 2008; St-Arnaud, 2011). In this study, the MINI was used to interview patients and their family members. The original version of the MINI was administered to SAW without alteration. For family members, the same interview protocol was implemented with a slight modification to keep the focus of each question on the patient's experience. As a result, the patient was referred to in the third person when interviewing family members. For instance, instead of asking "When did you experience the psychotic symptoms for the first time?", the family member was asked: "When did she/ your loved one/daughter experience the psychotic symptoms for the first time?". Please see Appendix 1-4 for more information.

The Structure of the MINI. The MINI has five sections, which are outlined below (Groleau et al., 2006). The first section, *Initial Illness Narrative*, seeks to provide a narrative which traces the spatial and temporal order of the events faced by the participants as they encountered their illness. The interview is deliberately less structured at this point and includes a series of open-ended questions such as: *When did you experience your health problem or difficulties (HP) for the first time?* and *We would like to know more about your experience. Could you tell us when you realized you had this HP?* In the second section, *Prototype Narrative*, the participants are asked to reflect on how their illness experience is similar or different compared to that of other people (e.g., a family member, a friend, a colleague, a character in a movie or book, etc.). With this narrative, the researcher can examine whether and how participants use analogies to reason about their health problems and behaviors. This is of importance as people's modes of reasoning can also be shaped by their cultural beliefs. Here are some of the questions asked in this section: *In the past, have you ever had a health problem that you consider similar to your current HP*?

and *Did a person in your family ever experience a health problem similar to yours?* The third section, *Explanatory Model Narrative*, seeks to understand how individuals attempt to make sense of their illness, the label they use to describe it, and the causes they believe contributed to their illness. As a result, this section provides insight into the meaning individuals assign to their experience and challenges they face. The questions such as: *Do you have another term or expression that describes your HP* and *according to you, what caused your HP?* are asked in this section. Section four, *Services and Response to Treatment*, focuses on service utilization and treatment experience and aims to explore what kinds of help were sought and whether they were helpful. Most importantly, it allows participants to further elaborate on whether the treatment they received met their needs. Here are some of the questions asked in this section: *During your visit to the doctor (healer) for your HP, what did your doctor (healer)tell you that your problem was?* and *what treatments did you expect to receive for your (HP) that you did not receive?* Finally, in the fifth section, *Impact on Life*, the participant's narrative provides insight into how their self-perception and identity were impacted by their illness. This is particularly relevant in the context of chronic conditions in which the participant can express how the illness has changed their view of themselves and their life. Of particular interest, this section also offers some questions related to the possible cultural resources that the person may employ to overcome the difficulties they experienced. For instance, *how has your (HP) changed the way you feel or think about yourself?* and *how has your spiritual life, faith or religious practice helped you go through this difficult period of your life?*

As mentioned in the previous section, the MINI is a suitable tool to navigate participants' experiences by establishing a culturally cognizant approach. Furthermore, the semi-structured nature of the interview allows the researcher to delve deeper into cultural factors important to the participant through asking carefully crafted probing questions. For instance, in section 4, *Services and Response to Treatment*, the interviewer asked a few follow up questions to ensure that the participant is given an adequate opportunity to evaluate current services and how cultural factors can be incorporated into services to provide better care. Examples of the follow up questions asked in this section are: *Is there anything clinicians should know about your cultural background that you think is crucial? Did you ever encounter language barriers or communication difficulties while seeking help from your clinical team?*

A participant's preferred term for describing their illness can be elucidated by the MINI, which uses the general term, "Health Problem", and which will change to the term the participant prefers. To do so, at the beginning of the session and prior to initiating the interview, the participant was asked: *What is the term you would be most comfortable with? When we discuss your experience with psychosis, are you okay with me using the term psychosis or do you prefer another term instead; a term that you believe better describes your experience?* This was checked at the beginning of all interviews and all participants declared that they were fine with the term psychosis.

Data Analysis

Interpretative Phenomenological Analysis (IPA): A methodology to explore the lived experience with small-number studies. The core aim of this study is to explore how cultural factors, both challenges and strengths, have shaped the lived experience of SAW with psychosis. As such, due to its strong emphasis on lived experience, IPA was chosen as an appropriate analytical approach for this study. Drawing upon the theoretical underpinnings of phenomenology, hermeneutics, and ideography, by tapping into the person's lived experience, IPA provides an understanding of how people make sense of important life experiences, particularly those of existential significance (Smith, 2011). With its phenomenological component, IPA attempts to capture every aspect of a person’s lived experience by paying close attention to their desires, wishes, attitudes, and belief system (Eatough & Smith 2017). This is further reinforced by the idiographic element of IPA that emphasizes the necessity of an extensive and meticulous case-by-case analysis of each person (Smith & Shinebourne, 2012). This implies that prior to attempting a comparative analysis, each case must be assessed and analyzed independently and only after this, can the researcher examine the divergences and convergences across cases (Shinebourne, 2011). A further benefit of IPA is that, under the hermeneutic framework, it engages the researcher in an iterative and complex analytical process to interpret the narratives. In other words, IPA, as a linguistically based methodology, requires the use of double hermeneutic which is defined as the researcher's quest to make sense of how the participant makes sense of their own experience and events that occurred to them (Smith, 2011). To achieve this, the researcher stays close to the participant's narrative; this is imperative to gain a comprehensive and granular account of a person's lived experience. At the same time, the researcher should be careful not to uncritically accept at face value what has been narrated to them, but rather through carefully prepared probing questions they should delve deeper into aspects of the participant's lived experience that are vital but may sound initially obscure or not easily accessible (Eatough & Smith, 2017).

IPA was originally developed in the 90s in the UK as a methodology for studying lived experience in health, clinical, and counseling psychology; since then, it has been used in various other fields including health sciences (Eatough & Smith, 2017). As a commonly used approach for investigating the illness experience, IPA lends itself well to research questions exploring how illness phenomena shape a person's lived experience (Smith, 2011). The idiographic component of IPA demands an extensive and detailed analysis of each participant by which each case is thoroughly assessed individually, and which explains why small sample sizes (even a single case) may be appropriate because they yield in-depth data that would provide a sufficient foundation for a comprehensive analysis (Eatough & Smith 2017; Smith, 2011). IPA studies often use semi-structured interviews because it allows the researcher to have a real-time dialogue with the participant and collect detailed first-person accounts. During semi-structured interviews, the researcher can also ask probing follow-up questions to shed light on hidden or not readily accessible aspects of the participant's experience (Smith & Shinebourne, 2012). Through the MINI's open-ended questions, participants in this study were able to elaborate their lived experiences.

Analytic Strategy and Process. Analyzing data within the IPA framework requires the adoption of an iterative, dynamic, and nonlinear approach (Eatough & Smith, 2017). Prior to carrying out the analysis, the interviews were first transcribed verbatim using a Computer Aided Qualitative Analysis program, NVivo (Release 1.6.2). The analytic strategy in this study follows the procedure described by Smith and Shinebourne (2012), and the researcher followed the guidelines proposed by Smith (2011) to ensure a high-quality analysis. The first phase of the analysis entails *Immersion* in the data, which is achieved by close reading of the transcript. For this purpose, the student researcher first read the transcripts while simultaneously listening to the audio file to ensure the interviews were accurately and thoroughly transcribed. The student researcher also took this step to familiarize herself with the participant's narrative. She then re-read the transcripts several times and took notes on important issues mentioned by the participant, paying attention to details, as well as context, figures of speech, and pauses expressed during the interview. The second phase, called *Extraction*, involves selecting meaningful statements to identify the initial emergent themes. As part of this iterative process, the researcher utilized higher levels of abstraction to identify the key messages that the participants intended to convey about their lived experience. During this stage the researcher remained close to participant's account. In the third phase, after pinpointing the patterns among the initial emergent themes, the themes that tended to reflect the same topic were grouped into clusters, and finally each theme was assigned a name. This was a recursive step as each cluster needs to be revisited again to make sure it is meaningful and aligned with the original transcript. In the fourth phase, themes and sub-themes were defined, and their respective extracts were compiled in a *Summary* table. All interviews underwent the same procedure and phases 1-4 were repeated for each case. Afterwards, the *Write-up* phase provided a clear description in which each theme was introduced and accompanied by its relevant extracts before being elaborated to provide an in-depth interpretation.

Methodological Integrity

Several steps were taken to ensure the rigour and methodological integrity of this study. First, to establish the trustworthiness of the findings, the framework proposed by Lincoln and

Guba (1994, as cited in Johnson et al., 2020, p. 141) was followed. The first criterion, *Credibility*, entails providing supporting evidence to the reader and demonstrating that the collected data and results are in line with the research question that the study attempts to address. To ensure credibility, the student researcher fully adhered to the MINI protocol to gather information pertinent to the research question, along with contextual information needed to have a better understanding of the participants' lived experiences (Liamputtong, 2013). The latter is also related to the second criterion, known as *Transferability*, which refers to the detailed contextual information that will help the readers to judge whether the findings are applicable and comparable to other settings or contexts. This was done by providing a deep dive analysis of narratives to provide a multidimensional account of the social and ethnocultural context in which the participants' lived experiences were shaped. The third criterion, *Dependability*, deals with transparency and traceability of research procedures such that other researchers can reproduce the work (Hanson et al., 2019). To provide an understanding of the exact steps taken to achieve the results, the researcher provided a detailed description of all the research methods and procedures used in this study, from recruitment and data collection to data analysis.

Last, *Confirmability* requires the researcher to provide compelling evidence illustrating that the findings are based on the data obtained from participants and not the researcher's bias. Multiple citations of participants' quotations demonstrated this. During the interview, when necessary, the researcher asked the participant to elaborate on their responses to avoid confusion and minimize the risk of misinterpretation. Moreover, to enhance the validity of the findings, the researcher engaged in member checking at the end of each interview. As part of the member-checking process, the researcher verified that her understanding of participants' accounts was accurate and matched the real message the participant intended to convey during the data collection (Gray, 2017). Echoing, paraphrasing, summarizing, obtaining clarifications from participants about ambiguous answers, and allowing the participant either confirm or correct the interviewer's interpretation are examples of member-checking strategies (Coleman, 2022) applied by the researcher to ensure the validity of the study findings.

To avoid personal bias and as part of reflexivity, the researcher considered how her research and academic background might influence data collection. Full adherence to the interview protocol and remaining open to what the participant shared were steps taken to avoid bias. Additionally, the position of student researcher was also disclosed to the participant at the beginning of each interview. To do so, the researcher shared her social, ethnocultural, and academic background with the participants and explained her role as a master's student and student researcher who wishes to gain a cultural understanding of factors impacting the treatment and recovery of SAW with psychosis.

The guideline proposed by Smith (2011) was also applied to further ensure the quality and accuracy of findings. Smith explained the characteristics of a sound IPA and provides step-by-step guidance on how to conduct and write a good IPA. First, it is essential that the study has a *Clear Focus*. In this study, the research question was clearly defined and a homogeneous sample was selected. A key aspect of this study was the focus on the lived experiences of SAW with psychosis in their socio-cultural context. The second criterion underscores the importance of gathering *Strong Data*. An appropriate method of data collection and the capability and skills of the person responsible for data collection are essential for the collection of strong data. In this study, the MINI was used as it offers culturally rich and in-depth narratives of participants' lived experiences. Due to its semi-structured structure, the MINI allows researchers to ask follow-up or probing questions to enrich and clarify the data. To gain the knowledge and skill required to conduct semi-structured interviews the researcher successfully completed two courses on Qualitative Research Methods (i.e., Qualitative Research in Health Care, and Social and Cultural Research Methods) offered by McGill University. As well, she received a certificate from King's College London and Birzeit University for successfully completing a course on Qualitative Research Methods for Mental Health in War and Conflict. She also participated in a 9-hour workshop designed to promote the skills essential to conduct the MINI interview. The courses and workshop contributed towards developing the skills necessary to conduct and analyze qualitative studies in general, and to conduct semi-structured interviews using MINI specifically.

Third, the guideline discusses the *rigour* of the study, which was explained in the previous section. The next criterion stresses the importance of *Sufficient Elaboration* of each Theme. Each transcript was thoroughly analyzed by the student researcher, and each transcript was re-read several times to identify patterns of convergence and divergence within and across cases. The goal of this step was to provide a solid foundation for interpreting and analyzing the collected data. In a similar vein, the guideline also stipulates that the analysis should be *Interpretive* and meaningful rather than merely a *Descriptive* report that reiterates what the participant has already stated. While reading and rereading the transcripts, the student researcher took notes on her important observations and interpretations. The results section provides an interpretive report on each theme. It is also of great importance to capture the *Convergences and Divergences* that arise from narratives. To identify differences and similarities between participants, each transcript was analyzed independently, then compared with those of the other participants. Lastly, *Good Writing* is a crucial factor. This requires well planned and coherent writing that is founded on the data collected during the course of the study. The student researcher conducted all steps mentioned in this section with the support and guidance of her supervisor and committee members, whose knowledge and expertise directed her to conduct a rigorous study.

Results

Semi-structured Qualitative Interviews

Semi-structured qualitative interviews were conducted to explore the lived experience of SAW with FEP, their real-life needs, cultural challenges they encounter, as well as cultural strength and resources they draw upon to overcome some of the difficulties they face because of psychosis. A total of five South Asian, English speaking, female-identifying patients, who were actively followed by one of the participating clinics, were recruited. All participants were female and single, between the ages of 21 and 40 years, and all had either university or college education. Table 1 shows the demographic information of participants. Participants took part in a one-time online individual interview which lasted between 1 hour and 15 minutes and 2 hours and 10 minutes. Figure 1 illustrates the three principal themes that emerged from the interviews. In the following section, each theme is presented with its subthemes. The analysis yielded 10 subthemes.

Themes

Three principal themes emerged from interviews; *Predicaments, Treatment Experience and Help-Seeking Efforts*, as well as *Cultural Knowledge*. Each theme and its subthemes will be discussed in details in the following section.

Theme 1: Predicaments

This theme consists of three subthemes: *Meaning of Psychosis, Need for Independence,* and *Challenges*. Here the emphasis is placed on the challenges caused by psychosis to uncover the hardships SAW face as they struggled to live a fulfilling life.

Meaning of Psychosis? This subtheme was present in all five interviews. All participants stated that they had no prior knowledge of psychosis and had never heard of the term psychosis before their illness. Reflecting on their first reaction to psychosis, participants reported two very different experiences. For three of the participants, the initial stage of psychosis was described as *weird*, *distressing*, and a *fictitious dream world inside the head that has nothing to do with reality.* They felt something was not normal and didn't look right, but due to a lack of knowledge about psychosis they had no idea what they were experiencing and what to do about it.

> P01: When I was admitted to the hospital, I realized I had psychosis, but there were some weird feelings happening before, which I didn't and never experienced before. When it started, I had no idea what the heck psychosis was, and I suspect that whatever I was thinking was crazy and I wanted validation and wanted somebody to tell me like no this is not true. But nobody would confirm anything. When it was getting a little bit uncomfortable when I was hearing things and believing in very supernatural things like I can communicate telepathically; that was when I started to feel like this is weird, this is not normal. But I also couldn't tell people because then they would be like, oh you're

> crazy. But I would also like to like figure out like is this true? Not true? I definitely didn't know what to think of.

The other two patients, however, said they didn't realize something was abnormal until they were admitted to the hospital. Their experience was described as a sense of confusion, *being more spontaneous*, having difficulty in distinguishing between *what is real and what is not real*, *losing grasp of reality and letting the thoughts take over*, and not being fully aware of what was happening to them. Only after being hospitalized did these patients begin to realize that they had psychosis. As reported by one of the participants, psychosis did not occur as an abrupt change in her life. Instead, it was described as a gradual progression from "*normal to psychotic thoughts*".

> P04: I was told by the nurses and the hospital that I experience psychosis. I didn't know what I was experiencing at the time it was happening. I thought everything was real. Right now, I can say that those things were delusions and it wasn't real but at that time what I was experiencing was normal for me; that's what I thought reality was. So, I had no idea I was going through a psychosis I just thought everything was real.
> It was just a slow transition from normal thoughts and then slowly slowly towards psychotic thoughts until I had the episode the first episode. I stopped differentiating between normal thoughts and psychotic thoughts. Everything just became normal to me. It was a continuously normal. Like, it was a normal thing for me until I woke up in the hospital. And then I actually realized that OK, something was wrong

Another issue raised by participants was the uncertainty surrounding the diagnosis, and how this impacted their experiences. Some participants described the situation as speculation about possible diagnoses like schizophrenia or bipolar disorder, but either their symptoms were not diagnosed (because their symptoms did not meet the diagnostic criteria for these mental illnesses), or it took their treatment team a very long time to diagnose the illness. They stuck with the term psychosis which is referred to as a symptom rather than an illness for a long time until their illness was finally diagnosed. The rest of the participants experienced the opposite, meaning that their diagnosis was changed several times. Consequently, both of these circumstances made it more difficult for patients to find out what their illness was and why it happened to them in the first place.

> P01: I haven't been diagnosed with anything like there was a suspect that I may have had bipolar early but it wasn't; so far one episode of psychosis. So, they can't give me a diagnosis.
> I: Do you have another term or expression that describes psychosis, any other term or phrase that you may use to describe psychosis?
> P01: Yeah, maybe like episode I think I've heard that before like mental health issue. I don't know whether it's all the same. It's all the same to me. I don't know because I haven't been diagnosed. If you like saying something like schizophrenia or bipolar is too specific and it's usually attached to someone who's been diagnosed with that. When I was in the emergency ward, there was a lot of speculation that, oh, it could be bipolar and I feel like I personally and maybe even my family kind of pigeonholed those possibilities to my psychosis. And I keep asking my psychiatrist because there's no diagnosis, I don't have like a confirmed diagnosis. I don't know what it means, but definitely it seems to me some kind of mental instability.

This subtheme clearly shows that having an understanding of psychosis is a crucial step for SAW to make sense of their situation, and several factors, including a lack of knowledge about psychosis and a change of diagnosis or not receiving a diagnosis, adversely affected their experience.

Need for Independence is the second subtheme that was present in 4 out of 5 interviews. For these SAW, independent living encompassed a broader need that has profound existential importance. According to the participants, having a job, pursuing academic goals, and establishing and maintaining a fulfilling relationship play a pivotal role in having a successful and independent life. Despite living with their families at the time of this study, some participants used to live on their own (and not with their families) prior to the onset of their illness. However, due to illness, they had to move back to their parents' house and that created challenges for them. Being overly reliant on the family was mentioned as a factor that limited the possibility of building connections with a broader social network outside the family. Considering that in South Asian contexts, it is culturally acceptable for women to stay with their families until marriage, this finding is particularly notable. Moreover, there were concerns about future life and how to manage life when parents are no longer present to provide psychological, as well as financial supports,

> P01: [before psychosis happened] I was very excited to be independent and so, I was happy, I had created a schedule for myself. I would spend my weekends taking care of a laundry and go to the farmer's market and do the grocery. And so, I had a nice routine and I loved the independence factor about it. [After psychosis happened] I didn't want to go home. I was having these very existential, kind of weird, paranoid state and there was this voice in my head saying, if you go home, you know, it's over. What are you going to do? What do you want? It was very weird like I can’t explain it. It was maybe existential. I'm living at home [with my family] now; but there are times where my whole aim is to get out and be independent.
>
> P05: I went to see a psychologist and I think it was helpful for me. I got to talk about what was going on at home. I moved back to my parents’ house and that's not easy. I had someone to like kind of vent to and I'm not finding a job and that I stuck in my parents' house. I don't always get along with my parents and I kind of had no choice but to live with them. Very few people know that I’m a psychiatry patient. My parents know my brother knows and my sister knows a few of their friends know, not very many people. So, I guess all these people realize I have some challenges and some of those challenges result in me living with my parents again.

It is worth emphasizing that a range of factors, such as living in one's own place (and not with the family), employment, academic pursuits, and meaningful relationships, contributed to the sense of independence among these participants. Indeed, the participants' ability to cultivate a sense of independence through a combination of these factors played a vital role in sustaining their journey towards recovery and regaining self-confidence.

Challenges. The third subtheme which was present in 4 out of 5 interviews, illuminates general challenges and difficulties SAW encountered. For instance, psychosis led some participants to doubt their ability to maintain a relationship. One participant stated that since her mind was overly occupied with so many thoughts, she felt completely zoned out during social interactions. Other participants, however, attributed this challenge to a perception of incompetence or incapacity to fulfill the roles and responsibilities expected of them, whether in friendship or romantic relationships.

> I: And how has your psychosis changed the way that others look at you?
> P02: I don't know and that terrifies me. I wish I knew. OK, so, I'm like fairly easy to be friend with I think I have a good amount of friends, you know I've never been super popular but people enjoy my company. Apparently, I have, however, lost a lot of friends because of it. It's just it's a lot for people to handle. It's very intense and sometimes I'm not very good at being friends with people or being there a lot of the time. My friends have very hard times and I kind of can't be there for them as much.
>
> P04: When I was going through the psychotic episode and right before that time, I was texting my boyfriend and I still have those texts. So, sometimes I don't know why I do this but sometimes I go back to the old chats and I'm about to read what I said but I can't finish reading it because of the embarrassment and I don't know how but he was very supportive about it and he didn't ever bring it up again. But sometimes I feel guilty for having dragged him into it; I just sometimes don't feel good enough for him; I have thoughts like this.

As reported by participants, psychosis also affected their academic and work performance. As a result of psychosis, some SAW found it difficult to find and maintain a job. Academic performance was also negatively impacted by difficulty maintaining attention.

> P04: I had to leave my term that year so I left my term, I went back to Pakistan for a mini vacation. Then when I came back, I resumed my studies. So, because of this episode I'm technically one term late from graduating. There could be some challenges in terms of studying because you're going through thoughts which are not necessarily true and they're just in your head so you might do things which people who don't have psychosis would consider bizarre. For example, I remember because I was in university when it was

> happening to me, so, when I was reading the instructions for an assignment, I remember over analyzing the question to the point where I would look for like hidden messages in there. So, you're making your study time longer and you're not answering the questions in the proper way. So, it would definitely be challenging to well studying, I think.

Sleep problems, difficulty coping with stressful situations, and constant concern about resurfacing psychotic symptoms were other challenges reported by participants. The latter caused them to keep scrutinizing their thoughts to determine if they are normal thoughts or if they are indicative of another psychotic episode. The participants' quality of life was adversely affected by all these challenges.

> P04: I think more about my thoughts and if they're normal or not, which is a little distressing. Having to think ok this thought is normal and this thought might not be normal all the time; It's a little distressing. Like I have negative thoughts about myself and I always am thinking if something is alarming, which I should tell my mom that I was thinking this and it might be coming back. So, I'm always second guessing myself and wondering if this thought is normal or not and sometimes, I think about the episode a lot and it upsets me.

As illustrated by this sub-theme, SAW encountered a multitude of challenges encompassing both physical and psychological aspects, which spanned across various domains, including work, relationships, and education.

Theme 2: Treatment Experience and Help-Seeking Efforts

The second theme consists of four subthemes and provides an understanding of SAW's experiences with treatment and factors that either facilitated or hindered the treatment and recovery processes.

What Worked Best and Why? This subtheme appeared in all five interviews. The participants had a positive attitude towards the mental health and early intervention services they received, and they were willing to engage and continue with those services. Participants viewed psychiatric services favorably if they were accessible and could meet their needs. This included guiding them on a recovery path, providing them with needed skills, or answering their most challenging questions about the illness and diagnosis.

> P04: I haven't been to anyone other than the medical team and just my mother at home and then just the medical team. That's it. I could talk about my issues to medical team, which helped a lot. My case manager said that I could even meet her like outside of the institute; in a coffee shop. So, I did actually meet her in a coffee shop two times. Yeah, it was helpful, it was kind of like talking to a friend.

This subtheme also shows how and why certain aspects of treatment were helpful to SAW. For instance, one participant described how her clinician helped her through her confusion about not being diagnosed. The psychiatrist, as the participant described, was clearly committed to addressing her question about psychosis. In this case instead of emphasizing the medication the clinician assured the patient that they can work together and try to understand psychosis better. Furthermore, another participant noted that for the treatment team to provide the most appropriate treatment, they should listen to their patients to gain a full picture of their concerns and needs. According to this participant, having a successful treatment plan relies on the patients feeling heard and having their most pressing needs met. This can be achieved by taking patients' situations into consideration and designing treatment steps that guide them through the recovery process. By *having a third party look into one's life*, encouraging the patient to do things at their *own pace*, and even encouraging the patient to continue doing *simple daily chores*, SAW felt that they had accomplished something, and that motivated them to continue the treatment.

Also discussed were various services that were offered to either SAW or their family members. Participants mentioned that through a range of services provided to them, they were able to gain a better understanding of themselves, explore their challenges from different perspectives, and gain tools and solutions to help them overcome those challenges. As reported by the participants, non-medical approaches were particularly effective in achieving these goals.

> P01: The clinic was very helpful because they give us a lot of tools in terms of therapeutic tools, mindful meditation, structured routine, art therapy, CBT. We were a group so we can go too deep but we would explore our little issues in our day-to-day life and we learned a lot of things about functionality of behavior, fight-flight, you know, I didn't know about the fight and flight and I kind of realized, oh maybe I'm avoiding certain things. And so, it was not just helpful to build that confidence, it also helped me reflect on my day-to-day life. So, there I was doing CBT with a psychologist; that was helpful mostly for my regular day to day not very much specific to my experience. Whereas talking with my psychiatrist, that's more specific to my experience in life. I think I do still practice certain aspects of mindfulness, exercises, having a daily routine exercise frequently. But more than anything, the insight and the perspective that I get about myself, you know, when people are asking me questions; a question that I would never ask myself, so I get this really good insight, from the professional, and then it gives me a better perspective on myself, it helps me reflect on something that's more relevant than things that are not relevant.

> P04: So, they recommended breathing exercises to me. They helped me realize that it's OK to think certain thoughts so, yeah, it was helpful in many ways, in how to better deal with the thoughts I'm going through. Also, listening to music when I was first admitted into the program, they offered something called music therapy, which was basically experimenting with instruments; for example, the piano, which is what I did. I just played the piano in whatever way I could, just to listen to the sounds and not to perform like a special song or something, but just putting my hands on any key just to see and test the sound and just play according to my mood and it would really help me.

A participant also mentioned how a service that was provided to her family member was beneficial to her, as well.

> P05: There were meetings going like an in-person meetings and webinars for family members of patients with the first episode psychosis. So, when my parents signed up, they went to the meetings; they learned more about psychosis. They signed up for

> webinars, where a psychologist or psychiatrist, talked about the first episode, and they got much more knowledgeable about it because I went through this.
> I: And was that also helpful to you?
> P05: Yeah. One of the main things they told my parents and the other people in the audience is that this is a condition that the family members have to be patient.

Similarly, participants also mentioned that they sometimes struggled to share their feelings and experiences with family members and friends, and the treatment team filled that gap by listening to them and providing them with a non-judgmental environment where they could discuss their challenges.

> P01: I can talk to my family but there's a big lack of understanding and there's moment when I talk to them about how I feel and my family takes it very personally and it's not my intention to make it personal. That's hard to share my feelings with family because they'll take it personally. So, I'm able to express myself to a professional. I see closure as something that is critical to me but closure isn't something my family can fully complete; there's no closure. So, when we have a fight, we just change the topic, there's no closure. I prefer closure but it's not coming.
>
> P02: I enjoy life and living, and it's after I started the medication. Therapy is fine, I guess. I like having a place where I can talk about my feelings because obviously, I don't want to harass my friends every day about how I'm feeling. But I don't know if it's having a huge impact on my life. It helps, for sure, but I can't really gauge how much, it's nice.

The extent to which SAW felt heard and understood, the opportunity given to express their concerns and needs, and the treatment team's dedication and commitment to addressing their questions all significantly contributed to their positive attitude towards treatment.

Medications, Acceptance of Benefits or Hesitancy over Effectiveness. This subtheme appeared in all five interviews. Despite some of the difficulties associated with taking medication such as side effects almost all participants agreed that there are certain benefits in consuming medication. It was noted that participants were able to identify symptoms and functions that improved after taking medication. In addition, they stressed the importance of adhering to the prescribed medical regimen to prevent symptoms from deteriorating.

> P03: It was pretty straightforward the way they told me if I took my medication, I would get better and I had an appointment actually two days ago and my psychiatrist was very keen on reminding me that it's because of the medication that I'm able to be in a good state; I mean the state that I am today. Being consistent, I think with the medication that was very important. I'm taking anti-psychotic but I'm also taking anti-depressants and I remember one of the nurses told me that it will take me some time, it'll take me about two weeks before it starts working. And I remember she said sometimes medication is the answer. You just need to take the pills and it'll all go away. And she was right, I don't really have that much suicidal ideation anymore.

> P05: A couple of times I stopped medication for whatever reason, and then the voices came back like tenfold. Voices came back very loudly in my head and very distressing. And I think one of the times I did that I was with a social worker and she told me, you have to keep on top of your medication. [if you don't take you medication] Its going to happen; the voices will get much worse.

Participants' attitudes towards medication were not necessarily entirely positive, however, and there were factors making them reluctant to take the medication. One participant, for example, mentioned that although she was not entirely against taking the medication, her family made her believe that medication was not the best way to improve her mental health. This finding provides further evidence of how familial beliefs can shape the attitudes of patients towards medication. It could be argued here that medication is viewed as an indicator of mental illness and refusing to take medication is an attempt to conceal mental illness and the stigma that results from it.

> P01: It's my own perception but it's very much built upon my family. Taking any kind of medication for the brain is kind of frowned upon anything that can alter your state. So, like having a prescription of anti-psychotic and anti-depressants [my family would say] why are you taking this, this is bad you shouldn't be taking it, and I personally felt that way. It's just because of my family, we talk about it and look at it, we frown upon it. It was like a stigma, my own stigma. I still live with that stigma of "don't take

> medications", and even it was prescribed and I stopped taking it on my own. I stopped taking my medication.

The participant provided another layer of insight that could help us better understand the reason behind the unfavorable attitude towards medication. In patient's and her family's view, medication is an *artificial* way to heal since it alters brain chemicals and *supresses feelings* instead of addressing any real-life problems or providing the skills patients need to develop. Moreover, this attitude toward medications extends not only to mental health but also to general health issues. Medication was therefore seen as an artificial motivator that influences behaviors, whereas the patient and her family believed healing should be a conscious effort initiated and accomplished by the person.

> P01: What helped with the medication at first was oh, I feel that I could do my potential with the medication. But then I didn't like that if this was artificial. I didn't like that the medication that I was given was helping me, because it wasn't me, it was the medication that was doing it, so, I stopped taking the medication. My family does not like taking medication, they like to be natural; so, that's kind of instilled in me and that's how my mind works. I personally don't like the fact that it's an artificial kind of motivator.

Similarly, other participants described difficulties they experienced regularly taking the medications that made them doubt the effectiveness and benefits of medication. Among them are medication side effects and taking too long to find a medication that works effectively. Furthermore, participants mentioned that medication was helpful for certain problems, but not for others. In some cases, the medication was too strong, which was accompanied by more severe side effects.

> P02: I tried in the past two separate medications that made me feel terrible terrible terrible. Yeah, but now I'm on another one like a third one and I feel good, really good. And for a long time, I thought that medication was not good and it was the worst thing that you could do, but now I guess that has changed a bit. It took a very long time to get

> here. Yeah, I've basically kind of just stopped trying to get better because it's hard to find things that work.
>
> P05: I can't sleep without medication; I really need to be sedated to sleep. Right now, I'm only taking medication at nighttime.
> I: OK, I understand that you found medication useful for sleeping at night, but in general, did you find medication helpful?
> P05: Only to sleep. I'm not sure the medication at day time is having any effect other than making you gain weight. Because there were some periods when I wasn't on medication during the day and I didn't really feel that medication taking in the morning was having much of an effect but I've been gaining weight nonstop since I have been on Medication. Yeah, the medication I'm on right now it makes me sleep like 12 hours a night, I'd say it's working, I find it very difficult to wake up.

Despite acknowledging the benefits of medications, SAW cited several reasons for their reluctance to take it. In some cases, these factors can be directly related to the medication itself, such as side effects or symptoms not being adequately alleviated by the medication. As for indirect factors, they include the stigma associated with taking medication and families' beliefs about medication's unsuitability since in their view, recovery must come from the individual rather than medication. This further emphasizes the importance of engaging in culturally respectful conversations with families to address potential challenges that could otherwise compromise medication adherence or treatment compliance. The subsequent subtheme, helps to delves deeper into the exploration of this issue.

Communicating Information. The third subtheme, which appeared in all five interviews centers on how the treatment team communicated information to patients and their families. In this case, the real problem is that patients sometimes report not receiving adequate explanations from the treatment team. It should be mentioned that this issue influenced participants' experiences both when receiving inpatient, as well as outpatient care. This is of significant importance as it indicates that SAW's initial experiences in an inpatient unit influenced their perceptions and attitudes toward outpatient services. Given that none of the participants had any knowledge about psychosis prior to their illness, they had many questions about their illness and diagnosis. Nevertheless, SAW felt that this information was not readily available to them because, from their perspective, the treatment team emphasized the importance of taking medication without adequately explaining the illness and what led to psychosis.

> P01: I talked to them about my experience. They didn't tell me anything other than that they would discharge me and I would have to go to the outpatient program. They admitted me into a two-year program at the outpatient. That was it. I never really got any concrete explanations for what happened to me? When I was at the hospital, I wasn't told anything other than I got admitted, and they started giving me medication. I wasn’t even explained why I was given this. I was told that I have to take it so, I took that. I never argued it because I didn't think I have any say.

Similarly, in response to a question on how the treatment team explained the illness, one participant declared:

> P04: They didn't explain it to me. I think I just heard the term once and then I saw it on paper, like when they wrote I guess they wrote what happened or something like that. So, then I saw the word psychosis. I didn't ask them about psychosis. I was just too confused at that time. I was like, I don't know what happened to me. Something wrong happened to me, clearly. My mom said that I was sick, but I didn’t know what happened to me, and I was just busy processing what happened. I just remember the nurse showing me a chart in her room which said something like thoughts leads to feelings like it was like a diagram. I just remember her explaining the diagram, but she didn't mention psychosis at all. They explained to me what each [medication] was for. They gave me a medication for sleep and risperidone for the symptoms themselves, and they just told me about what each of it does and how much I should take and when I should take it. They just explain the medication to me.

Continually insisting on taking the medication without addressing patients' concerns, for instance, would make patients feel their treatment team is ignorant of or unwilling to understand and address their needs. As part of the treatment process, the treatment team should be aware of other challenges that may impact SAW experience. The clinicians' failure to see the whole picture and without taking into account the familial and cultural context undermined SAW confidence in the treatments being offered. Furthermore, to maintain harmonious relations, and due to the fear of damaging the relationship with the treatment team, SAW refrained from discussing some of their struggles. They also felt less empowered to express their needs and concerns.

> P05: Some of my concerns about what is realistic for me, so she [case worker] made it sound like I should be able to study to work like anyone else. And so, things are not addressed like weight gain. She's like, oh it's fat, do sit ups, and it's normal for Indian people to store fat on their belies. So, I feel that some of my concerns, not only mental but physical, she wasn't addressing them. I think she didn't want to kind of admit that I'm a disadvantage. She wanted me to do my best. I felt I had to put on like a positive air to talk to her.

Participants also highlighted a lack of information about the services available. Almost no information was provided about what kind of services participants could expect upon admission to the FEP program. This made it difficult for patients and their families to navigate through the program.

> P01: I wasn't really told what to expect. When I got in, the assessment was done and the person who did the assessment put me with a psychiatrist, and that was it. I didn't know any other facilities or any other thing. It was only while I was with the psychiatrist and having to push and instigate and you know opposed medication after a while, I was referred to do CBT. I don't know what other treatments are there for me, other than that. I've been doing my own research. But I don't know what I have access to in the program.

Language barrier is another critical aspect of the treatment experience to consider, which occurs when an individual is offered services in a language that is not easily understood or spoken by the service users. As a result, services that may otherwise be beneficial will be rendered ineffective in the face of language barrier.

> P03: My Doctor, suggested that I bring my family over to this program where they explain everything like psychosis and bipolar and all of that and unfortunately, my mom can't speak English or French, so, I guess it would have been nice if there was … I mean, my brother would be there to translate to my mom.
> I: That's certainly very important. But did your brother participate in the family psychoeducation?
> P03: They never called us back so, I don't know. Or maybe they did but we weren't able to answer, so, we never got around to doing it.

The language barrier, however, is a much broader issue and does not solely arise due to a difference between a service user's native language and the language in which services are provided. In this study the majority of SAW and their families were perfectly fine with the language spoken by service providers, but the information itself was not conveyed in an accessible and culturally sensitive way. As pointed out by some of the participants, in order to help family members better understand their situation and provide supportive care, certain pieces of information such as the role of medications, managing side effects, and challenges related to psychosis are crucial. However, the failure to communicate information in a timely and culturally sensitive manner can result in negative consequences for patients, thereby preventing patients and their families from taking advantage of services that are available to them.

> I: You mentioned the psychiatrist didn't really do a good job in terms of explaining your situation to your family member, was it due to a language barrier or the way the person was explaining the situation?
> P02: It was more the way he was explaining. With my brother he's really good in English. He spent his childhood in Bangladesh and then he moved here, so he's fluent in Bangla and English; he's the perfect translator to have. But just the way that the psychiatrist was expressing himself, it was questionable at best.

When a language barrier is coupled with poor general communication, SAW are left with even more challenges. They must find solutions on their own, which could become yet another obstacle to treatment and recovery.

> P02: With my last psychiatrist, we had one meeting. It was me, her and my mom. And it did not go well. It was very uncomfortable, I don't know, it was uncomfortable for me, I don't know how it went for anyone else but it was just basically my mom asking me to ask the psychiatrist how much longer I have to go to therapy before I can be better and then how much longer I have to take meds. And that's kind of all she wanted to hear and then she didn't want to listen to anything else. And yeah, none of my therapists or psychiatrist, have really ever helped give me ways to talk to my family better. So, I kind of think that I am more likely to just kind of figure something out.

The lack of knowledge about psychosis and insufficient information regarding available services presented substantial obstacles for SAW and their families when attempting to navigate the healthcare system. Additionally, there was a clear discrepancy between the treatment team's emphasis on medication and the individual preferences of SAW. These combined factors underscore the failure to adequately provide information to SAW and their families, revealing a crucial gap in communication. The ramifications of these circumstances were particularly pronounced for SAW, which resulted in further challenges such as conflicts between SAW and their families, as SAW expressed that their families struggled to comprehend their situation, while the treatment team failed to offer a satisfactory solution.

Treatment Gaps: Let Me Tell You What's Missing. The final subtheme in this category that was present in all five interviews was the gaps patients identified in their treatment and recovery path. The participants framed the gaps in two different ways. Firstly, gaps were discussed from a cultural perspective. A participant explained how important it is to have a clinician with the same ethnocultural background, as this clinician is already familiar with cultural challenges and may be better equipped to address them. Having such cultural knowledge readily available to a clinician with a similar cultural background could be helpful in addressing some of the cultural challenges patients encounter, including stigma and negative attitudes toward medications.

> P01: It would be good if we have more practitioners who come from our backgrounds and that we have the option to sit down and speak to a practitioner who has that cultural background just so that they can clarify to that family dealing with mental health. Maybe the psychiatrist can give real life examples, that they [the family] can relate to. Maybe using like one thing that's very big in my culture is Ayurveda and so we believe in that. We will take ashwagandha and it's very useful. It's coming into medical records now for the benefit of all of these ayurvedic compounds. But there's nothing wrong with taking an anti-psychotic if you need it. And if there's a way a doctor can explain it, in the same relevant way like look if you take ashwagandha, it's an adaptogen and helps lower your cortisol or your stress or whatever. And this medication does this too, now the only difference is that one is natural one is prescribed, you know, and there's more benefits to the medication or at least there is more research about something that's prescribed so, it’s certified and explaining that will help people to understand. So, that's what I feel, sharing that knowledge in a way that is transmissible to other people.

Additionally, there are some cultural nuances that are of importance to patients, but the clinical team may not be aware of them, and at the same time, SAW may not feel comfortable discussing them with their clinical team due to a sense of "*cultural shame*", which happened when the patient felt ashamed to highlight some aspects of their culture negatively.

> P04: Cultural understanding is definitely important to help understand the client better and where they're coming from. For example, I'm currently with someone and we're about to introduce our parents to each other so that we can maybe get engaged. So, them [the clinical team] knowing a bit about how this goes in our culture would be helpful and just nuances like that. It would help because you wouldn't have to explain everything to them. Some people have this kind of shame associated to their culture, so, it's best if the other person knows already or has some sort of an idea. Like over here, this would be considered like my boyfriend but in our family, we don't call it that because boyfriend has negative connotations. So, if I say boyfriend to my mom, it would seem very negative, the boyfriend to my family is just someone you have a casual thing with and then you just leave them, and that’s it. But the proper term like term my parents would have preferred is the one I'm about to get engaged to, significant other, potential spouse. These are the terms which are like acceptable to my parents.

Another key finding was that physical difficulties are as important as psychological difficulties. Physical symptoms can even be seen as an opportunity to further explore the cultural challenges that SAW faced. For instance, according to the following quote from one of the participants, weight gain was misjudged as pregnancy out of marriage, which, itself, may be viewed negatively in their culture. Furthermore, it was mentioned that although help was available for her psychological symptoms, the treatment team did not really address her physical needs. Neglecting physical symptoms may put patients in a difficult situation.

> P05: I'd say I'm satisfied except ever since I became a psychiatry patient, I also gained weight. Every doctor I went to, a psychiatrist, an M.D. was just like Oh, it's fat, or do some sit ups, Oh, it's just nothing. And my belly just got bigger and bigger to the point that I look kind of pregnant. Um, the only thing that bothers me culturally is that I'm walking around with this big belly and I'm not married and I live with my parents to a person who is an outsider who just sees me, they probably think I'm pregnant out of wedlock. That I told to my social worker, and she completely dismissed it. For the mental symptoms I feel if you want help, help is available. There is a psychiatrist, you can pay fees for a psychologist, help is available but there are other things that are kind of physical symptoms that should be addressed, as well. I wish the sleep problem had been addressed either not sleeping at all or sleeping way too much, and the weight gain, like there's a whole bunch of massive physical things that aren’t really being that well addressed.

Another major gap in treatment is related to a lack of space to discuss spirituality and religion. As reported by one participant, she began experiencing psychosis as a result of some religious concerns she was experiencing (i.e., disbelief in religion, doubts about God, and extreme anxiety about death and the afterlife). Nevertheless, not being able to discuss this with the treatment team had a major impact on her because for her religion and spirituality were deeply entwined with other aspects of her life, such as a sense of purpose, death anxiety, and attitudes towards life. Failure to pay attention to this issue left patients' religious and spiritual needs unmet.

> P04: I feel like treatments today in mental health don't really have spirituality included in it, which kind of limits the ways to treat someone, because for many people spirituality is an important part of their life and sometimes the things they're going through, they need answers spiritually, as well. I think I did become an agnostic and that was bothering me because I didn't want to become agnostic, I wanted to actually find what is right for me in terms of spiritually, I wanted to know what to follow, which religion to follow. But I didn't know which one. So, those things were bothering me. I didn't know the purpose of my life and then I thought of death and how I didn't have the answers to what would happen to me after death and because of my fear of death, I couldn't sleep. So, I feel like if spirituality was a part of treatment, I could maybe get the answers to, not the answers but maybe some support on my journey. If I could talk about it with someone, that would help. So, all of these things lie in more of the religious and spiritual side, which I feel is missing in the treatment I'm receiving.

Another gap that was discussed by participants referred to certain services participants would have liked to receive, but they were either unavailable to them or missing from the program. A participant, for instance, stressed the importance of appropriate counseling services in schools. Having poor knowledge of psychosis among school staff presented a serious challenge for her.

> P02: Well, they [school staff] reacted positively not positive but no one was mean or judgmental, which I'm really grateful for. Everyone was kind but it's kind of one of those things that you're not equipped to deal with as a high school guidance counselor, you know. So, they were just, I don't know, I think they just didn't know what to do. I'm sure they did their best; everyone was really kind but a lot of the advice that was given to me was very questionable.

There were also discussions about services that could have been very helpful but were not provided to the participants. This includes sport activities and meeting people with a similar lived experience (i.e., peer support group). The COVID-19 pandemic and cancellation of in-person services, as well as cost and accessibility issues accounted for some of the reasons patients were unable to utilize these services.

> P02: This isn't technically treatment, well, this isn't treatment at all. I think one thing that I would have liked and I guess the only way that it could have been possible was probably through the hospital. I really want at least once in my life to meet someone else who has psychosis, at least once. And I know the hospital has access to these people because they're treating them. It feels very alone, I feel very alone. It's very hard like there is a limit to how much I can tell my friends about it but like they don't understand, they don't know what it's like. I can't like make them watch a little VR psychosis simulator and make them understand.

> P05: I signed up for CBT in group sessions and I wasn't selected and got kind of upset about that. But why am I not selected? I'm willing to pay the fees and to show up, and my psychologist just didn't have an answer for me. So, when I didn't get selected to be part of the group therapy, I stopped the one-on-one therapy, too. The psychologist was all paid for privately, so, getting a little bit expensive and eventually, I just stopped because I didn’t feel I was progressing that much. it was it was good to talk to someone but it's too expensive to just talk to someone.

In this subtheme, SAW highlighted the significance of adopting a culturally sensitive approach that is cognizant of their unique needs. Furthermore, they emphasized the importance of providing diverse services to support their recovery process.

Theme 3: Cultural Knowledge about SAW with Psychosis

The last theme consists of three subthemes. Through a cultural lens, this theme provides insight into cultural challenges faced by SAW, as well as cultural strengths and resources they employed to overcome some the difficulties caused by psychosis.

Cultural Challenges. This subtheme was present in four out of five interviews and refers to the variety of cultural challenges encountered by SAW. Among the most pressing challenges that these patients faced was stigma. Moreover, this study identified two different sources of stigma targeted at SAW. On the one hand, SAW discussed stigmatizing behaviors of their co-workers or classmates. This form of stigma may in fact caused by individuals' lack of knowledge or even misconceptions about psychosis. On the other hand, SAW also mentioned culturally oriented stigmas that can best be understood in light of cultural beliefs hold by members of the South Asian communities with respect to mental illness, medication, and hospitalization. participants reported that one of the most significant difficulties they faced was the negative impact psychosis had on their self-confidence, described as *feeling isolated in the category of psychosis*. Importantly, losing confidence was largely influenced by the experience of hospitalization. Participants also mentioned how difficult it was for them to share their experiences with friends outside their immediate family due to the stigma involved.

> P02: I'm very lucky that no one has really given me a very prejudiced way of reaction. Well, sometimes high school people were like, Oh I'm scared that you might hurt me. I think in recent years, the only remark that has been made was one of my co-workers saying wow I'm really surprised you could hold down a job, which I just thought it was a little funny; I mean I guess it's upsetting. We talked about it after she said it and then I was like that's not nice. And then she walked me through it and apparently her thought process was in movies. [She said] I've never met anyone with psychosis but like naturally this is my perception because of the media, so, thanks for educating me.
>
> P01: I didn't want to be hospitalized. I think I could have had outpatient care immediately, because being hospitalized is stigma. I think it's even culturally, you know, like if you're part of a small community and you are known to be hospitalized, you're immediately pigeonholed into like you're crazy and so it's kind of hard to get out of that. You personally end up labeling yourself that way. There is also a criticality like Oh, how come this person has to take anti-depressants, what happened in their life that they need to take anti-depressant oh, this person is depressed, their life is hard and there's criticism; there is criticality. But then also, there is some empathy for sure, there were understanding but there's always that element of like this shouldn't have happened.
>
> P04: My family reacted pretty well, but I know if my extended family found out, they wouldn't react very … they would get overly worried and they would think that something's wrong with you like there's the defect in you or something like that. Or they

> might just think I'm crazy, like they wouldn't understand the psychosis itself. They would just think that I’m crazy, that's the word they would use for it.
>
> P02: Usually when I'm talking to my friends, I usually don't say psychosis just because I feel like it's too dramatic. I'll find any other ways to say it and it's usually very stupid. I think yesterday I texted my friend I am being tormented by voices and I'm eating cereal about it. Yeah, I'll refer to them as voices even though it's not necessarily voices. I hope that it kind of gets the idea across. And then I have a friend who kind of knows about it a bit more than others because I talked to him a bit more about it so I can kind of just be like the people are bothering me and he'll be like I know what people do. [But I also] lost a considerable number of friends, but never right at the beginning when I tell them so that's good. I try not to think of myself as an insane crazy person but sometimes I do. Like I'm not like my friends and I can't be like them and I don't like it.

The second cultural challenge discussed involved religion and spirituality. The religious beliefs of a family can sometimes create a situation in which seeking and receiving medical services becomes difficult. This can occur when the family's religious or spiritual solutions conflict with what the patient wants.

> P02: The first time I went to the hospital my mom told me that she was going to get me exorcised because we're Muslim and I don't know if she wanted to get any Muslim exorcised. It didn't end up happening. Yeah, I don't know if she thought whether it was like some evil in me, some demon. So, she thought an exorcism was the only way to go and like prayer and everything. I guess my family is very religious. So again, that made it kind of hard for me to reach out for help not because of religion per se, but it's just like because of the way that they are, because of their religion, it's a little hard.

The lived experience of SAW with psychosis is profoundly influenced by two types of culturally oriented stigma originating from their own community, and non-cultural stigma stemming from the broader society. These forms of stigma contributed to a spiralling cycle of social exclusion that can have severe repercussions on the health and mental well-being of SAW.

Personal and Cultural Sources of Strengths. This subtheme was present in all five interviews and sheds light on sources of strength that SAW drew upon to overcome some of the challenges they faced due to psychosis. Religion and spirituality were among the most frequently mentioned topics by participants. It should be noted, however, that participants hold different views about religion and spirituality. Some viewed religion and spirituality as a source of comfort, rather than as an active part of their life. This means that they may not actively participate in religious activities but see religion and spirituality as a source of help and refuge they can turn to whenever they need it. Interestingly, a number of interesting variations were observed in how SAW conceptualized religion and spirituality. In one view, religion and spirituality were described as a form of knowledge or a philosophy of life.

> P01: I was feeling very much without control and I didn't feel comfortable and I didn't feel safe with my roommates too so, I went to seek like spiritual help. So, I went to a temple and it was a woman, the healer, a spiritual woman. I felt a little bit peace and contentment in there and it was a way for me to be away from my roommate to feel free and I was just happy. So that was kind of helpful. Culturally, we are also very aware of our spiritual knowledge, so although we're Indian, the temple, it's not so much about going to temple and just, you know, praying to God, it's about the way we look at religion is more through the philosophy from the Vedic philosophy, and that is built on a lot of knowledge, Ayurveda science and spiritual knowledge, scientific knowledge. And respecting knowledge is so critical to me. I might not go to temple all the time but I always know it's there if I need that kind of solace somewhere. But to me, knowledge is my religion and so that's kind of a cultural thing that's embedded in me culturally.

Of course, not all participants considered religion necessarily a source of help or coping. For these participants, religion and spirituality were not core aspects of their lives; hence it was not something they would actively use to overcome the challenges they faced. On the other hand, for those who were more religiously active, religion and spirituality were regarded as helpful coping methods. This extended well beyond conventional religious practices to include other efforts including listening to religious podcasts, attending community events, and educating oneself about religion. Having attributed onset of psychosis to questions and concerns related to religion and spirituality, one of the participants decided to engage in community activities that would allow her to find answers and eventually alleviate some of the distress she experienced. Moreover, by participating in these activities, she was also able to develop a sense of belonging to her community.

> P04: I recently joined the Muslim Student Association at my university just to feel a part of a community. But in terms of actually getting answers, it would be best to talk to scholars and stuff like that, which I feel is available in Montreal. It's just my anxiety, social anxiety, which stops me from going there because it's hard to admit that you're having thoughts about death, and it's hard to admit that you're having questions about religion at least for me at that time. So, I didn't I didn't really go to anyone.

She further explained how she used religion as a means of healing and coping with anxiety, depression, and negative thinking. Through this personal journey, the patient sought to learn more about her faith and began applying some religious knowledge and practices, which helped her overcome some of the difficulties she encountered.

> P04: So, I began treating myself as a revert to Islam, kind of. I began to take baby steps like who am I praying to? Why am I praying? How do my answers in life get solved by this religion? So, after I had the answers to basic understandings of the religion, I began to pray with more meaning. I also downloaded an English version of the Quran to understand everything and everything made sense to me. So, then I began praying with meaning and afterwards I just sort of started listening to Islamic lectures on YouTube just for a better understanding because the more you learn, the more you realize you don't know, so, I just began to learn more and more about it, and a lot of aspects about it was about how to deal with anxiety and how to deal with depression, how to deal with negative thoughts. So, I began to learn those as well and how to cope with it from a religious perspective. And that sort of helped my recovery a lot. And it also helped me distinguish between which thoughts are psychotic and which are not. [My faith helped me] by providing answers to difficult thoughts like the purpose of existence. And second of all, by providing ways to deal with negative thoughts. By giving ways to deal with anxiety. We have different prayers for anxiety, which I think help with depression.

There were also several other sources of strength discussed. Having a daily routine, for instance, helped participants to become self-motivated and return to their former levels of functioning and resume activities they had stopped due to psychosis, such as schooling and social activities. Doing exercise, listening to podcasts, and reading books were other activities mentioned. The books and podcasts were either chosen out of general interest or were specifically related to psychosis. Obtaining a better understanding of psychosis was a way to regain confidence and better cope with the illness. In addition, some participants talked about art-based activities such as listening to music (either western music or music from their home country), as well as painting. According to one participant, the role of art extended beyond coping with distress and acted as a vehicle to express experiences related to psychotic illness.

> P02: Music very much is my top, my go to way to deal with it because it's something to listen to other than everything else there is to listen to. And then I make a lot of art and that helps. People see my art and I personally don't think it's very nice. It's a little out there but people usually see my art and their response is huh, you have a very interesting way of looking at things. I know it sounds like a bit of a backhanded compliment, but my art is kind of a way of dealing with everything. And it's a way of kind of like processing everything. So, the way it comes out, it looks a little funky. But yeah, I think psychosis informs it, you know. It helps you make art, and art helps you deal with it.

Participants also discussed how the illness itself affected their self-image. Despite the range of difficulties brought about by psychosis, some participants viewed the illness as *a moment of awakening*. This was an opportunity to confront major challenges in their lives, rebuild their confidence, and take steps forward to achieve their goals.

> P01: I know I had psychosis, it's still something that I feel tagged on me it's still kind of there and so I'm a little bit more vigilant. I'm a little bit more cautious and that's something I'm trying to work on with my therapy. So, yeah, it did change my life at the time in the early stage because I lost a lot of confidence in myself. But then I was able to regain it and go back to normal life. Psychosis changed my perspective definitely; I feel confident and I feel a lot stronger than I was before cause my experience was very

> challenging state of mind. But now I understand, like, there are times where your brain loses control and you lose control of your mind and but it's not the end of the world, you can recover, that's very reassuring.
>
> P03: I feel like because of my psychosis, I was able to go outside and I was able to go to school again, and I was able to do things that I probably wouldn't have done if I didn't have my psychosis because I would have been stuck and stuck in my house. So, in a way, it was kind of a moment of awakening. And then I was able to do my responsibilities that I was supposed to do.

SAW utilized a range of activities, some of which were deeply rooted in their culture, to effectively cope with psychosis. The wide array of these activities exemplifies SAW's proactive approach towards rebuilding confidence, improving their self-image, and fostering a strong determination to recover from psychosis.

Family and Friends in Cultural Contexts. The last subtheme that was present in all five interviews addressed how family and friends can impact patients' treatment and recovery. As mentioned by the participants, South Asian culture emphasizes the importance of supporting family members, and SAW referred to it as a cultural value. Findings also showed that support was provided by people from various social groups, including parents, siblings, friends, and other relatives. Family, for instance, offered support by helping their loved one with medication, being there for them during times of distress, and acknowledging and reinforcing their positive changes and achievement. Parents' and siblings' efforts to understand their loved one's situation is another meaningful and effective way of expressing support. This can be demonstrated by paying attention to the patient's needs and identifying symptoms that may require immediate attention while at the same time giving them time and space and asking if they need assistance. In this way, family members demonstrate their willingness to help while simultaneously respecting the patient's independence and autonomy. Participants also mentioned that even simple acts of listening, reminding them to go to bed early, or waking them up in case they oversleep (due to medication side effects) made them feel loved and taken care of because it showed that the family is attentive to their needs.

> P01: It doesn't matter what trouble you're in, they'll always be there for you and that's something that's always embedded in my family, you know, thick and thin we're always there. And I think that's a cultural value we see in Indian culture that family stick together very tightly and that's kind of known. Having the support of my family, my self determination to push through a lot, and to get help and to work on myself, I think is definitely built in me from my cultural and my family values. So, those are really important things that helped me through psychosis.
>
> P05: My parents, the way they treat me has changed. Before they used to be very quick to criticize. They would be very quick to say change your behavior and to change this change that without worrying about my reaction. since psychosis, they're kind of a little bit more walking on eggshells around me like they don't want to say anything offensive. They don't want to say anything to hurt my feelings. When I say something that I'm improving myself, or I made some changes in my life that will benefit me, [they say] this is good, good job. So, the way they treat me is with a much more positive spirit. If I sleep in too much, my mom wakes me up. Since I got the first episode psychosis there are more understanding. If I go to a social engagement and I don't talk very much, they just give a gentle hint that try to make a little bit of conversation. They don't yell at or calling me anti-social or anything, but they just drop little hints that, you know, people like to know what's going on in your life just talk as much as you feel comfortable.

The majority of SAW in this study approached friends as a source of support. Friends showed their support by listening, being available, mobilizing help, and not treating the patient differently. Friendship with people who have had the same experience was also reported to be helpful. One participant mentioned that she would only discuss her illness with her family and not with her friends. She commented, however, that while she was in the hospital, she became friends with another patient. Having the same lived experience enabled them to easily communicate and understand each other's struggles.

> P03: I don’t really share with my friend. I think it’s only my parents who know about my situation. But when I was at the hospital, I made a friend there. Well, she is now part of the family. So, this friend, she and I share similar family dynamics in a way. You, know our parents are very similar, as well. She is also schizophrenic and bipolar, so we get along quite well. And when it comes to sharing our experience, we have similar experiences.
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> P02: My friends are very nice and most of them I can go to when I'm having any kind of problem. A lot of them are kind of like relatively aware on how to like ground me. So, if I'm ever having a little Oh no, I don't know what reality is moment, I can kind of text them and they can help walk me through it. Um, they're there for me. The most recent time I was hospitalized, it's because I had once again planned to kill myself and I told my friend, and he's the one who like, kind of organized an intervention and he's kind of the reason that I'm not dead right now.

Furthermore, as reported by one of the participants, reuniting with friends and relatives in her country of origin was another helpful way. The participant described how a short trip to her home country eased her isolation, relieved symptoms, and facilitated her recovery.

> P04: I went back to Pakistan for a mini vacation, which helped me a lot, and it reduced the symptoms a lot. I feel like I was very isolated when I was over here. I was just studying and especially online learning, I was in front of a screen all the time. So, meeting with people helped me a lot and somehow my symptoms reduced, as well. I don't know how that happened, but it just happened like when I was over there meeting family and friends the symptoms just reduced and I no longer had the remaining psychotic thoughts I had.

Even though family was mentioned as a great source of support, SAW’s experiences were not always totally positive. There were times when families failed to understand patients' situations and the challenges they faced. The views of family members were sometimes at odds with the views of SAW who may view the issue in a very different way. This, in turn, had a detrimental impact on patients' autonomy and independence.

> P01: They [family] are loving and being comforting but they don't truly understand and as much as they want to help you, they'll be like, no, you can try harder, you can do it,

> you don't need this or whatever. They don't understand what's happening internally that doesn't allow you to move forward now. The one thing I don't appreciate is when I tried to just even talking about this desire to be independent again, to be on my own, there is always this eye roll, there's always this kind of like, well, you know, we saw what happened to you last time, and that's kind of hard. But they're supportive of my independence, they want that for me, too, but then there's also times where that reaction is automatic.

Participants also reported difficulty sharing some of their concerns with their families. A couple of factors led to this, such as fear of the family's reaction or inability to understand the patient's struggles. This had major consequences because when SAW were scared of the family’s reaction, they tended to hide their problems, delay seeking medical help, or would feel guilty as their illness was seen as something shameful. For one participant talking about her illness with her family was only possible in the psychiatrist’s office as she and her family rarely talked about her symptoms and emotional struggles that were directly caused by psychosis. Another participant mentioned that despite having a very supportive family there was a certain issue that she decided not to share with her family.

> P04: My mom was very calm when I was going through the episode, and she was very calm when she took me to the hospital and they (my parents) helped me like, for example, if I was about to forget to take medication, they would remind me that. They would be supportive in terms of listening to what I'm experiencing. They tried a lot to ask me about why I experienced it and what do I think happened but I couldn't tell them because I would have to admit that I was having doubts about Islam, which I didn't want to do. So, I just told them, oh, it was lack of sleep. So, my mom thinks that it was lack of sleep which caused it. But other than that, like in terms of the episode itself and like other stuff, they're very supportive about it.

Social support from various groups, including parents, siblings, relatives, and friends, significantly contributed to SAW's recovery from psychosis. In South Asian cultures, family is of utmost importance, as staying together and offering support during difficult moments is a deeply ingrained cultural value. Nonetheless, SAW and their families encountered difficulties arising from a limited understanding of the patient's condition. Consequently, SAW may feel compelled to conceal certain aspects of their personal experiences, driven by the fear of how their family might react.

Discussion

This study contributes to the literature by exploring the lived experience of SAW with FEP. By using an exploratory qualitative research design and semi-structured individual interviews, the researcher explored the needs and challenges faced by SAW, along with the cultural dilemmas they faced and the resources they drew upon as they learned to live with psychosis. Using an interpretive phenomenological approach, the analysis revealed that SAW are often faced with the challenge of maintaining a delicate balance between the familial culture of the heritage and the values of the broader host culture. Living independently and separately from their parents was one of the key aspects reported by SAW. Considering their dependence on family - psychologically and financially, and due to their struggles with psychosis - participants expressed concerns about how they would manage their life without their parents. It should be emphasized though that living with the family until marriage is a common practice in South Asian contexts (Basra, 2000). As a result, this rather unexpected finding should be carefully considered in light of the fact that most SAW in this study (i.e., four out of five) were second-generation immigrants. Even though South Asian cultures place a strong emphasis on family ties, having been born in Canada and exposed to a culture that values independence could also influenced SAW's views on living an independent life. Furthermore, this continuum of dependence and independence also highlights the fact that although first-generation immigrants tend to maintain traditional values, second-generation immigrants seem to more readily adapt to the mainstream culture in the larger society (Buchignani 1984). While reliance on family is cherished by the culture of heritage, the desire for independence may increase the risk of conflict depending on the degree to which independence will be accepted by the family with respect to marriage, education, and carrier choice, for instance (Talbani & Hasanali, 2000).

When discussing independence, participants also referred to having a job, pursuing academic goals, establishing and maintaining a fulfilling relationship. However, feeling inadequate and incapable of carrying out certain roles and expectations also led SAW to doubt their ability to meet their obligations with respect to family, friends, and romantic partners. In a study done with individuals diagnosed with severe mental illnesses in India, Samuel and Jacob (2020) found that having a job contributes to physical, psychological, and cognitive well-being, promotes a sense of empowerment, provides financial stability, and reduces family burden. However, their findings also highlighted differences in attitudes towards the importance of work between men and women. Even though most patients and care providers believed that women should work, family members believed that women should prioritize household duties rather than work. This gender-based expectation underscores how certain sociocultural factors could impact recovery and patients' attempts to regain their sense of independence. Regaining self-confidence and independence is a vital part of the healing process for SAW, and failure to do so is a major hinderance to their wellbeing. It should be noted, however, that although some of these issues (e.g., abiding by certain expectations) may be salient in South Asian cultures, some are generally associated with gender roles and patriarchal systems that exist worldwide.

As mentioned, for the SAW who took part in this study holding a job and performing well in the education domain was a way to minimize the adverse impact of psychosis. This highlights the need for a multidimensional approach to psychosis treatment that addresses SAW's psychosocial needs and facilitates their return to school. In other words, successful academic reintegration after psychosis requires addressing obstacles such as medication side effects, cognitive dysfunction, and stigma to help persons regain their previous level of functioning, attain developmental milestones, and reconnect with peers (Zafran et al., 2012).

Some of the challenges shared by SAW were directly associated with psychosis. These challenges include a lack of knowledge and or confusion over what psychosis is. Due to a lack of knowledge about psychosis, uncertainty surrounding the condition, and challenges posed by the illness, these participants struggled to come to terms with their new diagnosis. Some participants described the initial stages of psychosis as a shock and a devastating experience. Others, however, viewed their initial encounter as surprising because they were not fully aware of what was happening to them. Findings of a study done by Macnaughton et al. (2015) showed that during the early stages of psychosis participants often assigned benign explanations or causes to the psychological and experiential changes caused by psychosis, and they did not actively consider the possibility of a serious mental illness until they experienced intense distress and disturbed behavior. A lack of familiarity with psychosis, difficulty recognizing its signs and symptoms, denying the illness, or assuming that symptoms will resolve on their own - all of these may hinder South Asian people from seeking help (Patel et al., 2023). According to the participants of the present study, understanding psychosis was far from a straightforward and linear process where symptoms manifest and lead to a final diagnosis. In some cases, it took a very long time to get a diagnosis, while in others, the diagnosis changed several times before the treatment team reached a conclusion. This, combined with a lack of adequate prior knowledge of psychosis, left SAW with critical unanswered questions about what happened to them and why. Interestingly, evidence shows that for some individuals, it is a relief to know that their symptoms were caused by an illness, and the diagnosis could be comforting because it clarified a treatment plan and the potential to re-establish a normal life (Macnaughton et al., 2015).

Other challenges were poor access to mental health services, the stigma surrounding mental health problems, and the feeling that they are pressured to take medications. In spite of the fact that these challenges are shared by other individuals with psychosis, there are some nuances that may explain why and how these challenges affect SAWs. A key finding of this study is that participants spoke about stigma in two different ways. One type of stigma was imposed by members of the general community, regardless of their ethnic or cultural background. Participants explained how their self-esteem was affected by the negative reactions of their classmates, colleagues, and peers towards their psychosis. This type of stigma can place individuals with FEP in a disadvantaged position and cause social marginalization and low social status (Birchwood et al., 2007). The second type of stigma, however, focuses exclusively on stigma originating from one’s own ethnic group. This intracultural stigma may be experienced at the same time as stigma originating from elsewhere. For some individuals, the stigma associated with mental illness may be even more debilitating than the symptoms of psychosis itself (Al-Adawi et al., 2002). It is imperative to recognize this phenomenon of double stigma, as different approaches may be required to tackle it. The findings of the present study are consistent with previous studies, namely, Islam et al. (2015), Penny et al. (2009), that mental illness diagnosis, medication use, and hospitalization can result in stigmatization from one's ethnic group.

Participants in this study reported that illness and hospitalization undermined their self-confidence. South Asian individuals with psychosis often feel excluded from society due to stigmatization and fears of negative judgment and many choose to isolate themselves and refrain from social activities with individuals in their community or society as a whole; this is a defensive reaction to avoid stigma at work, school, or other social occasions (Vyas et al., 2021).

One of the striking findings of this study is that compared to what is generally assumed in the literature, South Asian women had a more favorable view of mental health services. Overall, the participants expressed positive attitudes about treatment and were willing to continue with the offered services. This positive attitude may be explained by the fact that participants perceived treatment as a way of learning new skills and obtaining relevant information that would allow them to return to a desired level of functioning. A study conducted by Islam et al (2017) examined factors influencing mental health service use among South Asian youth in Canada. Despite some reluctance to use mainstream psychiatric services due to the excessive emphasis on medication and the lack of cultural considerations, some South Asian youth, on the other hand, strongly advocated for medication use and preferred standard psychiatric approaches to treating mental illness. In line with the notion of person-centered care for individuals with psychosis (Allerby et al., 2022), the present study also found that SAW were more likely to adhere to treatment when they felt heard and when they received services tailored to their needs.

Nonetheless, SAW also elaborated on difficulties they experienced while seeking and receiving early intervention services. Participants mentioned that they did not feel adequately informed about the treatment options and services available to them in the FEP program. In addition, they did not have an appreciation of what they could expect from the treatment plan or how it could help them explain their situation to their families. Based on the narratives, this was one of the difficulties they faced when it came to talking about psychosis and its associated difficulties with their families. This made it particularly difficult for them to navigate the FEP program. A systematic review by Prajapati (2019) investigated help-seeking, and barriers to accessing and utilizing mental health services among South Asians in the United Kingdom. Her findings revealed lack of awareness of the availability or scope of services, as well as perceived shame as a result of being labeled with a mental illness posed a major obstacle to seeking and accessing services.

SAW also discussed how treatment overlooked their physical needs, such as weight gain and sleep problems. Participants mentioned that the offered treatments addressed psychological issues (i.e., psychotic symptoms), but they were not satisfied with the treatment approach for their physical concerns. Sometimes South Asian patients may even use physical symptoms as a means of expressing psychological problems such as depression or anxiety, which suggests that further assessment is imperative to clarify their significance (Ahmad et al., 2005). Additionally, as findings of the present study showed, some of the physical symptoms faced by SAW may, in fact, shed light on the cultural challenges they face. As an example, for an unmarried South Asian woman who is not in a relationship, weight gain may be assumed to be an out-of-wedlock pregnancy, resulting in further stigmatization.

Moreover, SAW also expressed disappointment about services they would have liked to receive but were not offered to them. These services included peer support, sports programs, and psychological support, such as CBT. The inability to access services was caused by various factors, including discontinuing the service due to the COVID-19 pandemic, a long wait list, and a high cost, which is in line with previous studies conducted in the US and Canada (Basri & Rolin, 2022; Bornheimer et al., 2022; Lynch et al., 2020; Saunders et al., 2021). Another substantial gap was the lack of knowledge among school staff about how to help students with psychosis. Due to insufficient information about psychosis, school staff were unable to provide proper advice. Islam et al. (2017) showed that the lack of mental health education in the Ontario educational system further hinders access to mental health services among South Asian youth. Participants reported that learning about mental health, warning signs, and available services from a young age would have helped them be more open to seeking mental health treatment and psychological counseling.

SAW’s narratives provided another layer of insight into which services worked well for them, and why. According to the participants, the most helpful aspect of the program was the range of non-medical services offered to them. This includes psychological services such as individual counseling, group therapy, cognitive behavioral therapy, art therapy, mindfulness meditation, and family psychoeducation. The latter proved useful to SAW since it helped their family members gain a better understanding of issues related to psychosis. In the Indian context, Grover et al. (2017) emphasized the importance of developing a supportive and empathic relationship between patients and professionals to build a meaningful collaborative alliance that encourages continued engagement and promotes healthy lifestyles to reduce some of the difficulties caused by psychosis. Furthermore, the authors reported that patients and families consistently ranked personalized support as among the most highly valued services offered to patients with schizophrenia.

When discussing their treatment experience, SAW made a distinction between medical and non-medical treatments. Despite the favorable reception for the latter, there were mixed feelings regarding medication. This study expands the findings and identifies the specific factors contributing to unfavorable views toward medication In the South Asian context. Although SAW acknowledged benefits associated with taking medication (i.e., the importance of the prescribed medications to prevent symptoms from resurfacing or deteriorating), medication was not always viewed in a positive light. From the perspective of a participant, medication was merely a temporary and artificial cure that suppressed feelings rather than helped her deal with real-life problems or learn coping strategies. Additionally, the family's attitude toward medication affected the patient's perception, as well. In other words, patients were less likely to see medication positively if their family held a negative opinion about it. A negative view of medication could emerge and be reinforced by family and culturally rooted stigma, which explains family concerns about how the community will view their child and how negative judgments could affect their marriage prospects (Basri & Rolin, 2022). This is of critical importance as it illustrates that medication nonadherence among South Asians is not necessarily because they do not believe in the benefits of medication, but rather because of serious social consequences that may not be known to the treatment team. This is consistent with previous studies showing that an unfavorable attitude about medication among the South Asian population is related to a variety of factors such as a high level of positive and negative symptoms, the perception that medications are only effective for certain symptoms, but most importantly shame and stigma associated with psychiatric illnesses and treatments (Chaudhari et al., 2017; Raghavan et al., 2019).

Another key finding of this study concerns SAW's evaluation of the way the treatment team conveyed information to them and their families. Despite a basic lack of knowledge about psychosis among patients and family members, the treatment team was reported not to provide key information in a culturally appropriate and timely manner. Putting too much emphasis on medication instead of addressing SAW's questions about illness had a detrimental effect on the patient's relationship with the treatment team in the long run. South Asian service users may feel excluded from decision-making and disempowered from making treatment decisions when the clinical team fails to communicate pertinent information such as their roles, the causes and course of psychosis, and details of the treatment plan, resulting in a major obstacle to collaborative care between providers and service users (Prajapati, 2019). Moreover, as each person faces unique challenges and needs, when developing treatment plans, the treatment team must consider familial and cultural contexts surrounding SAW and find the most efficient, accessible, and culturally appropriate way to address their concerns and questions. It encompasses a range of cultural issues related to living an independent life, interacting harmoniously with family and the community, and coping with psychosis. These are extremely important aspects of SAW lived experience illustrating how their needs and challenges that they faced differed from those of other genders or ethnicities. Due to the crucial role played by families in the South Asian context and their willingness to participate in the treatment process, failure to address the issue of communicating information can negatively affect the patient's recovery and treatment (Grewal et al., 2005; Kalla, 2005; Shefer et al., 2013). SAWs in this study stated that it would have been enormously beneficial if the treatment team had given them advice on how they can talk with their families about psychosis, and how psychosis affected their lives, such that families can be more supportive of and attentive to their desires and needs.

Another pertinent challenge involved language barriers. Although high level of English proficiency was demonstrated by all SAW participating in this study (i.e., all were fluent in English, and most could speak French, too), parents were not necessarily in the same situation. This is a serious issue because language barriers can exclude family from the triangle of care, which includes the treatment team, the patient, and the family. Nonetheless, it should be re-emphasized, that language barrier is part of a much larger problem. In this study, most parents were fluent in one or both languages that are spoken in Montreal (i.e., English and French). However, there was a major problem with providing information in an understandable and culturally sensitive way. In most cases, SAW experienced challenges in their relationships with their families and needed the treatment team to educate them about psychosis and the difficulties caused by it. Hence, when language barriers are combined with poor communication, SAW face additional challenges because on one hand, they face the stress of living with psychosis, and on the other hand, they find it difficult to explain their situation to their parents. In a study done in the UK with South Asian individuals receiving early psychosis interventions, authors found that many participants avoided talking about their psychotic experiences with members of their close social circles, as well as members of the broader society due to fear of negative judgment and stigma (Vyas et al., 2021).

Several other problems were also identified that shed light on unique issues pertinent to the SAW with the lived experience of psychosis. For instance, there are some cultural issues that SAW may not feel comfortable sharing with the treatment team due to a sense of cultural shame. Typically, this occurs when SAW decide to refuse certain norms and expectations in their culture but are also concerned that if they share these aspects of their culture with the treatment team, the entire culture will be viewed negatively. As found in this study, talking about acceptable cultural norms surrounding marriage is one example of such cultural nuances. In a study of South Asian individuals receiving early psychosis intervention services, the authors found that participants chose not to disclose their cultural struggles to the treatment team because they feared the culture would be perceived negatively (Vyas et al., 2021). As an example, in the South Asian context family may view dating as a temporary relationship, rather than a committed one that would lead to marriage. In this case, cultural disobedience may manifest itself as being in such a relationship. Relationships that are more secret are already a concern for the person, and discussing such relationships with the treatment team may lead to a sense of shame and embarrassment. Dating and social interactions with the opposite-gender are a source of conflict between South Asian parents and their children, and this, in turn, reflects cultural expectations and traditional norms surrounding marriage, which particularly impact women (Islam et al., 2017). To address this issue, the treatment team must create a safe and non-judgmental environment where SAW feel comfortable discussing these challenges. Treatment teams should take the time to educate themselves about the cultural factors that influence treatment and recovery among SAW.

Another cultural issue was a lack of space to discuss spirituality and religion. Evidence shows that there is a link between religious beliefs and spiritual practices and South Asians' mental health and well-being (Kent et al., 2020). As found in the present study, some individuals viewed religion and spirituality as deeply intertwined with other aspects of their lives, such as their sense of purpose and general view of life. For many individuals in the South Asian context, religion is an ingrained part of their cultural identity (Amarasingam, 2008) and individuals who receive early psychosis interventions often feel that this defining part of their identity has been neglected by the treatment team (Vyas et al., 2021). In a similar vein, Rastogi et al. (2014) investigated facilitators and barriers to mental health services among South Asians in the US. Although clinicians stressed the importance of exploring and respecting cultural and religious values in members of South Asian communities, they also pointed out that there is a great deal of heterogeneity when it comes to religious practices, languages, and cultural customs, so it is crucial to remain open to exploring and discussing religious beliefs and practices with SAW to provide tailored and person-centred care. Yet, as the present study showed, SAW believed religion and spirituality were not something they could discuss with their treatment team, which may, in fact, indicate a secular paradigm within the health care system in Canada.

However, what we need to be mindful of is that religion and spirituality can sometimes act as a double-edged sword. While religion and spirituality may influence recovery and treatment in a positive way for some people, they can also pose major hindrances in some circumstances. In line with previous studies, the findings of the present study indicated that this primarily occurred when families viewed religion and spirituality as a preferred way to heal and used religion to explain the causes of psychosis (e.g., demons, Jinn, etc.) despite patients not necessarily adhering to those beliefs (Islam et al., 2015). In this scenario, SAW may perceive themselves to be alone on the path to recovery. This is because they preferred to use psychiatric services, while their families were more inclined to use traditional healing methods of healing, which, in turn, can adversely affect help-seeking and delay treatment (Sharma et al., 2020).

Understanding the cultural aspects of SAW experiences with FEP would also require adopting a strength-based approach to give insight into the cultural strengths and resources they rely on to overcome some of the challenges caused by psychosis. To better serve members of ethnic minorities, the integration of this cultural knowledge into practice is necessary, and sometimes the right solution lies in seeking information about cultural practices and resources available among members of an ethnic group. In this study, SAW referred to a variety of activities that helped them cope with psychosis-related difficulties. Firstly, religion and spirituality were endorsed as a crucial source of coping. It is important to note, however, that SAW in this study held different attitudes about religion and spirituality. Some participants viewed it not as an active part of their lives, rather as a source of comfort and support in times of need. Interestingly, this provides a less conventional view of religion and spirituality, describing them as a form of knowledge or a philosophy of life. Another participant, however, expressed a much stronger connection to religion. Besides actively engaging in religious activities, she used other means such as listening to religious podcasts and attending community events. In the absence of any discussion on religion with the treatment team, she decided to engage in activities offered by the religious community to find answers to her religious questions. As a result, she felt more connected to her community and was able to overcome her sense of isolation. Participating in faith-related gatherings fosters a sense of belonging and facilitates the resumption of social lives for individuals with psychosis (Virdee et al., 2016). One participant in the present study described how certain prayers helped her cope with anxiety, depression, and negative thinking. In line with these findings, evidence shows that religion and spirituality are invaluable sources of coping for patients and their families, facilitating recovery, and reducing the burden of illness (Hilton et al., 2001; Rathod et al., 2010; Virdee et al., 2016).

Furthermore, SAW discussed how having a daily routine, doing exercise, listening to podcasts, and reading books were useful to them. Chiu et al. (2005) conducted a study with East and South Asian immigrant women in Canada with serious mental illnesses, including psychotic disorders. Women in this study employed a variety of innovative strategies to cope with mental illness including art/music, writing, reading, exercise, and walking in nature. SAW, also, placed a great deal of importance on art-based activities such as playing or listening to music (either western music or music from their home country), or painting. One of the participants in this study viewed art as a means of self-expression rather than merely a coping mechanism. Even in her case, psychosis influenced her artwork and helped her reflect on her psychotic experience. According to Lynch et al (2019), individuals diagnosed with FEP found art to be an engaging and stimulating experience that helped them express feelings and develop a sense of identity.

Despite the adverse impact of psychosis on SAW's self-image, some participants viewed it as a turning point in their lives during which they faced many difficult challenges, devised strategies to overcome them, rebuilt their confidence, and took courageous, yet difficult, steps to achieve goals that initially seemed beyond their reach due to their psychosis. Jordan et al. (2020) investigated factors that predict positive change and posttraumatic growth among individuals with FEP. Authors found that psychosis was perceived as an influential driver of positive change by participants. As their findings showed, posttraumatic growth was enhanced by making use of personal (i.e., self-motivation) and social resources of support. The authors also found that as individuals with FEP attempted to better understand their experiences they also actively engaged with mental health services; this, in turn, facilitated positive change following psychosis. Furthermore, positive change can be observed on three levels: 1) the individual level, by providing insight into how to manage psychosis, 2) the interpersonal level, by helping individuals establish healthy relationships, and 3) the spiritual level, by helping individuals become closer to their faith (Jordan et al., 2018). This process of meaning-making would allow individuals to re-evaluate their personal narratives, develop a sense of identity, and achieve posttraumatic growth (Ng et al., 2021).

Participants in the current study also stressed the importance of social support. Support was received from a variety of people, including parents, siblings, relatives, and friends. The importance of family and family support in South Asian culture is well documented (Grewal et al., 2005), and family is recognized as having an active role in the treatment of their loved ones (Malla et al., 2020; Stanhope, 2002). Friends also showed their support by listening, being available, mobilizing help, and accepting the patients as they are. Moreover, making friends and talking with people with the same lived experience benefited both parties in a meaningful way. With a shared understanding of psychosis, peer support offers patients a unique opportunity to disclose their experiences in a relatable way and foster post-FEP growth (Ng et al., 2021). Visiting relatives and friends in the home country was also found to reduce symptoms and speed up recovery. In the South Asian context, mental illness is often viewed as something that can be resolved within the family or extended family, and returning to the home country is sometimes advised to help individuals recover from psychosis (Chiu et al., 2005; Rathod et al., 2010).

Despite the pivotal role played by families, as discussed earlier, there may be some conflicts between patients and families that may impede recovery. As the findings of the present study illustrated, failing to understand their loved ones' challenges and desire to have an independent life, can all lead to a deterioration of SAW's relationships with their families. In addition, some SAW did not feel comfortable discussing their concerns and difficulties with their families; doubting one's own religion or dating issues are a few examples. To avoid negative reactions from their families, some SAW initially hid their problems, which delayed seeking medical help. Similarly, Rathod et al. (2010) found that South Asian Muslims chose to conceal their psychosis because mental illness may be viewed as a disgrace to the community or family. Thus, it is imperative for the treatment team to pay attention to familial and cultural factors that may contribute to conflicting understandings of psychosis between SAW with psychosis and family.

Implications

Research Implications. This study contributes to the research literature by addressing the gap that exists with respect to the lived experience of SAW with FEP. Findings of this study shed light on how SAW reacted, perceived, and made sense of psychosis. This study also offers insight into the needs they faced and challenges they strived to overcome and takes it one step further by examining the sociocultural factors that may contribute to these challenges, such as stigma, attitudes about medication, and conflicts with family. Although findings of this study demonstrated cultural challenges SAW encountered, it is important to emphasize that in this study culture was not merely regarded as a negative phenomenon that would always act as a hindrance to recovery or treatment. Rather, SAW's narratives provided invaluable information about cultural assets that can inform clinical practice in a meaningful way. The author strongly believes that to improve services and provide a culturally sensitive approach, recognizing the value of cultural strengths is as pivotal as identifying cultural challenges. By incorporating some aspects of culture such as religion and spirituality, a healthy lifestyle that centers on exercise and proper nutrition, as well as arts-based activities, recovery can be facilitated among SAW.

Clinical Implications. The findings of this study can be used to inform clinical services for SAW with FEP. Findings of this study offer cultural knowledge that may guide the FEP programs while providing services to SAW. Studies on South Asian women with FEP are scarce. Research to date has overwhelmingly focused on demographic findings, such as the age of onset, and symptom presentation among South Asian female patients (Kirkbride et al., 2012; Morgan et al., 2016; Naqvi et al., 2010). As a result, there is still much to learn about the cultural factors that influence women's experiences with FEP. For this reason, the treatment team should strive to create a safe, non-judgmental environment in which SAW feel welcome and comfortable sharing some of their culturally related struggles. This will enable the treatment team to gain a better understanding of the factors that may prevent recovery among SAW. For some SAW, discussing their experience with family, relatives, and friends is already difficult, and they need to feel heard by their team, otherwise, this will lead to an isolating situation for them, which will have negative consequences for their treatment. Moreover, this study may provide insights into cultural factors that can be integrated into family-focused interventions such as family psychoeducation. To hear their concerns and learn more about cultural factors, it is of crucial importance to establish an open dialogue with families and address their questions in a culturally appropriate way.

Limitations

A number of limitations were identified in this study. First, a major study limitation was recruitment, particularly during the COIVD-19 pandemic, where the researcher had to halt most in-person recruitment activities, mainly due to pandemic precautions. SAW who agreed to be contacted by the student researcher were contacted via telephone call, email, as well as in-person recruitment (at the end of the project when COIVD conditions improved slightly). Due to these complications, only five SAW agreed to took part in the study. Stigma may as well be a factor because one of the SAW contacted by the student researcher stated that she did not want to be associated with anything related to psychosis. Second, this study utilized the IPA analytical framework, which offers a detailed, rich analysis of participants' lived experiences (Eatough & Smith, 2017). Although IPA is ideally suited to small samples (Eatough & Smith, 2017; Smith, 2011), it should be noted, nonetheless, that the findings of this study cannot be generalized to SAW in Montreal, Canada, or elsewhere. Third, although participants expressed some negative experiences with respect to the treatment, overall, they acknowledged the benefits of services and were willing to continue the treatment. Thus, there is a possibility that only individuals with a positive attitude toward FEP services took part in this study, further limiting the generalizability of the findings. Fourth, although the initial goal was to recruit SAW and their families, too few family members were recruited to permit analysis of the data. Lastly, all interviews were conducted online because of the pandemic, and all interviewees were at home at the time of the interview. Although participants were in a private room behind a closed door, being at home may have limited the amount of information they wished to share due to worry that their families could hear what they were disclosing.

Future Directions

A more accurate picture of SAW experience can be provided by future studies with a larger sample size, as well as sampling that does justice to the diversity of what is currently collapsed under SAW. Hence, future studies are needed to focus on other sociocultural factors such as country of origin, spoken languages, immigration histories, and also religious, caste, and educational backgrounds. Involving other stakeholders such as family members, members of the clinical team, community centers, and religious leaders could also be valuable. Through the contributions of these stakeholders, a richer and more complete understanding of the cultural factors that can affect treatment, recovery, and the illness experience of SAW could be developed. There is also a need to investigate the most effective ways to share information about mental health and psychosis within South Asian communities. Schools and universities, as well as less formal settings such as community and faith centers, can be suitable places to conduct awareness campaigns. Also, South Asian community centers can serve as a bridge between service users and providers, and their involvement in planning these events will encourage more South Asians to participate. The author also hopes that this study will inspire larger research projects, which would develop ways to culturally adapt services and identify the components of interventions that will lead to greater success in providing first-episode psychosis services to South Asian communities in general, and South Asian women in particular.

Conclusion

There is a glaring gap in the literature regarding the lived experiences of women with FEP, particularly so for women from ethnic minority groups. In Canada, little is known about the cultural factors that can influence treatment, recovery, and illness experience among SAW using FEP services. Through an exploratory qualitative research design and the use of semi-structured qualitative interviews, this study sought to explore the lived experience of SAW with psychosis, their real-life needs, the cultural challenges they encountered, as well as cultural strengths and resources they drew upon to cope with psychosis. As a result of this study, three key themes emerged: *Predicaments*, *Treatment Experience and Help-Seeking Efforts*, as well as *Cultural Knowledge*. These themes illustrate the range of challenges that SAW face from the onset of psychosis through the treatment and recovery phases. From the perspective of the SAW, clinical teams lacked the necessary cultural information to serve them effectively. The findings of this study also lend support to the fact that culture should not be viewed as merely an obstacle to treatment and recovery but must become an integral component of it. Given these examples of cultural issues relevant to the SAW with FEP in this study, treatment teams can modify their services to ensure that similar kinds of cultural problems may be explored and become part of the clinical discussion. To understand the cultural background of service users, the treatment team can also benefit from basic cross-cultural clinical tools, such as linguistic interpretation and culture brokers, as well as employing culturally safe and humble practices where patients and families can provide additional insight into factors that facilitate or hinder treatment. This process will help SAW with FEP to move forward on the path of recovery as clinicians learn from their resilience and cultural strengths.

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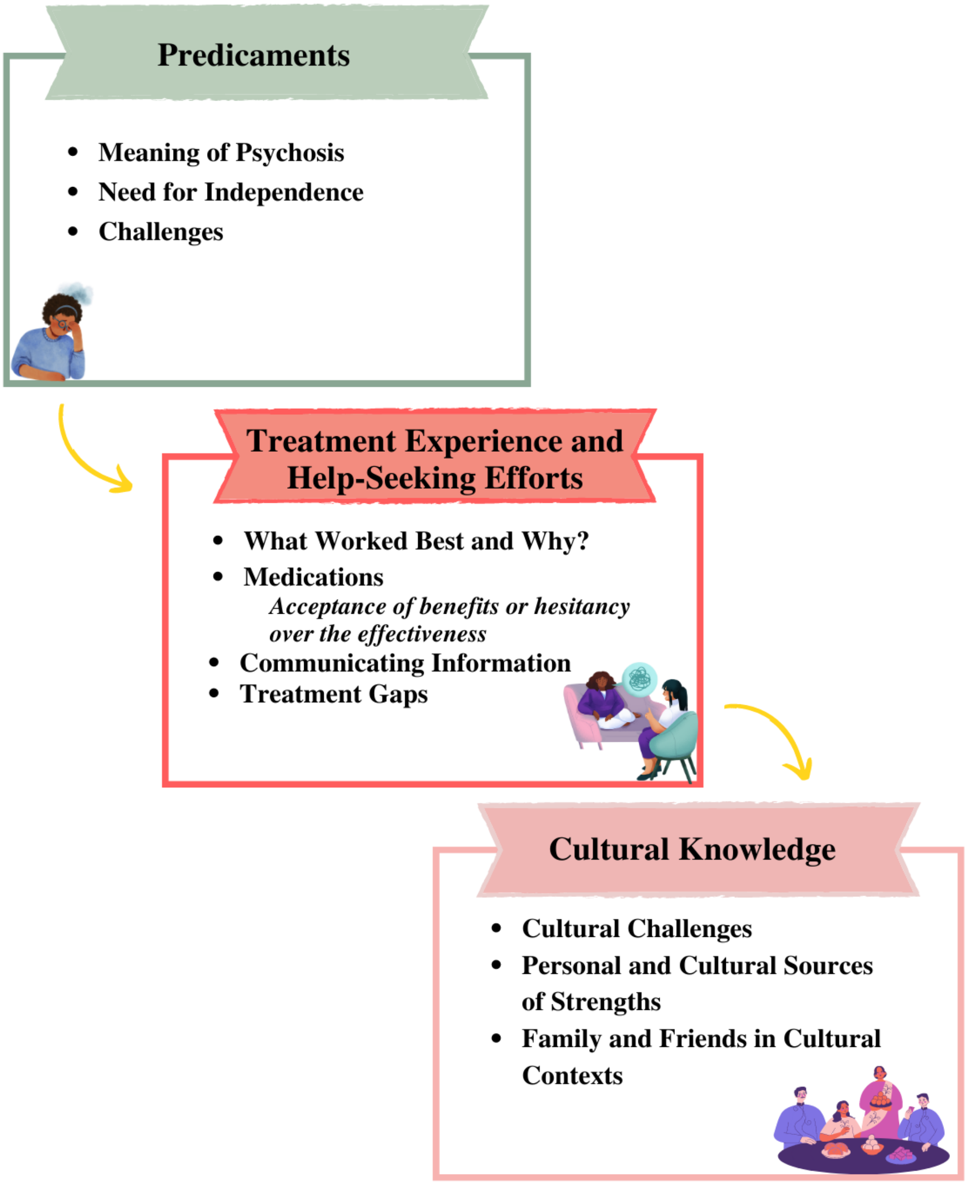
Table 1

Demographic Information

	Ethnic Background	First/Second Generation Immigrant	Age	Religion
P1	Indian	SG – Born and raised in Montreal	33	Hindu
P2	Bangladeshi	SG – Born and raised in Montreal	21	Muslim
P3	Sri Lankan, Tamil	SG – Born in Toronto	25	Atheist
P4	Pakistani	FG	24	Muslim
P5	Indian	SG – Born and raised in Montreal	40	Non-Practicing Hindu

Figure 1

Themes and Subthemes



Appendix I

McGill Illness Narrative Interview (MINI)

Generic Version for Disease, Illness or Symptom

Danielle Groleau, Allan Young, & Laurence J. Kirmayer ©2006

Section 1. INITIAL ILLNESS NARRATIVE

1. When did you experience your health problem or difficulties (HP) for the first time? [Substitute respondent's terms for 'HP' in this and subsequent questions.] [Let the narrative go on as long as possible, with only simple prompting by asking, 'What happened then? And then?']
2. We would like to know more about your experience. Could you tell us when you realized you had this (HP)?
3. Can you tell us what happened when you had your (HP)?
4. Did something else happen? [Repeat as needed to draw out contiguous experiences and events.]
5. If you went to see a helper or healer of any kind, tell us about your visit and what happened afterwards.
6. If you went to see a doctor, tell us about your visit to the doctor/hospitalization and about what happened afterwards.

6.1 Did you have any tests or treatments for your (HP)? [The relevance of this question depends on the type of health problem.]

Section 2. PROTOTYPE NARRATIVE

7. In the past, have you ever had a health problem that you consider similar to your current (HP)? [If answer to #7 is Yes, then ask Q.8]
8. In what way is that past health problem similar to or different from your current (HP)?
9. Did a person in your family ever experience a health problem similar to yours? [If answer to #9 is Yes, then ask Q.10]
10. In what ways do you consider your (HP) to be similar to or different from this other person's health problem?
11. Did a person in your social environment (friends or work) experience a health problem similar to yours? [If answer to #11 is Yes, then ask Q.12]
12. In what ways do you consider your (HP) to be similar to or different from this other person's health problem?
13. Have you ever seen, read or heard on television, radio, in a magazine, a book or on the Internet of a person who had the same health problem as you? [If answer to #13 is Yes, then ask Q.14]
14. In what ways is that person's problem similar to or different from yours?

Section 3. EXPLANATORY MODEL NARRATIVE

15. Do you have another term or expression that describes your (HP)?
16. According to you, what caused your (HP)? [List primary cause(s).]

16.1 Are there any other causes that you think played a role? [List secondary causes.]
17. Why did your (HP) start when it did?
18. What happened inside your body that could explain your (HP)?
19. Is there something happening in your family, at work or in your social life that could explain your health problem? [If answer to #19 is Yes, then ask Q.20]
20. Can you tell me how that explains your health problem?
21. Have you considered that you might have [INTRODUCE POPULAR SYMPTOM OR ILLNESS LABEL]?
22. What does [POPULAR LABEL] mean to you?
23. What usually happens to people who have [POPULAR LABEL]?
24. What is the best treatment for people who have [POPULAR LABEL]?
25. How do other people react to someone who has [POPULAR LABEL]?
26. Who do you know who has had [POPULAR LABEL]?
27. In what ways is your (HP) similar to or different from that person's health problem?
28. Is your (HP) somehow linked or related to specific events that occurred in your life?
29. Can you tell me more about those events and how they are linked to your (HP)?

Section 4. SERVICES AND RESPONSE TO TREATMENT

30. During your visit to the doctor (healer) for your HP, what did your doctor (healer) tell you that your problem was?
31. Did your doctor (healer) give you any treatment, medicine or recommendations to follow? [List all]
32. How are you dealing with each of these recommendations? [Repeat Q. 33 to Q. 36 as needed for every recommendation, medicine and treatment listed.]
33. Are you able to follow that treatment (or recommendation or medicine)?
34. What made that treatment work well?
35. What made that treatment difficult to follow or work poorly?
36. What treatments did you expect to receive for your (HP) that you did not receive?
37. What other therapy, treatment, help or care have you sought out?
38. What other therapy, treatment, help or care would you like to receive?

Section 5. IMPACT ON LIFE

39. How has your (HP) changed the way you live?
40. How has your (HP) changed the way you feel or think about yourself?
41. How has your (HP) changed the way you look at life in general?
42. How has your (HP) changed the way that others look at you?
43. What has helped you through this period in your life?
44. How have your family or friends helped you through this difficult period of your life?
45. How has your spiritual life, faith or religious practice helped you go through this difficult period of your life?
46. Is there anything else you would like to add?

Appendix II

McGill Illness Narrative Interview (MINI)
Entretien Narratif sur la Maladie de McGill
Version générique d'une maladie, d'un malaise ou d'un symptôme
Danielle Groleau, Allan Young, & Laurence J. Kirmayer ©2006

Section 1. RÉCIT INITIAL DE LA MALADIE

1. Quand avez-vous rencontré votre problème ou vos difficultés de santé (PS) pour la première fois? [Remplacez le terme "PS" par celui de l'enquêté dans cette question et les suivantes] [Laissez le récit se poursuivre aussi longtemps que possible, en demandant simplement: "Que s'est-il passé ensuite? Et ensuite?"]
2. Nous aimerions en savoir plus sur votre expérience. Pouvez-vous nous dire quand vous avez réalisé que vous aviez cette (PS)?
3. Pouvez-vous nous dire ce qui s'est passé lorsque vous avez eu votre (PS)?
4. Est-ce que quelque chose d'autre est arrivé? [Répétez si nécessaire pour faire ressortir les expériences et les événements contigus].
5. Si vous êtes allé voir un assistant ou un guérisseur quelconque, racontez-nous votre visite et ce qui s'est passé ensuite.
6. Si vous êtes allé voir un médecin, racontez-nous votre visite chez le médecin/à l'hôpital et ce qui s'est passé après.
6.1. Avez-vous subi des tests ou des traitements pour votre (PS)? (La pertinence de cette question dépend du type de problème de santé].

Section 2. DESCRIPTION DU PROTOTYPE

7. Dans le passé, avez-vous déjà eu un problème de santé que vous considérez comme similaire à votre problème actuel (PS)? [Si la réponse à la question 7 est Oui, posez la question 8].
8. En quoi ce problème de santé passé est-il similaire ou différent de votre problème actuel (PS)?
9. Une personne de votre famille a-t-elle déjà eu un problème de santé similaire au vôtre? [Si la réponse à la question 9 est Oui, posez la question 10].
10. En quoi considérez-vous que votre (PS) est similaire ou différent du problème de santé de cette autre personne?
11. Une personne de votre environnement social (amis ou travail) a-t-elle connu un problème de santé similaire au vôtre? [Si la réponse à la question 11 est Oui, posez la question 12].
12. En quoi considérez-vous que votre (PS) est similaire ou différent du problème de santé de cette autre personne?
13. Avez-vous déjà vu, lu ou entendu à la télévision, à la radio, dans un magazine, un livre ou sur Internet une personne qui avait le même problème de santé que vous? [Si la réponse à la question 13 est Oui, posez la question 14].
14. En quoi le problème de cette personne est-il similaire ou différent du vôtre?

Section 3. MODÈLE EXPLICATIF NARRATIF

15. Avez-vous un autre terme ou une autre expression qui décrit votre (PS)?
16. Selon vous, quelle est la cause de votre (PS)? [Énumérez la ou les causes principales].

16.1. Y a-t-il d'autres causes qui, selon vous, ont joué un rôle? (Enumérez les causes secondaires.)
17. Pourquoi votre (PS) a-t-elle commencé quand elle a commencé?
18. Que s'est-il passé à l'intérieur de votre corps qui pourrait expliquer votre (PS)?
19. Y a-t-il quelque chose qui se passe dans votre famille, au travail ou dans votre vie sociale qui pourrait expliquer votre problème de santé? [Si la réponse à la question 19 est Oui, posez la question 20].
20. Pouvez-vous me dire comment cela explique votre problème de santé?
21. Avez-vous pensé que vous pourriez avoir [INTRODUIRE L'ÉTIQUETTE DES SYMPTÔMES OU MALADIES POPULAIRES]?
22. Que signifie pour vous [LABEL POPULAIRE]?
23. Qu'arrive-t-il habituellement aux personnes qui ont [LABEL POPULAIRE]?
24. Quel est le meilleur traitement pour les personnes qui ont [LABEL POPULAIRE]?
25. Comment les autres personnes réagissent-elles face à une personne qui a [LABEL POPULAIRE]?
26. Qui connaissez-vous qui a eu [LABEL POPULAIRE]?
27. En quoi votre problème de santé (PS) est-il similaire ou différent de celui de cette personne?
28. Votre (PS) est-il d'une manière ou d'une autre lié(e) à des événements spécifiques qui se sont produits dans votre vie?
29. Pouvez-vous m'en dire plus sur ces événements et sur la façon dont ils sont liés à votre (PS)?

Section 4. SERVICES ET RÉPONSE AU TRAITEMENT

30. Lors de votre visite chez le médecin (guérisseur) pour votre PS, quel était, selon votre médecin (guérisseur), votre problème?
31. Ton médecin (guérisseur) t'a-t-il donné un traitement, un médicament ou des recommandations à suivre? (Énumérez-les tous)
32. Comment réagissez-vous à chacune de ces recommandations? [Répétez les Q. 33 à Q. 36 au besoin pour chaque recommandation, médicament et traitement énuméré].
33. Êtes-vous capable de suivre ce traitement (ou cette recommandation ou ce médicament)?
34. Qu'est-ce qui fait que ce traitement fonctionne bien?
35. Qu'est-ce qui a fait que ce traitement a été difficile à suivre ou a mal fonctionné?
36. Quels traitements vous attendiez-vous à recevoir pour votre (PS) et que vous n'avez pas reçus?
37. Quels autres thérapies, traitements, aides ou soins avez-vous cherché à obtenir?
38. Quels autres thérapies, traitements, aides ou soins aimeriez-vous recevoir?
Section

5. IMPACT SUR LA VIE

39. Comment votre (PS) a-t-il changé votre façon de vivre?
40. Comment votre (PS) a-t-il changé la façon dont vous vous sentez ou pensez à vous-même?
41. Comment votre (PS) a-t-il changé votre façon de voir la vie en général?
42. Comment votre (PS) a-t-il changé la façon dont les autres vous regardent?
43. Qu'est-ce qui vous a aidé à traverser cette période de votre vie?
44. Comment votre famille ou vos amis vous ont-ils aidé à traverser cette période difficile de votre vie?

45. Comment votre vie spirituelle, votre foi ou votre pratique religieuse vous ont-elles aidé à traverser cette période difficile de votre vie?
46. Y a-t-il autre chose que vous aimeriez ajouter?

Appendix III

McGill Illness Narrative Interview (MINI)

Danielle Groleau, Allan Young, & Laurence J. Kirmayer ©2006

Adapted Version for Family Members of Patients with First Episode Psychosis

Section 1. INITIAL ILLNESS NARRATIVE

1. When did your loved one experience her health problem or difficulties (HP) for the first time? [Substitute respondent's terms for 'HP' in this and subsequent questions.] [Let the narrative go on as long as possible, with only simple prompting by asking, 'What happened then? And then?']
2. We would like to know more about your experience. Could you tell us when you realized she had this (HP)?
3. Can you tell us what happened when she had her (HP)?
4. Did something else happen? [Repeat as needed to draw out contiguous experiences and events.]
5. If she went to see a helper or healer of any kind, tell us about her visit and what happened afterwards.
6. If she went to see a doctor, tell us about her visit to the doctor/hospitalization and about what happened afterwards.

6.1 Did she have any tests or treatments for her (HP)? [The relevance of this question depends on the type of health problem.]

Section 2. PROTOTYPE NARRATIVE

7. In the past, have you ever had a health problem that you consider similar to her current (HP)? [If answer to #7 is Yes, then ask Q.8]
8. In what way is that past health problem similar to or different from her current (HP)?
9. Did a person in your family ever experience a health problem similar to hers? [If answer to #9 is Yes, then ask Q.10]
10. In what ways do you consider her (HP) to be similar to or different from this other person's health problem?
11. Did a person in your social environment (friends or work) experience a health problem similar to hers? [If answer to #11 is Yes, then ask Q.12]
12. In what ways do you consider her (HP) to be similar to or different from this other person's health problem?
13. Have you ever seen, read or heard on television, radio, in a magazine, a book or on the Internet of a person who had the same health problem as hers? [If answer to #13 is Yes, then ask Q.14]
14. In what ways is that person's problem similar to or different from hers?

Section 3. EXPLANATORY MODEL NARRATIVE

15. Do you have another term or expression that describes her (HP)?
16. According to you, what caused her (HP)? [List primary cause(s).]

16.1 Are there any other causes that you think played a role? [List secondary causes.]
17. Why did her (HP) start when it did?
18. What happened inside her body that could explain her (HP)?
19. Is there something happening in family, at work or in social life that could explain her health problem? [If answer to #19 is Yes, then ask Q.20]
20. Can you tell me how that explains her health problem?
21. Have you considered that she might have [INTRODUCE POPULAR SYMPTOM OR ILLNESS LABEL]?
22. What does [POPULAR LABEL] mean to you?
23. What usually happens to people who have [POPULAR LABEL]?
24. What is the best treatment for people who have [POPULAR LABEL]?
25. How do other people react to someone who has [POPULAR LABEL]?
26. Who do you know who has had [POPULAR LABEL]?
27. In what ways is her (HP) similar to or different from that person's health problem?
28. Is her (HP) somehow linked or related to specific events that occurred in her life?
29. Can you tell me more about those events and how they are linked to her (HP)?

Section 4. SERVICES AND RESPONSE TO TREATMENT

30. During the visit to your clinical team for her HP, what did her clinical team tell you that her problem was?
31. Did the clinical team give her any treatment, medicine or recommendations to follow? [List all]
32. How is she dealing with each of these recommendations? [Repeat Q. 33 to Q. 36 as needed for every recommendation, medicine and treatment listed.]
33. Is she able to follow that treatment (or recommendation or medicine)?
34. What made that treatment work well?
35. What made that treatment difficult to follow or work poorly?
36. What treatments did you expect to receive for her (HP) that you did not receive?
37. What other therapy, treatment, help or care have you sought out for her?
38. What other therapy, treatment, help or care would you like to receive for her?

Section 5. IMPACT ON LIFE

39. How has her (HP) changed the way she lives?
40. How has her (HP) changed the way she feels or thinks about herself?
41. How has her (HP) changed the way she looks at life in general?
42. How has her (HP) changed the way that others look at her?
43. What has helped her through this period in her life?
44. How have the family or her friends helped her through this difficult period of her life?
45. How has her spiritual life, faith or religious practice helped her go through this difficult period of her life?
46. Is there anything else you would like to add?

Appendix IV

McGill Illness Narrative Interview (MINI)
Entretien Narratif sur la Maladie de McGill

Danielle Groleau, Allan Young, & Laurence J. Kirmayer ©2006

Version adaptée pour les membres de la famille des patients présentant un premier épisode psychotique

Section 1. RÉCIT INITIAL DE LA MALADIE

1. Quand votre proche a-t-il rencontré son problème ou ses difficultés de santé (PS) pour la première fois? [Laissez le récit se poursuivre aussi longtemps que possible, en vous contentant de demander simplement: " Que s'est-il passé ensuite? Et ensuite? "]
2. Nous aimerions en savoir plus sur votre expérience. Pouvez-vous nous dire quand vous avez réalisé qu'elle avait ce (PS)?
3. Pouvez-vous nous dire ce qui s'est passé quand elle a eu son (PS)?
4. Est-ce que quelque chose d'autre est arrivé? [Répétez si nécessaire pour faire ressortir les expériences et les événements contigus].
5. Si elle est allée voir un assistant ou un guérisseur quelconque, parlez-nous de sa visite et de ce qui s'est passé ensuite.
6. Si elle est allée voir un médecin, parlez-nous de sa visite chez le médecin/à l'hôpital et de ce qui s'est passé ensuite.
6.1. A-t-elle subi des tests ou des traitements pour son (PS)? (La pertinence de cette question dépend du type de problème de santé].

Section 2. DESCRIPTION DU PROTOTYPE

7. Dans le passé, avez-vous déjà eu un problème de santé que vous considérez comme similaire à son problème actuel (PS)? [Si la réponse à la question 7 est Oui, posez la question 8].
8. En quoi ce problème de santé passé est-il similaire ou différent de son problème actuel (PS)?
9. Est-ce qu'une personne de votre famille a déjà eu un problème de santé similaire au sien? (Si la réponse à la question 9 est Oui, posez la Q.10).
10. En quoi considérez-vous que son problème de santé (PS) est similaire ou différent de celui de cette autre personne?
11. Une personne de votre environnement social (amis ou travail) a-t-elle eu un problème de santé similaire au sien? [Si la réponse à la question 11 est Oui, posez la question 12].
12. En quoi considérez-vous qu'elle (PS) est similaire ou différente du problème de santé de cette autre personne?
13. Avez-vous déjà vu, lu ou entendu à la télévision, à la radio, dans un magazine, un livre ou sur Internet une personne qui avait le même problème de santé que le sien? [Si la réponse à la question 13 est Oui, posez la question 14].
14. En quoi le problème de cette personne est-il similaire ou différent du sien?

Section 3. MODÈLE EXPLICATIF NARRATIF

15. Avez-vous un autre terme ou une autre expression pour la décrire (PS)?

16. Selon vous, quelle est la cause de son (PS)? [Énumérez la ou les causes principales].
16.1. Y a-t-il d'autres causes qui, selon vous, ont joué un rôle? [Énumérez les causes secondaires].
17. Pourquoi son (PS) a t-il commencé quand il l'a fait?
18. Que s'est-il passé dans son corps qui pourrait expliquer son (PS)?
19. Y a-t-il quelque chose qui se passe dans sa famille, au travail ou dans sa vie sociale qui pourrait expliquer son problème de santé? [Si la réponse à la question 19 est Oui, posez la question 20].
20. Pouvez-vous me dire comment cela explique son problème de santé?
21. Avez-vous pensé qu'elle pouvait avoir [INTRODUIRE L'ÉTIQUETTE SYMPTÔME OU MALADIE POPULAIRE]?
22. Que signifie pour vous [LABEL POPULAIRE]?
23. Qu'arrive-t-il habituellement aux personnes qui ont [LABEL POPULAIRE]?
24. Quel est le meilleur traitement pour les personnes qui ont [LABEL POPULAIRE]?
25. Comment les autres personnes réagissent-elles face à une personne qui a [LABEL POPULAIRE]?
26. Qui connaissez-vous qui a eu [LABEL POPULAIRE]?
27. En quoi son (PS) problème de santé est-il similaire ou différent de celui de cette personne?
28. Est-ce que sa (PS) est liée d'une manière ou d'une autre à des événements spécifiques qui se sont produits dans sa vie?
29. Pouvez-vous m'en dire plus sur ces événements et sur la façon dont ils sont liés à son (PS)?

Section 4. SERVICES ET RÉPONSE AU TRAITEMENT

30. Lors de la visite de son PS à votre équipe clinique, quel était son problème selon l'équipe clinique?
31. L'équipe clinique lui a-t-elle donné un traitement, un médicament ou des recommandations à suivre? (Énumérez-les tous)
32. Comment réagit-elle à chacune de ces recommandations? [Répétez les questions 33 à 36 si nécessaire pour chaque recommandation, médicament et traitement énuméré].
33. Est-elle capable de suivre ce traitement (ou cette recommandation ou ce médicament)?
34. Qu'est-ce qui fait que ce traitement fonctionne bien?
35. Qu'est-ce qui a fait que ce traitement a été difficile à suivre ou a mal fonctionné?
36. Quels traitements vous attendiez-vous à recevoir pour elle (PS) et que vous n'avez pas reçus?
37. Quels autres thérapies, traitements, aides ou soins avez-vous cherché à obtenir pour elle?
38. Quels autres thérapies, traitements, aides ou soins aimeriez-vous recevoir pour elle?

Section 5. IMPACT SUR LA VIE

39. Comment son (PS) a-t-il changé sa façon de vivre?

40. Comment son (PS) a-t-il changé sa façon de se sentir ou de penser à lui-même?

41. Comment son (PS) a-t-il (elle) changé sa façon de voir la vie en général?

42. Comment son (PS) a-t-il (elle) changé le regard que les autres portent sur lui (elle)?

43. Qu'est-ce qui l'a aidée à traverser cette période de sa vie?

44. Comment sa famille ou ses amis l'ont-ils aidée à traverser cette période difficile de sa vie?

45. Comment sa vie spirituelle, sa foi ou sa pratique religieuse l'ont-elles aidée à traverser cette période difficile de sa vie?
46. Y a-t-il autre chose que vous aimeriez ajouter?