

Your Mind Matters:
An African Nova Scotian Youth Education Project

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Executive Summary

Study Aim

- The aim of the study documented in this report is to create culturally appropriate community education resources to enable young African Nova Scotian youth (18-30 years old) to recognize early warning signs of psychosis, and to encourage them in looking after their own mental health and that of their peers.

Study Objectives

The objectives of this study include the following:

- To examine perceptions and beliefs about mental illness and specifically psychosis, among African Nova Scotian youth in the Halifax Regional Municipality (HRM).
- To examine perceptions and beliefs about help-seeking among African Nova Scotian youth in the HRM.
- To examine the barriers and opportunities experienced by these youth in seeking help for mental illness.
- To obtain feedback on the preferred content and format of educational resources and other educational activities that should be developed to educate these youth, their families and their communities about psychosis, promote self-care, encourage help-seeking and reduce stigma around mental illness.

Methodology

Sample

- The total sample size for the study is 75 participants.
- Four main categories of participants were recruited for this study:
 - Youth in recovery and their caregivers in the Nova Scotia Early Psychosis Program.
 - Youth, caregivers, community leaders and service providers in Dartmouth North.
 - Youth, caregivers, community leaders and service providers in North Preston, East Preston and Cherry Brook (the Prestons).
 - Youth, caregivers, community leaders and service providers in North End Halifax (Gottingen Street).

Data Collection

- Data were collected from 14 focus groups, each comprised of a maximum of 8 participants.

Summary of Findings

- Perceptions and beliefs about mental illness among African Nova Scotian youth reflect the perceptions and beliefs in the broader African Nova Scotian community.
- In general, the African Nova Scotian community tends to avoid the topic of mental illness or deny its prevalence in the community.
- There is a considerable lack of knowledge and understanding about mental illness, which can be attributed to the lack of education people receive on the topic in schools or in conversations at home.
- African Nova Scotians are brought up to be self-reliant and strong, which make it difficult for them to reach out for help.
- A fear of police involvement in their care contributes to a reluctance to seek help and a dismissal of the gravity of mental health concerns in the African Nova Scotian community.
- For many youth self-medication in the form of drugs and alcohol was used to cope with mental health struggles.
- There is a long history in Black communities, including African Nova Scotian communities, of relying on the church and religion to address emotional and mental health struggles, which have been impediments to help-seeking from formal mental health services.
- There is a general lack of trust in the health system, as well as a lack of comfort with health providers.
- The lack of cultural competency demonstrated by mental health professionals is a significant barrier to help-seeking among youth.

Summary of Recommendations

Addressing Barriers To & Enhancing Opportunities for Help-Seeking Among African Nova Scotian Youth:

- Create a list of Black health professionals that can be provided to youth.
- Advocate for the hiring of an African Nova Scotian mental health advocate in the health care system who can support youth and families that are dealing with psychosis and other mental health problems.
- Offer training and education to church ministers and other spiritual leaders about ways to support people with mental illness.
- Partner with community organizations to provide referrals to mental health services.
- Identify key young Black leaders or initiatives that can help spread the word about the need to seek help for psychosis and other mental illnesses.
- Set up a 311 African Nova Scotian help line.

Sharing Information & Providing Education on Psychosis & Other Mental Illnesses to African Nova Scotian Youth & Their Families:

- Develop partnerships with African Nova Scotian groups, churches, health programs at schools, universities, and other organizations in the community to collaborate with on providing information and organizing workshops on psychosis and other mental illnesses for African Nova Scotian youth.

- Form a youth advisory committee that can organize and hold educational sessions on psychosis for youth.
 - Form a group comprised of African Nova Scotian mental health professionals, youth workers, and individuals from the Nova Scotia Health Authority that can hold sessions on psychosis and mental health in African Nova Scotian communities.
 - Provide opportunities for African Nova Scotian youth to design their own mental health campaigns.
 - Develop creative tools to share information about psychosis, such as an app, videos, plays, art, music, and television ads/educational commercials.
 - Share information about psychosis and other mental illnesses in the African Nova Scotian community through *Bell Let's Talk* and other media campaigns.
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Study Description

Study Aim

The aim of this study is to create culturally appropriate community education resources to enable young African Nova Scotian youth (18-21 years old) to recognize early warning signs of psychosis, and to encourage them in looking after their own mental health and that of their peers.

The Nova Scotia Early Psychosis Program (NSEPP) aims to reduce treatment delay for African Nova Scotian youth who develop psychosis throughout the province of Nova Scotia. To support this goal, we are expanding upon an existing community education initiative called *Because Your Mind Matters* (BYMM), which was launched in October 2013. This education outreach project targets young people ages 18-19 years in making the transition to their first year of postsecondary education, a recognized time of vulnerability for the development of mental disorders in youth. BYMM promotes early help seeking to prevent or reduce delays in getting appropriate treatment for psychosis. Feedback was obtained through focus group consultation with (1) well youth in post-secondary study, (2) youth recovering from psychosis and (3) family caregivers to guide the content and format of the BYMM education campaign. Using the feedback, a website (www.becauseyourmindmatters.ca) was designed with a multimedia approach incorporating videos, animations, interactive quizzes, and print materials. Wrist bracelet flash drives preloaded with selected education materials were designed and offered as a giveaway. BYMM was launched as a pilot education project at a metro university. A successful pilot resulted in partnerships being established with three other universities and several college campuses. Implementation methods varied at each campus with student reach ranging from 25-500 per session. Interactive presentations offered by NSEPP clinical staff in college and university classrooms included information on the signs and symptoms of psychosis, where to go for help and introduction to website elements.

Evaluation results gathered through an online survey of students were extremely positive, with 97% rating the website as very good/excellent, 93% describing the videos as the right length, 70% recommending the website to others, 13% reporting seeking help as a result of the presentation and 16% reporting that they recommended a friend seek help. The process of implementation provided valuable information concerning mental health literacy among students, their preferences regarding education materials and the challenges and opportunities faced in implementing awareness initiatives on psychosis. The provincial early psychosis network (EPION) in Ontario has incorporated the resource into their strategy for reaching out to post-secondary education students. BYMM sessions continue to be offered each year. In addition, significant spinoffs have occurred with individualized education sessions on psychosis being designed and implemented for faculty, counselling and health services personnel and general practitioners.

While implementation of BYMM has been very successful, it is recognized that a gap exists within BYMM resources for culturally appropriate education materials on early phase psychosis to reach African Nova Scotia youth. Furthermore, there is no known existing material on early phase psychosis which is suited or designed to address the needs of this segment of the population. Thus, NSEPP acknowledges a need to initiate research to guide development of culturally relevant information for indigenous African Nova Scotian youth.

Study Rationale

Given the dearth of studies on mental illness in African Nova Scotian communities, as well as the specific experiences of mental illness among African Nova Scotian youth, the rationale for this study is the need to collect more data on the experiences of African Nova Scotian youth in seeking help for psychosis in order to inform educational resources that will decrease and remove the barriers they face accessing and utilizing mental health services, encourage help-seeking and self-care, and decrease stigma.

Study Objectives

The objectives of this study include the following:

- To examine perceptions and beliefs about mental illness and specifically psychosis, among African Nova Scotian youth in the Halifax Regional Municipality (HRM).
- To examine perceptions and beliefs about help-seeking among African Nova Scotian youth in the HRM.
- To examine the barriers and opportunities experienced by these youth in seeking help for mental illness.
- To obtain feedback on the preferred content and format of educational resources and other educational activities that should be developed to educate these youth, their families, and their communities about psychosis, promote self-care, encourage help-seeking and reduce stigma around mental illness.

Background: A Review of the Literature

Experiences of Psychosis Among Black Populations & Pathways of Care

Despite the exponential growth of early intervention services (EIS) in Canada over the last several decades, there is a paucity of research regarding access and pathways to care for EIS for ethnic minorities in Canada. Given the fact that 20% of our population is foreign born and nearly one in five Canadian identify as a visible minority, there is a compelling need for service providers and program planners to examine the degree to which their services reach this population (Statistics Canada, 2013). The Mental Health Commission of Canada has identified a need to improve our understanding of mental illness within our diverse populations as one of its strategic directions for a transformed mental health system (Mental Health Commission of Canada, 2012). Within the province of Nova Scotia, The Nova Scotia Health Authority and the IWK provincial mental health and addictions (MHA) strategy has identified a strategic objective to increase collaboration with diverse communities such as African Nova Scotians, “to ensure timely and equitable access to a continuum of safe quality care and supports.” (Courey et al, 2017). Moreover, the MHA strategy recommends the reorientation of health services to promote better health and wellness and ensure policies and programs, reduce disparities and barriers to services, and respond to the needs of diverse communities.

An individual’s ethnicity has the potential to affect the nature and direction of pathways to care and help-seeking. Limited research is available about pathways to mental health care for ethnic groups in Canada. No known research is available in Nova Scotia. Existing research suggests that African, Afro-Caribbean, Asian and other ethnic minorities often reach EIS services from emergency room referrals. In a systematic review and metanalysis on ethnic difference in the pathways to care in first episode psychosis (FEP),

Anderson et al, (2010) found significant differences in the likelihood of GP involvement and police involvement for Black patients in Canada and England relative to white patients. Black patients were less likely to have GP involvement and twice as likely to have police involvement in their pathway to care. They also reported that there may be ethnic differences in the likelihood of involuntary admissions for Black patients with FEP though there was effect modification by sociodemographic factors.

The Nova Scotia Early Psychosis Program (NSEPP) is a well-established early intervention program situated within the Dalhousie Department of Psychiatry and Mental Health and Addictions at Nova Scotia Health Authority. Since the program's inception in 1996, NSEPP has been at the forefront of early detection and optimal treatment. Interventions included in NSEPP are tailored to address the unique needs of adolescents and young adults. Core elements include (a) early detection (ED) to shorten the time between onset of psychotic symptoms and effective treatment, referred to as duration of untreated psychosis (DUP) (b) initiating comprehensive evidence-based stage specific therapeutic resources for patients and their caregivers and (c) sustained diagnostic and therapeutic follow-up throughout the first five years of treatment focused on supporting recovery.

Psychotic disorders, including schizophrenia, are among the most serious of all medical conditions in terms of personal suffering, disability, and cost to society. The yearly direct costs of care, medical and non-medical, for schizophrenia alone in Canada for the year 2004 were estimated at over 2 billion dollars (Goeree et al, 2005). Indirect costs, including lost productivity, were estimated at close to 4 billion dollars in the same year (Goeree et al, 2005). The personal suffering combined with these costs underscore the necessity of developing, implementing, and evaluating effective secondary prevention programs (early detection and optimal treatment) for psychotic disorders. Over the past twenty-five years, early detection coupled with optimal stage specific treatment has emerged as the most effective approach to these disorders (Jacson et al, 2004). Service Standards for early psychosis have been developed internationally, nationally and in Nova Scotia (Bertotle et al, 2005; Nova Scotia Department of Health, 2004). As the disability caused by psychosis appears to be largely determined within a critical period that encompasses the first five years after the onset of illness, a narrow window exists for effective implementation of treatment and recovery strategies.

Early detection strategies for psychosis are shaped by three well established findings. First, psychosis and related mental health issues, including anxiety and mood disorders, most frequently begin in late adolescence or early adulthood (16-25 years old). Second, despite availability of highly effective treatments that reduce disability, many young people go for months and even years before coming into care and beginning treatment. Third, severity of disability in psychosis is strongly associated with the delay between the onset of symptoms and initiation of effective treatment. Longer treatment delay is correlated with relatively more severe disability. Since onset of psychosis commonly occurs during adolescence and early adulthood it can disrupt achievement of important developmental milestones such as the transition from high school to postsecondary education, separation from parental supports, acquiring life skills for independent living, and relationships. Derailment from successful progression through these tasks can result in educational, occupational, and interpersonal deficits that alter the trajectory of the young person's life in ways not easily repaired, resulting in significant distress and suffering for the individual and their families. Studies on pathways to care for young people with psychosis suggest that treatment delay is determined by a complex range of factors, including the nature of the presenting symptoms, the knowledge and attitudes of physicians and helping professionals the young person contacts to seek help, and the knowledge and attitudes of the young person, their family, and friends. The latter two factors can potentially be changed through education, with the major focus of this initiative being the knowledge and attitudes of young African Nova Scotians.

A study by Jarvis, Toniolo, Ryder, Sessa and Cremonese (2011) found that Black people are at risk of developing psychosis, possibly due to discrimination. With the hypothesis that Black psychiatric inpatients have higher rates of psychosis diagnosis than non-Black individuals, regardless of whether the location is in

Western Europe or North America, this study assesses the disparities in the diagnosis of psychosis in two settings: Padua and Montreal. It uses data on psychotic patients admitted to the psychiatry unit at general hospitals in Padua and Montreal. It concludes that despite the different settings, Black patients admitted to psychiatry are more likely to be diagnosed with psychosis than other patients in both Padua and Montreal. The results obtained in both Padua and Montreal show that being Black is independently and positively associated with being diagnosed with psychosis compared to patients from other ethnic groups. This finding leads to the conclusion that Black patients admitted to psychiatry are more likely to receive a psychosis diagnosis than other patients, whether in Padua or Montreal. When controlled for sex and age, Black psychiatric inpatients were approximately three to four times more likely to receive a psychosis diagnosis than those of other ethnic groups. Although possible explanations include discrimination, poverty, and barriers to health services, whether the disparities are truly due to these factors remain unknown. In an earlier study, Jarvis, Kirmayer, Jarvis, and Whitley (2005), it revealed that in Montreal, Afro-Canadian patients admitted to the hospital with psychosis are more likely to be brought to emergency psychiatry services by police or ambulance, when compared to Euro-Canadians or Asian-Canadians. A potential explanation for the findings was identified as the possibility of the Afro-Canadian patients experiencing a delay in seeking help, resulting in the exacerbation of symptoms and the need for urgent psychiatric interventions. Another explanation was identified to be the increased presence of police in the Afro-Canadian community.

Rotenberg, Tuck, Ptashny and McKenzie (2017) investigated the role of ethnicity in pathways to emergency mental health care in Toronto for clients with psychosis while accounting for the clinical and neighborhood factors in the client's presentation. It concludes that East Asian and South Asian origin clients in Toronto with psychosis are more likely to present to emergency psychiatric services involuntarily via police or ambulance, whereas South Asian origin clients are less likely to be accompanied by family and friends. Black Africans and Black Caribbean origin clients were not found to be associated with increased odds of a coercive pathway, and clients living in areas with high levels of residential instability were found to be more likely to encounter a negative pathway. Although East Asian origin groups in Ontario have lower incidence of psychosis and lower levels of symptoms, this study found that they are at increased risk of being brought to emergency psychiatric care via negative pathways. This finding could be related to the tendency for East Asian-Americans to seek mental health services only as a last resort, as well as language barriers, and stigma. Although Toronto offers a variety of ethno-specific services for East and South Asian origin clients with severe and persistent mental illness, they are not available throughout Ontario. Having a primary care provider was associated with decreased odds of a negative pathway. Having a primary care provider could indicate a larger social network and greater organization of social supports available, both of which are known to decrease frequency of hospitalization in clients with a severe and persistent mental illness. These findings suggest that ethnic minority communities in Toronto access resources differently during a crisis and have unique experiences regarding social networks and community level social cohesion.

Anderson, Flora, Archie, Morgan, and McKenzie (2014) conducted a systematic literature review and meta-analysis that shows that there are significant differences in the likelihood of both GP involvement and police involvement for Black patients in Canada and England, relative to white patients. Black patients were more likely to have police involvement and less likely to have GP involvement on their pathway to care at the time of FEP, despite the limited availability of data for the meta-analyses. It is also important to note that the reviewed studies also reported ethnic differences in other indicators of the pathway to care, such as the type of first contact, the source of referral into psychiatric services, the total number of contacts on the care pathway, family involvement in help-seeking, and the likelihood of contact with emergency services. The results of this article suggest that when the data from past studies are pooled, there is a significantly reduced likelihood of GP involvement and an increased likelihood of police involvement for Black patients at the first episode of psychosis, relative to white patients. There is a need to design and perform more detailed studies

on ethnic differences in pathways to care to explain the relative contributions of immigration, culture, and social inequalities.

In a later study by Anderson, Flora, Ferrari, Tuck, Archie, Kidd and McKenzie, K. (2015) findings show that the Black-Caribbean group experiences increased likelihood of being referred to Early Intervention Services from an inpatient admission, decreased likelihood of GP involvement on the pathway to care, and least total contacts. The reduced likelihood of GP involvement among Black-Caribbean people could potentially be due to their negative attitudes toward primary care, disparities in access to family physicians, or a greater tendency to delay help seeking to the point where emergency services are needed. In addition, Black-Africans were found to be more likely to make first contact with an emergency department while there were no significant differences found in referral delay, police involvement, or duration of untreated psychosis between the ethnic groups. Of the Black-Africans who had greater odds of first contact with the emergency department, most were first-generation immigrants, suggesting that they could potentially be relying on emergency departments due to lack of knowledge regarding the availability of services. The study articulates that there is evidence to suggest that GPs could play a role in mitigating aversive pathways to care and that they could be a potential aid in reducing disparities in patterns of service use.

Stigma as a Barrier to Help-Seeking

Taylor and Kuo (2019) found that stigma and double stigma are significant factors influencing help-seeking behaviours for mental illness among African Americans, and that in both the United States and Canada, Black communities hold three main culturally-determined beliefs about mental illness: 1) Black people are not affected by mental illness; 2) Black people must always show strength, regardless of the circumstances; and 3) people who seek help from mental health professionals lack faith in God. Similar to Black Canadians, many African Americans rely on religion and spiritual institutions to address their mental health issues, which is partly attributed to a fear that they will be perceived by others in their community as lacking faith in God or as spiritually weak. Black Nova Scotians also believe that they could be healed of their mental illness through their faith in God.

Stigma and lack of trust in mental health service providers are some of the most common reasons why African American women underutilize mental health services, according to a study conducted by Woods-Giscombe, Robinson, Carthon, Devane-Johnson and Corbie-Smith (2016). Compared to non-Hispanic white Americans, African American women were also more likely to have unmet mental health needs. As has been observed in other studies, these women were more likely to use religion, spirituality, and resilience to deal with mental health issues. The authors determined the extent to which the Superwoman Schema (SWS) influenced the use of mental health services among African American women using five characteristics of SWS. These include a perceived obligation to present an image of strength, perceived obligation to suppress emotions, fortitude to succeed despite limited resources, prioritization of care for others over self-care, and resistance to being vulnerable or depending on others for help. Many of these women equated help-seeking with weakness and shared that they would prefer to suffer with mental health issues than access mental health services if it meant they could maintain an image of strength or cope with the issues by relying on religion and spirituality. Some of the other reasons these women were reluctant to utilize mental health services include cultural expectations that they suppress emotional distress, concerns related to miscommunication between themselves and mental health professionals, and limited access to mental health service providers who were culturally sensitive and compassionate, and who understood the challenges they face and how the SWS concept contributed to those challenges.

Brenick, Romano, Kegler and Eaton (2017) explored the relationship between sexual orientation stigma and race-based stigma among Black women who have sex with women (BWSW), as well as the psychosocial obstacles to engagement in care among these women. They found that BWSW's racial background and sexual orientation resulted in higher rates of stigmatization related to multiple psychosocial barriers, higher levels of mistrust in health care services, and lower rates of engagement in care, including a reduction in physical examination engagement. There was an increase in engagement in physical examinations by health care providers among women who had reported low experiences of race-based stigma, sexual orientation stigma, and race-based distrust in healthcare services.

A study conducted in Toronto by Logie, Lacombe-Duncan, Lee-Foon, Ryan and Ramsay (2016) is one of few studies that address the gap in the Canadian literature on the experiences of African and Caribbean LGBT newcomers and refugees as they relate to the perceived benefits of social support groups in reducing health disparities and its impact on mental health outcomes. In looking at intersecting stigmas experienced by newcomers to Toronto, the researchers found that these individuals not only left behind experiences of oppression, imprisonment, sexual stigma, and the threat of execution in their home countries, but were also at high risk for intersecting stigmas associated with their gender, sexuality, race, class, and immigration status in their new home. These stigmas led to several challenges in addressing the social determinants of health following immigration that resulted in health disparities between them and the general population, including inadequate housing facilities, employment difficulties, lack of social support, disappointment and stress from unmet expectations before relocating to Canada, and post-migration experiences of sexual-orientation-based and race-based discrimination and stigma in Canada.

Methodology

The study outlined in this report used an interpretive, narrative approach (Polkinghorne, 1988, 1995) to collect and analyze the data. This qualitative approach involves data collection methods that enable participants to articulate, define and give meaning to their experiences. Within Polkinghorne's narrative methodology (1988, 1995), humans are recognized as self-interpreting beings and their interpretation of phenomena is embodied in social, cultural and linguistic practices. Polkinghorne observes that narratives are the "primary scheme by means of which human existence is rendered meaningful" (1988: 11). Therefore, narrative inquiry is not a mere retelling or description of an individual's story, but a dynamic process of interpretation that alters and contributes to the meaning of the story. The importance of individual experience to reality is a key characteristic of an interpretive approach to narrative inquiry. Individuals come to know themselves and others through stories and storytelling. Narrative knowing is a type of meaning that draws together events and actions and notes the contributions that they make to a particular outcome (1988). Human experience is organized along a temporal dimension. Attention to the past, present and future is a key feature of narrative inquiry and temporality an essential component of narrative theory.

Recruitment & Sample

Four main categories of participants were recruited for this study: 1) youth in recovery and their caregivers in the Nova Scotia Early Psychosis Program; 2) youth, caregivers, community leaders and service providers in Dartmouth North; 3) youth, caregivers, community leaders and service providers in North Preston, East Preston and Cherry Brook (the Prestons); and 4) youth, caregivers, community leaders and service providers in North End Halifax (Gottingen Street).

Recruitment for this study was conducted in two main ways: 1) the recruitment of youth in recovery and family caregivers at NSEPP occurred through referrals from clinicians who are connected to patients and families. Interested patient and family caregivers were directed to the focus group facilitator. 2) the recruitment of individuals in categories 2, 3 and 4 (mentioned above) was conducted by Black Nova Scotian focus group facilitators that were hired on the project. Each facilitator reached out to these community members to discuss the study and encourage participation. The total sample size for the study is 75 participants. The sample sizes for each participant category are as follows:

Nova Scotia Early Psychosis Program: Total Sample Size: 4

Youth in recovery: 3 participants (1 female; 2 male).

Families (youth in recovery): 1 participant (female).

Dartmouth North: Total Sample Size: 29

Community leaders (church/community): 8 participants (6 male; 2 female).

Service providers: 7 participants (5 female; 2 male)

Caregivers: 7 participants (5 female; 2 male)

Youth: 7 (6 male; 1 female)

North Preston/East Preston/Cherry Brook: Total Sample Size: 25

Community leaders (church/community): 8 participants (4 female; 4 male)

Service providers: 6 participants (6 female)

Caregivers: 4 participants (4 female)

Youth: 7 (5 female; 2 male)

North End, Halifax (Gottingen Street): Total Sample Size: 17

Community leaders (church/community): 6 participants (3 female; 3 male)

Service providers: 2 participants (2 female)

Caregivers: 5 participants (5 female)

Youth: 4 (2 female; 2 male)

Participants for the youth in community focus groups were required to be between 18-30 years of age, which is the most common age range for the onset of psychotic disorders. The mean age of patients of the NSEPP clinic is 23 years. Participants for the youth in recovery, family caregiver, and family in the community were required to be 18 years of age or older and self-identify as African Nova Scotian. Community leaders and health and mental health service providers were required to live in, work or provide services in the African Nova Scotian community.

African Nova Scotian youth in recovery were recruited to share their lived experience with help seeking, their knowledge of the factors which helped or hindered that process, and their perspectives on what information/resources would be helpful for youth. Family caregivers of African Nova Scotian youth in recovery were recruited to share their experiences providing care to youth with psychosis, including any challenges they face. African Nova Scotian youth who may or may not have accessed mental health services were sought out to provide their perspectives on mental illness, help seeking, knowledge of psychosis, as well as their suggestions regarding the preferred format for youth education. Since African Nova Scotian families raising youth in the community often facilitate help seeking, it was important to recruit them to obtain their perspectives on mental illness and psychosis, stigma, help-seeking, level of

knowledge about psychosis, and their knowledge about useful resources for youth. Including community leaders was important as they provide services in the community including spiritual, recreation, education, support, and government services. They also represent organizations/services that are very active in African Nova Scotian communities, and are strongly connected to youth. Finally, health and mental health service providers such as family physicians, nurses, social workers psychologists and other support workers who work and provide services in African Nova Scotian communities were recruited to provide insight into their experiences providing mental health services to youth.

Data Collection

This qualitative study collected data from 14 focus groups, each comprised of a maximum of 8 participants. A semi-structured focus group guide was used to facilitate the discussions, which were audio-taped and transcribed. Focus groups for the youth in recovery and caregivers for youth in recovery took place at the Early Psychosis Program. Focus groups for African Nova Scotian youth, caregivers, community leaders and health providers were conducted in the following three geographic areas in the Halifax Regional Municipality.

- The North End, Halifax
- North Preston, East Preston, and Cherrybrook (The Prestons)
- Dartmouth

Data Analysis

In keeping with the narrative methodology, the process of analysis for this study was guided by Polkinghorne's (1995) theory of narrative emplotment. The analytical process of narrative emplotment involves reading through the transcripts in their entirety to gain a sense of the whole story. The team developed initial narrative themes pertaining to participants' experiences related to the study topic and objectives. These themes, which emerged from the research objectives and focus group guide included: 1) perceptions and beliefs about psychosis and other mental illnesses among African Nova Scotian youth in the HRM; 2) perceptions and beliefs about help-seeking among African Nova Scotian youth in the HRM; 3) barriers, opportunities and facilitators experienced by African Nova Scotian youth in seeking help for mental illness; and 4) preferred content and format of educational resources and other educational activities that should be developed to educate youth, families and communities about early stage psychosis, reduce barriers to help-seeking, reduce stigma, promote self-care and encourage help-seeking around mental illness. Similarities and exceptions in relation to people's experiences of and priorities across the data were subsequently identified. Narrative methodology is inherently inductive by nature (Bryman & Burgess, 1994; Jain & Ogden, 1999). In inductive analysis the patterns, themes and categories of analysis emerge out of the data rather than being imposed upon them prior to data collection and analysis. A theme can be defined as a statement of meaning that runs through all or most of the pertinent data or is one in the minority that carries heavy emotional or factual impact. Themes typically reflect the questions posed during an interview, focus group, or consultation, and reflect the project objectives used to develop the interview, focus group or consultation questions. There are several components to an inductive approach. First, data analysis is determined by both the research objectives (deductive) and interpretations of the raw data (inductive). Second, categories are developed from the raw data into a framework that captures key themes and processes. Finally, the findings emerge from multiple

interpretations made by participants and from the raw data. These interpretations involve the researcher/principal investigator making decisions about what is more and less important in the data.

Findings

The findings documented in this section are based on the perspectives of four main participant categories: 1) youth in recovery and their caregivers in the Nova Scotia Early Psychosis Program (referred to as “patients” in this section; 2) youth, caregivers, community leaders, and service providers in Dartmouth North; 3) youth, caregivers, community leaders and service providers in North Preston, East Preston and Cherry Brook (the Prestons); and 4) youth, caregivers, community leaders and service providers in North End, Halifax (Gottingen Street).

The findings are categorized based on the following main issues discussed by the participants: 1) perceptions and beliefs about psychosis and other mental illnesses experienced by African Nova Scotian youth in the HRM; 2) perceptions and beliefs about help-seeking among these youth; 3) barriers, opportunities, and facilitators experienced by African Nova Scotian youth in seeking help for mental illness; and 4) the preferred content and format of educational resources and other educational activities to educate youth, families and communities about early stage psychosis.

Perceptions & Beliefs about Psychosis & Other Mental Illnesses Among African Nova Scotian Youth in the HRM

Participants discussed their perceptions and beliefs about psychosis and other mental illnesses, as well as how these perceptions and beliefs have been shaped by their community, their families and their education.

Youth

When asked about their perceptions and beliefs about psychosis and other mental illnesses, youth shared that there was considerable stigma around mental illness in their community, including labelling individuals with mental illness as “crazy” and weak. Mental illness was observed to be a topic that was avoided in the African Nova Scotian community. Youth also reported a general lack of knowledge and understanding in the community about mental illness, as well as denial of the existence of mental illness. A youth from Dartmouth observed that for these reasons, mental illness is not taken seriously:

A lot of people are just like if you’ve got mental health, they’ll say there ain’t nothing wrong with you, everybody got problems. But they don’t know certain people take situations differently, right? Certain people can handle like trauma and stuff. When a couple of your friends pass away and stuff, you know what I mean? That should stress you out. Some people will just say, “oh, it happens”. But other people, it’s harder for them to get through it, right? People don’t understand, you know, especially in difficult situations.

A youth from the Prestons shared that people with mental illness are perceived as crazy:

Well, not like trying to be rude or anything, but you are seen as crazy. I think that’s why there’s so much stigma around it though. It’s because people think like mental illness means you’re crazy.

When asked about perceptions of mental illness in the African Nova Scotian community, a North End youth also stated that there is considerable stigma around mental illness in the community:

I think our perspectives about mental illness is there's something wrong with that person. They're looked upon differently. They're weak, cast out, and maybe just pre-judged because of the situation that they're in and what it looks like to be someone unstable at hand. But we might not know the prior history of their life. And they could have been, you know, somewhat great before mental illness got a hold of them. So, I think the looking down upon it and the shame of it, being ashamed of having it, and looking down on it like it's a shame, and I think the casting people away is the biggest part. Because it gets darker for them when you do that. So, I think that's one of the biggest problems we have in the community, is just writing people off that have it.

Patients

According to patients living with psychosis, there is a tendency for African Nova Scotians to view mental illness as a weakness or even a myth. The lack of knowledge and acceptance of psychosis and other mental disorders was also mentioned. One patient discussed stigma and perceptions of mental illness as a weakness:

Well, I think there's kind of a stigma about it. There's a... I guess you're kind of seen as like you having some sort of weakness or seen as a weakness in our community.

Another participant stated that there is a belief in the African Nova Scotian community that mental illness does not affect the Black community:

It's a white people thing.

Another patient echoed similar sentiments:

I think it's just more like we don't have it. As a Black community, Black people don't have mental illness. We do. But it's just that we don't have it, type thing. This is not who we are.

The idea of lack of acceptance and/or lack of acknowledging mental illness was seen as a problem by another participant:

I think there could be a lack of acceptance, too. A lot of times I find that not just our communities but all other communities, that thinking that something may be off with your mental well-being can be something tough to accept.

Lack of knowledge about mental illness was also noted by another patient:

I don't know too much about it. I only know that there's different types of psychosis, like schizophrenia and stuff. But I don't know too much about it.

Caregivers

When asked about their perceptions and beliefs about psychosis and other mental illnesses, families also described a high level of stigma associated with mental illness. Mental illness was described as an overlooked issue, “taboo”, and an issue that was not talked about in the African Nova Scotian community. Negative labelling of individuals with mental illness as “crazy” and “weirdos” was reported to be common. In addition, family participants reported that a general lack of knowledge and understanding contributed to negative perceptions, lack of acceptance and denial of mental illness. Family members in Dartmouth reported that mental illness was a taboo topic. One participant observed:

We don't like to talk about it in the Black community. It's a taboo. That if you say that you have any type of mental illness like you're crazy. That's what everyone wants to say when you say you have mental health issues.

The lack of knowledge and understanding about mental illness among youth and parents, as well as the absence of education in the schools or conversations in the home about the topic was discussed by another family member in Dartmouth:

Well, I would say for my son, he would think of that person as being crazy. But that's because he doesn't know anything...no more than myself. I'm not saying that I know any more than he does. But if a young friend of his is acting different, he's not looking at that as a mental illness. You know, they have different names and things that they say about kids that are different, you know... I don't think that they realize that it's a mental illness because they haven't been informed about mental illness. Like we don't really talk about mental illness in my home. You know, it wasn't something that I was taught, that I talked about, but not, you know, the names and stuff that they have today for mental illness. So, I don't think that my son would even know or to be able to identify a mental illness.

A family member from North End, Halifax with an open view of mental illness also emphasized the existence of stigma and denial in the community:

I personally view it as a part of the human body that's troubled. The same as if you have a disease with the kidneys or the heart or the... The brain is a part of the body. It's a brain. It's an imbalance. It's a chemical. It's a disease. And some of them are treatable, some of them are manageable, some of them are out of control only when they're not treated. So, personally it's something that affects the body that hopefully always will be treated and then acknowledged. The stigma of mental health is what I find that the African Nova Scotian community doesn't acknowledge. Like they basically don't accept the fact that there's mental illness in our community. They will say, “Well, they're crazy or they're cuckoo or they're...well, you know they've got problems,” or whatever. Rather than looking at it as a part of, “Oh, that person needs a little help.”

Community Leaders

A community leader in the Prestons observed that there is still stigma and shame around mental illness in African Nova Scotian families, although that stigma has lessened over the years:

We have developed these principles and protocols and procedures as it pertains to Eurocentric views. But we're going to apply it to you and expect you to conform with this, and so on. So, that's flawed big time. So, there is a stigma. I think there's less of a stigma than it was years ago. I think there are African Nova Scotians now that are seeking help and seeking a better understanding in and by themselves. Yet, there is the stigma in the sense of our families because it's like, "Oh, I don't want everyone to know this is my son Johnny. It's like I failed somewhere because my son Johnny has this issue," or whatever, and so on. So, we have sort of, based on protection, a false sense of pride, if you will, in trying to keep Johnny out of the big picture and the embarrassment that might be associated with it that comes back and falls in our lap, and so on. And I think that's part and parcel of the stigma.

A North End community leader noted that while the stigma around mental illness in the community has decreased due to increased media attention, it is still difficult for Black men to admit they are struggling with mental health issues:

I'm still not saying it's like fully, you know, overlooked now or you get a label or anything, you know. But once upon a time, it was looked upon like, you know, in a negative way. And like you said, that's why a lot of them kept them in house, kept them in... or you know, they didn't even really get out and function when things were going on. Today, I think because there's so much media attention around it, I don't know if they really look at it as a stigma. But again, like I said earlier, especially in the Black male population, "No, man, I'm good. I'm good." Even though you have some issues, "I'm good, bro." Because that's the way we were taught – Black men to be strong.

Another North End leader spoke about the lack of understanding about mental illness in the community and how it presents itself in terms of symptoms:

I think in the community or even just thinking about young people that I work with, I don't even know whether they would be able to identify what mental illness is. And so, I think that there's often a thought of something's different about that person or the way that we talk about people is different. You know, so they can be a bunch of behavioural things. Like people might be acting out but they won't necessarily say that it's because that person may have a mental illness. So, I think that it's kind of like there's a lot of different behaviours that we observe in young people in our community, even within ourselves sometimes, that we don't really know if it could be a mental illness or not. So, I think there's still like a lot of uncertainty around what is mental illness and what does it look like in my child even or in myself. Is it depression? You know? So, I think that there's like a lot of maybe illiteracy...that we don't really have a whole lot of literacy to talk about our mental illness. Which then makes it hard for us to identify it or to point it out when we do see it. But then I think that at lot of times it starts with maybe ADHD. You know, like some of those diagnoses and all that kind of stuff. Yeah, I think diagnosis is actually really important – to have more people being able to kind of know what mental health is and mental wellness. And just I think the language is sometimes off for us too in our community. So, we don't really have the language sometimes to speak about it.

While there is stigma around mental illness among African Nova Scotian youth, they are becoming increasingly exposed to mental illness and acquiring the language to articulate it, according to another Dartmouth leader:

I do think that in general and specifically with Black youth in that demographic, like there's much more exposure to kind of the spectrum of mental illness in the research and trying to eliminate the stigma. So, I think like even just language. Like you know, youth would have more sense of even just the language and what it is. So, I think generally that's a good thing. But, will they internalize it and actually get help and actually talk about it? I still think there's a lot of work to do. And even in terms of the study, there's not a lot of even healthy safe outlets specifically for a Black person's experience of how to process that, including even in the systems. That's one thing, you want to create exposure and you want to create means of dealing with the issue. But then you don't have the services to help deal with the issue. Black students or black youth are the ones that are going to be the most underserved when those issues arise.

Service Providers

A service provider was doubtful that youth are able to recognize their own symptoms of mental illness:

So, from my experience and personally in working with people in the community, I would say that youth particularly aren't able necessarily to identify when they're experiencing symptoms related to a mental illness. It's often seen as taboo to talk about mental illness and mental health. So, I feel that it's not really talked about. Which means we don't really necessarily acknowledge when something doesn't feel the same as it's always felt. Or how it's always felt has not been healthy, we don't even recognize that.

Further to this point, another service provider in the North End added:

Historically in the African Nova Scotian community that I'm from, in my area mental health has been regarded as something to be kept quiet, you don't talk about that, that's Mrs. so and so or cousin so and so. One terminology that one of the elders in our community used for someone that was having mental health struggles, "Oh, their brains are a little addled." And that was a term that was used. We're already a Black community, but people are further marginalized because they're struggling with a mental health issue.

A service provider in Cherry Brook voiced similar concerns:

There's so much stigma around mental illness. I know personally in my very large family, like my father and his brothers and all that, that there have been...they call them special, and then they just kind of ignore their behaviour. And so that just becomes the norm where they don't actually actively address the behaviours that they're seeing.

In summary, as the conversations we held with the participant indicate, negative perceptions about mentally ill people as crazy or weak, discomfort around discussing mental illness, lack of education about

mental illness, as well as a lack of literacy in discussing mental illness are all prevalent in the African Nova Scotian community and in families and, consequently, influence the extent to which African Nova Scotian youth seek help for mental health problems – an issue we will turn to in the next section.

Perceptions & Beliefs About Help-Seeking Among African Nova Scotian Youth in the HRM

Participants also discussed the beliefs that African Nova Scotian youth and the broader African Nova Scotian community hold about seeking help for and coping with mental illness.

Youth

A North End youth emphasized the need for more information on where to get help and an environment that is open, accepting and encouraging of help seeking:

Like if you think that you might be having a mentally rough time, a lot of youth and people in our community have trouble with saying the words “I need help because I’m mentally in a crisis”. We’re used to calling on other people for the physical sickness and helping with things like that. But, when it comes to our mental health or our feelings, we’re not always so quick to jump up and say “my feelings are hurt” or “I’m in an unhappy space right now, my mental health is not where it should be”. To just be able to acknowledge that. Not within your own head but somebody to go to that would take it seriously and would say, “Well, you should look into the first steps of getting help.” There needs to be more, I don’t know, more information on it. Because even to want to get help sometimes, you get scared of even who to talk to. So, there needs to be more information so people are comfortable with it that want to get help.

Patients

The stigma around seeking help and where one receives help for mental illness was discussed by a patient:

Yeah, there is definitely a stigma there. I’ve definitely heard that growing up as a child. Like, “Oh, he or she should go to the Abbie Lane.”

Another patient echoed these sentiments regarding the stigma and the type of language used in the community:

Or if you’ve been there (to the Abbie Lane) “You went crazy. That person went crazy. It’s a bad thing to go there.” And it’s not.

Caregivers

A North End family member shared that mental illness is a neglected issues and attributed this to the lack of access to a safe place where people feel comfortable communicating their needs. Also mentioned was a cultural upbringing that emphasized self-reliance and strength:

I think it's something that's very common in our community but neglected. Probably because one of the main reasons is we don't have anywhere to go where we can be comfortable expressing that we have something wrong with us because we've been trained to be strong and to always stand and never buckle no matter what the situation is. So, there hasn't been a safe place created for us.

Another North End caregiver shared similar concerns about a reluctance to seek help for mental illness among African Nova Scotian youth due to the lack of safe and supportive places where they can go to address their concerns:

A safe place. Or having people or an environment that you can relate to as well. Instead of if you enter a place that you hope will help you, and they don't recognize your needs culturally or they don't identify with you, they don't identify with what you might be sharing with them because culturally most... I mean, you know, we have our culture, and we bring that with us because that's who we are. But, often people who are trying to treat that don't understand what you could be experiencing or going through. They can't relate, which is very problematic. And if you have somebody who doesn't relate to you or understand you, it's like "what am I doing here?". And that's what has happened, I find, as well. People just say, "I can't be bothered because they're not helping me.

Mental health concerns are often dismissed and help seeking avoided out of a fear of police involvement, according to another North End participant:

You know, some people say, "There ain't nothing wrong with you." Because we wouldn't want to be saying our sons are crazy because you know what the police are going to do to them, right? So, there is a stigma. And there's some reason behind it. We're not saying that it's always right and that it's always been good for us. But, realistically that's what we had to do to remain safe. And still, there are no safe places where we can go.

Community Leaders

According to a community leader in the Prestons, self-medication in the form of substance use is often the approach African Nova Scotian youth use to cope with mental illness:

And you know, another thing that I've noticed in my experience, they self-medicate. They smoke more, and they drink more. And then they smoke more, and then they drink more. And any other drug that's coming around that might make them feel good, they'll take it. Once the money's gone and then whatever, you know... it's such a viscous cycle.

The church, as well as the sole reliance on religion and spirituality have been impediments to help-seeking in the African Nova Scotian community, as a community leader in the Prestons observed:

The church is a part of the problem too. One of the reasons that people don't access... The church is a part of the problem because the church quite often is more apt to say, "Just praise Jesus and you'll be okay." So, you don't access anything else that might be available to you because this minister that you think can walk on water tells you this. And, therefore you don't

reach out beyond because he just wants you to get down on one knee or two knees or whatever it is and say “Jesus, please take this away from me.” And then poof, oh, you’re better now.

A North End leader noted that it is important to not pathologize normal everyday challenges community members experience:

We have I think as a society a tendency to over...just pathologize everything. And so, you know, the normal anxiety that we would feel in terms of, you know, having to do a presentation in front of a group of people, or go apply for a bank loan, or those kinds of things that are just a part of our everyday experience then becomes something medicalized. And so when there actually is a situation, we don’t necessarily have the words to explain it or define it, or for even others to be able to pick up on it.

Service Providers

Relying on a religious/moral framework was preferred in the community rather than seeking help from mental health services, according to a service provider:

Like I would hear a lot of like, “No, they just need Jesus. Like that’s what it is.” And it’s almost seen as like not even an acknowledgement of people living with mental health but it’s more like, “oh, like they’re just experiencing this, or they have done something, they’re bad apples”.

Another service provider observed that while young people are more willing to discuss mental illness, they are often not knowledgeable about the appropriate treatments they should seek out:

Yeah, it’s kind of just everyone’s more open to talking about it in the younger generations, but I don’t know if they know enough to seek the right treatment or ask the right questions. And some providers are not taking the time to ask those questions.

Youth are more likely to seek help from peers, especially through text, according to another service provider:

Because if they’re not willing to go talk to somebody in person, they may be willing to make a phone call but maybe not. Because there are some youth that don’t have those skills to just pick up the phone and have a conversation with an adult. So maybe it’s a youth-run hotline that they could text.

In summary, participants observed that perceptions about mental illness among African Nova Scotian youth and African Nova Scotians, in general, shape their beliefs about the most effective ways to seek help or to cope with mental illness. These include attending church, spirituality and prayer, reaching out to friends, self-medication in the form of substance dependence and, in some cases, seeking help from a mental health professional. The participants also noted, however, that there is considerable stigma around seeking help, a lack of information about where to seek help, and a dismissiveness by family members about experiences that youth have with mental illness. These factors also influence how and the extent to which African Nova Scotian seek help to address mental illness.

Barriers, Opportunities & Facilitators Experienced by African Nova Scotian Youth in Seeking Help for Mental Illness

Participants identified the following barriers to help-seeking among African Nova Scotian youth: 1) lack of access to Black service providers; 2) lack of financial resources; 3) lack of knowledge and understanding of mental illness; 4) and a cultural emphasis on personal strength and self-reliance. Reference was also made to the lack of comfort with and trust in the health system and health providers, as well as long wait times to obtain an appointment with a mental health provider.

Youth

The lack of Black mental health professionals presents a barrier to help seeking according to a Dartmouth youth:

It can be lack of representation. Like not enough Black people are in these fields. They might feel threatened to go and speak their feelings to a white person compared to an African Canadian, you know?

Lack of financial resources to cover the cost of medications required for treatment of mental illness was also raised as a barrier to help seeking:

The socioeconomic status. You know, because if they do give you medication, it could be outside the price range you can afford. Do you have a job, do you have benefits and stuff like that to help pay for it?

Partnerships with existing African Nova Scotian groups and organizations in the community that can provide information and hold workshops is as an effective way to communicate information to youth, as a Dartmouth youth observed:

Whether it's workshops, whether it's, you know, just having the information. But utilizing community centres that are already in communities. You know, utilizing things that are already out there that are reaching youth to kind of be able to push information, to be able to get more information, to be able to be a resource that people can go to. That says, "hey, you can go, you know, these are people that look like you that might be able to help you". Because that is a big thing for some people. They want to go to somebody that looks like them. And they might not know how to find that person.

Another Dartmouth youth also suggested that a list of Black health professionals be made available:

We've got a directory of Black businesses... why don't we have a directory of Black healthcare professionals? You know, if that's where you choose to go, then you have some place where you know that you don't have to explain your life before you can explain your problem. And you don't have to explain, you know, certain situations, how they made you feel because that person already knows. Because I think we spend so much time if you're going to a healthcare professional trying to explain why you feel that way.

A North End participant noted that another barrier to help-seeking are the challenges youth experience making their parents aware of their mental health struggles – many of who dismiss their concerns:

Yeah, just getting through to their parents. Because most parents are just like, “Oh, you're just stressed”. They don't treat it how you treat a physical illness. You go to the doctor right away if you broke your leg. They kind of just push it back and just think it's like a phase or something, or you're stressed.

Patients

The under-representation of non-White or racialized mental health professionals was also mentioned by a patient as a barrier to help-seeking:

I would say something that I noticed right away when I started at the Early Psychosis program was there was lack of visible minorities or people that looked like me. This is a suggestion. It's definitely not going to solve it. But I think if there were ads with visible minorities. Where maybe somebody's struggling and they see an ad where somebody looks like them, maybe that could help them connect to the resources that are available.

Medication access and coverage was also identified as a major barrier by a patient:

There's a lot of people that don't have coverage or medical insurance to be able to afford some medication. So, I think that is a barrier that needs to be tackled.

Another practical barrier that was identified was transportation limitations:

I would say that a concern would be transportation. Say, I don't know, if someone lived off of...didn't live on a bus route or wasn't old enough to drive themselves and didn't have a way there. You could provide bus tickets for the way home for people who need them.

Caregivers

A North End caregiver observed that there was a lack of access to Black service providers within the community with whom youth feel safe and comfortable to share their mental health concerns:

African-Nova Scotian communities need to have those people and those resources on site right there. Our people are not comfortable with going. They're not used to it. And it takes us a while to understand that you mean I can really go in there and seek the help that I need, that I'll feel safe, I'll feel comfortable, I'll get the help that I need, somebody will understand what I'm talking about. You know, you can't overestimate how important it is that those people look like me, they resemble me, and they come from my community.

Another barrier to help seeking discussed by a family member was the cultural expectation to be strong and to not share family problems with others:

And we think that we have to be that strong because we are taught as a community and as families that what goes on in this house stays in this house. And I know that I've heard different speakers over the years tell us where that comes from. The protectiveness of us, of our ancestors. It was a protectiveness of us, right? We weren't supposed to tell anybody. "Don't you tell nothing. You don't let mister know anything about what's going on". So, everything was kept right here.

A family member voiced concerns about her own lack of understanding about mental illness and psychosis and stated that parents need education and support to help them recognize when their family member may be experiencing mental health concerns or should be referred for help:

Or better yet, come in my community and equip me with the information and build me up as a parent and support me with that information so I can have those conversations with my children. Equip me with that information. You know what I mean? Then I don't have to always look for somebody on the outside because I'm well-prepared and educated and confident enough to share and sit down and have those conversations without shame.

Community Leaders

Experiences of being dismissed by hospitals and mental health professionals who question the reality of mental illness experienced by a loved one is a challenge to help-seeking among African Nova Scotian youth, according to a community leader in the Prestons:

You know it's a problem. You know because you've been dismissed by the hospitals. They're living with this reoccurrence over and over and over again. They're just living with it until another episode where the individual can't take it, and you take them back, and then they're sent home. And then it just starts all over again. That's it, you're just living with it. It's very stressful because you've got to live with it. And you can't do no more than that because you're not a mental health professional. You can't prescribe drugs. You know your family member is ill. But they (mental health professional) don't believe you. And they don't believe the person who is having the episode is actually having an episode. "They're on drugs. Tell them to stop doing drugs.". They're this, they're that, they're trying to escape their own undoing, escape justice, or whatever excuse they come out with. It's a justification for not helping your family member.

While there are several community initiatives that are providing young people with a safe space to share the challenges they are experiencing, the public school system has not done enough in this area, according to a North End community leader:

I've been definitely a part of a lot of different...I guess we'll just call them generally like safe spaces. And so lots of institutions and agencies are really trying to make their space safe, and having lots of events that are really focused on young people having a chance to just kind of come and be and talk. So, I feel like there's a lot of that work happening in the community. But I think for me where I'm feeling disappointed is that I'm not seeing enough of it is in the public school system. Like directly in the school. So, I think that, you know, the guidance processes that they have set up but there's just not enough depth that happens within the school system. Like P to 12, I'd say. Because guidance counsellors are like so stretched thin and there's always... Like

you know, they have their support workers and all that kind of stuff. But, I think that there's only so far that those things can go. And so, in the health centres that exist there now, I mean there's this ask for more deliberate, intentional focus in terms of African Nova Scotians. So that space that understands the culture and understands the basic needs. I guess it might be called navigating the system. Because if you start something with someone, you have to finish the journey with them, right? And it's been my experience for some of the things, particularly I don't know if you'd call them more intense, but things like the psychosis and ones like that, right, you know, trying to navigate that stuff through the system. And like how people understand, you know, the timeframe that that takes. And some of that is talked about in the sense about say... When you go forward and you look at the professionals in the field, the ones that don't look like us, there's no cultural competency within that group ...even has an inkling of how we are, who we are, our traditions, our history, lineage, culture – the whole nine yards. And so, they try, again as I said earlier, to paint us with the same brush they paint their own. And that's why we come out probably worse than when we went in, if we had a problem in the beginning.

Referrals from community organizations can be an effective first step in facilitating access to mental health services, according to another North End leader:

I think that we talked about it already in terms of the wraparound effect. Like the first referral doesn't always have to be to a psychologist or a psychiatrist. It could be to a community organization. So, one of the initiatives that we started in my educational institution, the school where I work, is we have moved beyond just hiring psychologists. So, we have people with counselling backgrounds. So, it could be social workers, it could be any number of professions. So I think that our health system and our systems really need to kind of pay attention to the time and the changing time, and the needs of students and of young people. Because a lot of times they might come to the table with knowing what they're struggling with because they've done their own research. So, they need a different kind of support now. And that's the thing – listening to users and I think all this research and focus groups is really good so that they can really get some current information.

A youth pastor in Dartmouth discussed the lack of cultural competency demonstrated by mental health professionals:

So being a youth pastor for many years, I've personally taken students that have been in crisis, have been suicidal, had extreme bouts of depression, and observed and watched them be treated by social workers at the IWK specifically, and it was a disgrace, to be honest with you. Just a lack of sensitivity to their experience, just totally out of touch, treating them very robotically and mechanically, and not a lot of empathy and rapport building and sensitivity. Just not even an awareness at all. From my experience when I witnessed this particular incident, I don't want to generalize everything, but this particular incident I think did more harm than it did help. And so I think there's just a lack of sensitivity on how to treat a Black young person who's struggling with their mental health, I think just in the system itself.

Service Providers

A clinician who participated in the study observed that many people with mental illness often avoid seeking help because of a fear of police involvement:

I also think like this same person we're talking about, like the person themselves told me that if they have a mental illness and sometimes police are called in emergency situations. And then when the police comes, just because of like historical like violence that... And I know I'm speaking from a place of privilege. But that African Nova Scotians experience quite significant violence at the hands of, you know, these institutions. And so, some of the young people have said to me too, like if I admit that there's something going on then the police are called. Then it's like feeling unsafe because police are responding and having to take them to the emergency department. And that's quite like a traumatizing experience.

Another barrier for youth to accessing appropriate care for psychosis is the fact that many health care providers are already overstretched and may not have the training or time to be able to appropriately screen for psychosis:

I'll screen youth for depression because like that's what's in current clinical guidelines. But there's so many things that are in current clinical guidelines that I'm supposed to do in a youth check-up that like psychosis just isn't on that list. So, it is not something I do routinely.

Preferred Content & Format of Educational Resources & Other Educational Activities

Participants shared suggestions for the content and format of educational resources and other educational activities that the *Your Mind Matters* project should develop as well as for the educational forum the program plans to hold to inform African Nova Scotian youth and others about early-stage psychosis, promote help-seeking and self-care, and reduce the stigma around mental illness.

Youth

Youth participants recommended that education be carried out using social media, such as Instagram, Twitter, Snapchat, and Facebook, as well as through videos, the creation of an app, brochures and pamphlets, educational commercials, and educational sessions in the schools and in the community that incorporated interactive group discussions and first voice stories. They also suggested that the content of educational material produced include information on the signs and symptoms of psychosis, stigma around mental illness, the relationship between stress and illness, stress management, grief, the role of trauma in illness onset, substance use and mental health, available mental health resources, and healthy lifestyles. Youth also recommended that the educational forum feature presentations by Black health professionals, pastors, and other community leaders and that these individuals be close in age to the youth who are attending the forum. Another suggestion provided was that information sessions take place monthly or bimonthly and that breakout groups be considered for small group discussions, with 12-15 people in each group. They noted that these sessions should be engaging and no longer than one and a half hours long. Refreshments and incentives, such as a draw for prizes, should be arranged since they would encourage youth to attend. Locations suggested for these sessions include the Dartmouth Sportsplex, the Family Resource Centre, schools, and community churches.

In addition, transportation should be arranged for the youth attending the forum since helps to facilitate their participation, as a Dartmouth youth observed:

I think the ads are a big thing. Because it's like if you see an ad that you're interested in, you're going to click on it to get more information. So, the people that want more information, the people that it's going to reach are going to click on those ads – whether it be Instagram, Facebook, Snapchat. And I think the visuals of that need to be very specific and target people that look like us. Because that's going to even make you want to click on it even more.

A North End youth recommended reaching out to leaders of various youth programs in their community to arrange information sessions:

I think there's a lot of youth programs that go on in these different communities. And the people who run these youth programs who are interacting with the youth, they can like speak on it and like let them know.

A youth in the Prestons with experience organizing youth events discussed how challenging it is to get youth to attend presentations and suggested that incentives such as prizes or gift cards should be provided to them to increase participation:

Honestly, if we're being completely honest... Like how do I say it? Because we were talking about this, like one time we were going to do something to try to grab youth, and we were like literally the only way nowadays is like incentives. Like it's sad to say. Yeah, giveaways and stuff because it was a way for them to engage and actually want to come, knowing that they could win things. Like you know what I mean? It just made it fun while learning.

Another suggestion from a youth was to have a separate break out option for people of diverse gender identities and age categories at the education sessions to allow maximum opportunity for sharing and discussion:

Because you're going to feel comfortable, you're going to sort of be at similar areas in your life experience and similar situations. And you're going to be more comfortable maybe sharing those experiences and learning from each other at the same time as gathering information. And I think, you know, because I just think women might be more comfortable, and men might be more comfortable, you know, speaking with their friends, speaking with people in their age group. And it's one thing for a female to say, "oh, I've gone through this and this is what's going on". You know, sometimes if another male gets up and speaks to another male, like, "Oh, wow, like he's gone through that. It's okay to share my experience." I think that would be beneficial as well.

Patients

When discussing the format that should be used to communicate information to youth, a patient participant stated the following:

The best way to get through to African-Nova Scotians, African youth, period, Black youth - music.

Another idea that was brought up was creating short cartoon clips:

Hire somebody to make a cartoon clip with African Nova Scotians in them. Like using Black people and use a cartoon clip.

Another patient suggested that peers from the Black community who have had considerable success in their careers be invited to speak to youth:

Also, you could have people of colour. You could show them what it's like living with the mental illness and succeeding. People that have already dealt with it. So, it would almost go along whereas somebody that looks like you is maybe feeling or dealing with some of the things that you are. So that would also help.

The timing of the educational sessions was also viewed as a key issue, with one participant stating:

No, don't do it in the summer because nobody's going to go to it in the summer because everybody's going to want to be out and about and have fun. But doing it during Black History Month for Black Nova Scotians is smart.

Caregivers

A North End participant suggested that the forum be promoted at community meetings:

I think having more openness and dialogue with regards to just community meetings. And that way we would know what's going on. Like this here is good but if we were having something on a regular basis, I think...so that we can talk about...

Obtaining the perspective of youth and using a peer-to-peer approach was considered important by one family member:

And if you're reaching youth, have youth... the reflection of the messages need to be reflected by the people you're trying to reach. Whatever information, if it's for youth, it needs to be youth that look like them and that are them. And maybe a little bit more popular or not so popular... It needs to be from all walks of life.

Another family member emphasized the importance of an Afrocentric approach in developing educational resources:

I guess whatever type of education programs that they have in place, let them be Afrocentric, not Eurocentric. So, it's going to have to be created by Black people, people of African descent.

Framing mental illness in a positive light and using simple language in the messaging was seen to be important by another caregiver:

Simple language, simple terms of whatever you're trying to share. So, if it's psychosis, what does that mean? Because that is a big word to some. Break it down in simple terms.

Another caregiver suggested involving local talent in the community such as mental health advocate Tyler Simmonds, as well as allowing families share stories:

Some of what Tyler has created, about reaching out and having more people... Having families in the community come forward to share their experience. What we see in commercials all the time are people we don't know. Look how much more valuable it is when you see people you do know.

A Preston family member suggested creating a game that would include viewing an educational commercial on psychosis:

But even if there could be the creation of some sort of game, some kind of video game that would help people. Like in order to get to this level, you have to listen to this public service announcement. Partnering with a gaming institution or partnering with the youth to develop the game.

Community Leaders

Community leaders indicated that information on psychosis and help-seeking should be shared through the following approaches: 1) brochures; 2) plays, art, videos, and other creative approaches; 3) education; 4) the Nova Scotia Health Authority website; 5) *Bell Let's Talk* and other media campaigns; 6) an African Heritage Month event on mental health issues in the African Nova Scotian community; 7) community organizations; 8) Black churches; 9) schools and universities; 10) community cookouts or barbecue events that focus on mental health; 11) a mental health forum where presentations are delivered and participants are able to ask questions; 12) social media; 13) webinars; 14) television ads; 15) focus groups; 16) community relations strategies; 17) the African Nova Scotian Directory; 17) face-to-face contact; and 18) health programs at schools. A community leader in the North End also discussed the importance of using art to share information:

I think it's really about getting written material into people's hands to be familiar with it. But I think within the artist community, it happens a lot too. There's an artist who basically created a whole piece around their experience with their psychosis. So, I think when people share their story about it, when they kind of come out of an episode of it and talk about it, there's education that can kind of come through art even.

Another community leader in the North End believes there is value in coming together in support groups to receive information about psychosis and help-seeking:

For me, the education experience was again the reaching out in response to a family need. So, to go and find out what I could so I could apply it. What I found really kind of useful, the empowerment part, was when I came across community folks who were experiencing the same thing, dealing with the same things. And so then, you know, you just organically formed this group of folks. You were a support group for each other. And so, you know, I could talk with her

about the experiences she was having with her son, and I was having with my nephew. And so we had this, you know, going back and forth, and being...you know, directing each other to what we came across in terms of supports and things. So, I think in kind of again thinking about what would be useful along the side of training is the opportunity for support groups, you know. And some kind of connection like that where you can reach out.

Providing opportunities for African Nova Scotian youth to design their own mental health campaigns is another effective way to share information about mental illness, according to a community leader in the North End:

But I think that there is actually a need for young people to actually design their own campaigns. You know, so like people who are experiencing it. And so get them to actually design the campaigns. So, I would say like, you know, more youth-led campaigns and asking them how they want to get their message out.

Another North End leader suggested that a group comprised of African Nova Scotian mental health professionals, youth workers, and individuals from the Nova Scotia Health Authority be formed to hold sessions on mental health in African Nova Scotian communities:

Take some African Nova Scotian mental health professionals or individuals that work with youth or whatever, somebody that has something to offer, other people that are from the Health Authority or whatever, and go in every African Nova Scotian community, hold sessions, let individuals know and communities know what's available, the accessibility and availability, and those kinds of things. Because not everyone, although young people tend to be, and we stereotype young people as everyone has a computer or a phone and they're on this, and they're on that, and they're on the other thing, so on and so on. Well, some people in the far out areas don't necessarily have the Internet.

A community leader in Dartmouth discussed the importance of providing a safe space for youth to receive the information:

Creating that safe space where people feel free to, you know, expose their most vulnerable parts and talk about what's happening and what they've had to deal with. Creating that safe space but also the support within that as well I think is extremely important. And having a non-judgmental professional that's attached to them, I think would be extremely good as well. So having professionals coming to share what that looks like. It could be through pamphlets, they could be through presentations, as well as sometimes just, you know, online. You know, we can always have a webinar or something like that going on. Those are all really good venues for us to learn for people who are experiencing that to get information. I think as well, schools. Schools are now playing a huge role. Because there are so many kids who are coming in with trauma that educators are becoming extremely well versed in that. But having a social network I think would be ideal as well. And groups that we can go to, and agencies that could support that, I think is extremely important. In communities, what I think is lacking is some offices that we could have where, you know what, this is where you go. You may not have a trained counsellor but someone who would be there to give you some information. This is the number you can call. Like the

mental health hotline. So just having exposure to all of that and having access to all of that I think is extremely important.

A community leader in the Prestons shared how important it is for community members to receive practical guidance on specific places to go for addressing mental health issues:

But the churches are starting to do that. I know out here in East Preston, they have a wellness centre. A wellness committee. And some days, Dr. Cookie was there and gave a good presentation. And for the first time, you know, you could hear... I mean he was giving you some place to go. Giving the audience a place to go. Because most of the time it's where do you go? You go down to the Dartmouth General? You know what I mean? Where do you go? But he was giving some information. And then there was somebody from Recreation who was talking about the necessity for our young people to become more involved in recreation.

Service Providers

A service provider discussed the importance of language in optimizing communication about psychosis and help-seeking to African Nova Scotian youth:

We need to be able to alter the way we assess and talk to African-Nova Scotian youth in a language that's plain to them and that's relatable to them. So, an example might be if we're asking the question "have you ever had any mental illnesses?", well, they may say "no". But if you continue to dig deeper into that conversation then you may tease out that, oh, okay, actually they may have had something in the past or may be experiencing something now.

Using online resources to communicate with youth was also noted by another service provider as an important way to reach youth:

I can recall this summer going to a youth conference. And someone was there, they had someone talking about mental health issues in the Black community. And so, one of the things that was offered – these are the resources. You can go to this website, that website, that website. And you know, they ate it up. The youth, they were like, "Oh, okay." You know, copying them down, making sure that they got them. Because that's where they live.

Another service provider discussed how important it is to meet youth where they are at by having conversations with them in places that are not typically considered:

We put up flyers around saying youth come out and learn about whatever. But I mean you have to meet them where they're at. Like I used to do a lot of teaching off the basketball court when they're supposed to be resting. So we need to meet them where they're at.

In summary, participants discussed a variety of approaches that may be useful in communicating information about psychosis to African Nova Scotian youth, including holding one or more educational forums, using social media, developing informational brochures, creating artistic resources, using the media and media campaigns, connecting youth to Black health and mental health professionals, and other

approaches. Regardless of the approach, many participants emphasized the need for the Mind Matters Project to involve African Nova Scotian youth in the creation and implementation of these approaches and associated resources since it is crucial that they see themselves reflected in all activities being developed to address mental illness experienced by youth in their community.

Conclusion

Perceptions and beliefs about mental illness among African Nova Scotian youth reflect the perceptions and beliefs in the broader African Nova Scotian community, including viewing mental illness as stigmatizing and as a taboo subject, as well as perceiving and labelling people with mental illness as “crazy” and weak. In general, the African Nova Scotian community tends to avoid the topic of mental illness or deny its prevalence in the community.

Perceptions and beliefs about mental illness among African Nova Scotian youth greatly influence their perceptions and beliefs about seeking help for and coping with mental illness. In addition to the stigma and taboo around mental illness among African Nova Scotian youth, their hesitance in seeking help for mental illness can be attributed to several factors, including: 1) a general ethos in African Nova Scotian and other Black communities that Black people should be self-reliant and strong; 2) the undermining and dismissal of the gravity of the mental health issues they are struggling with; and 3) a general belief in the community that mental illness can be addressed through church, religion, spirituality and prayer.

Participants also discussed the barriers, opportunities, and facilitators to help-seeking among African Nova Scotian youth, including: 1) challenges finding safe spaces with culturally competent service providers with whom you can share your mental health challenges, including the dismissiveness of health care professionals when African Nova Scotians seek out care for mental illness; 2) lack of cultural competence demonstrated by mental health professionals; 3) lack of access to Black mental health providers and other service providers; 4) mistrust of the health system; 5) a fear of police involvement in their care; 6) lack of access to transportation; 7) lack of financial resources; 8) barriers accessing medication and medical coverage; 8) denial by family members that they are suffering from mental illness; and 9) lack the knowledge about and literacy to discuss mental illness and identify and seeking out appropriate treatments for addressing it, which participants attributed to a general lack of education on the topic in schools and in the home. It should be noted that while African Nova Scotian youth are more willing than their parents and older generations of African Nova Scotians to discuss and seek out help for mental illness, many prefer to self-medicate by using drugs and alcohol.

Also discussed by participants were the facilitators and opportunities that enable help-seeking among African Nova Scotian youth, including: 1) identifying existing relationships in the community that can be used to develop community resources for addressing psychosis, rather than relying on the health care system; 2) educating church ministers and other spiritual leaders about how to support people with psychosis; 3) setting up a 311 African-Nova Scotian help line; and 4) hiring a mental health advocate for the African Nova Scotian community. In the following section, a list of recommendations is provided for how the *Your Mind Matters* project can respond to and address the needs of African Nova Scotian youth who are suffering from psychosis.

Recommendations

The recommendations outlined below highlight the issues that need to be considered and the actions that need to be taken by the *Your Mind Matters* project to address the barriers to and enhance opportunities for help-seeking among African Nova Scotian youth, as well as to share information on psychosis and other mental illnesses with these youth and their families.

Addressing Barriers To & Enhancing Opportunities For Help-Seeking Among African Nova Scotian Youth:

- Identify funding to support activities that help foster relationships and partnerships between African Nova Scotian youth and community-based organizations that can support them.
- Create a list of Black health professionals that can be provided to youth.
- Provide transportation money to youth to encourage their attendance at the *Your Mind Matters* educational forum and other events associated with the project.
- Advocate for the hiring of an African Nova Scotian mental health advocate in the health care system who can support youth and families that are dealing with psychosis and other mental health problems.
- Leverage existing community relationships to develop community resources that address psychosis.
- Offer training and education to church ministers and other spiritual leaders about ways to support youth experiencing psychosis.
- Set up a 311 African Nova Scotian help line.
- Partner with community organizations to provide referrals to mental health services.
- Identify key young Black leaders or initiatives that can help spread the word about the need to seek help for psychosis and other mental illnesses.

Sharing Information & Providing Education on Psychosis & Other Mental Illnesses to African Nova Scotian Youth & Their Families:

- Develop partnerships with African Nova Scotian groups, churches, health programs at schools, universities, and other organizations in the community to collaborate with on providing information and organizing workshops on psychosis and other mental illnesses for African Nova Scotian youth.
- Form a youth advisory committee that can organize and hold educational sessions on psychosis for youth.
- Form a group comprised of African Nova Scotian mental health professionals, youth workers, and individuals from the Nova Scotia Health Authority that can hold sessions on psychosis and mental health in African Nova Scotian communities.
- Organize support groups where youth can receive information about psychosis and help-seeking.
- Provide opportunities for African Nova Scotian youth to design their own mental health campaigns.
- Develop creative tools to share information about psychosis, such as an app, videos, plays, art, music, and television ads/educational commercials.

- Share information about psychosis and other mental illnesses to African Nova Scotian youth through social media and other online platforms, such as Instagram, Twitter, Snapchat, Facebook, webinars, the Nova Scotia Health Authority website, and the African Nova Scotian Directory.
- Create brochures and pamphlets to share information on psychosis and other mental illnesses.
- Share information about psychosis and other mental illnesses in the African Nova Scotian community through *Bell Let's Talk* and other media campaigns.
- Organize an event on psychosis in the African Nova Scotian community for African Heritage Month.
- Share information about psychosis at community cookouts or barbecue events that focus on mental health.
- Involve local talent in the delivery of information on psychosis, such as African Nova Scotian mental health advocate Tyler Simmonds.
- Reach out to youth leaders to host information/education sessions about psychosis and other mental illnesses:
 - Session topics should focus on signs and symptoms of psychosis, stress and stress management, stigma, grief, the role of trauma in illness onset, healthy lifestyles, substance use and mental health, available resource for supporting people with psychosis.
 - Black health professionals, pastors, and other community leaders who are close in age to the youth in attendance should be invited to deliver presentations at these sessions.
 - These sessions should include interactive group discussions and first voice stories.
 - The sessions should not be longer than one and a half hours long, and should provide refreshments and incentives (such as a draw for prizes or gift cards) to encourage attendance.
 - The sessions should be held in accessible spaces, such as the Dartmouth Sportsplex, the Family Resource Centre, schools, and community churches.
- Incorporate an Afrocentric approach into the activities, products, and material mentioned above.

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