Addressing Stigma and Promoting Help-Seeking Among African Nova Scotian Youth Experiencing Psychosis and Other Mental Health Problems

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Abstract

Objectives: The purpose of this study was to gain an in-depth understanding of perceptions of mental illnesses (especially psychosis), help-seeking, barriers to help-seeking, and opportunities to facilitate help-seeking in the African Nova Scotian Community.

Methods: A qualitative interpretive narrative approach, using the focus group method, was employed to engage African Nova Scotians in discussions on their perceptions and beliefs about mental illnesses and help-seeking in their communities. Youth in Early Intervention services, their caregivers, youth in the community, their caregivers, community leaders, and health service providers, were recruited from four locations in the Halifax Regional Municipality. A total of 75 individuals (37 female, 38 male) participated in the study. Narrative emplotment was used to analyse data from focus groups.

Results: Findings from focus groups were categorized based on four areas of discussion: (a) perceptions about psychosis and other mental illnesses among youth, caregivers, service providers and community leaders (b) beliefs about help-seeking among youth, caregivers, services providers and community leaders; (c) barriers and facilitators to seeking help for mental illnesses; and (d) the content and format of educational resources to educate and support youth, families and communities.

Conclusions: Stigma surrounding mental illnesses in the community, lack of knowledge of illness and available services, concerns regarding negative involvement with police, or dismissal of difficulties by health care providers represent significant barriers to help-seeking in this community. Additionally, barriers include a lack of trust in health care services and a dearth of African Nova Scotian service providers. Bolstering capacity of community organizations to support and educate individuals around illness as well as fostering collaboration between health services and community organizations could reduce barriers to care. Future research should focus on examining ways to engage African Nova Scotians in collaboration with existing community organizations.

Keywords

first episode psychosis, race, stigma, barriers to treatment, access to care, disadvantaged populations, health disparities, maritimes, qualitative

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Introduction

Despite the exponential growth of early intervention services (EISs) in Canada over the past several decades, there is limited research examining access and pathways to care for ethnic minorities. An individual's ethnicity and racial background have the potential to influence their experiences with health care. In the field of early intervention for psychosis, existing research suggests that Black individuals differ from other patients in their pathways to care and help-seeking experiences. When compared to white patients, Black patients with psychosis are more likely to access EIS through referrals from emergency psychiatric services[1–3] and are more likely to be brought in by police and ambulance services.[1, 4] Outside of emergency services, Black individuals with psychosis are twice as likely to have police involvement in their pathway to care.[3] In the Canadian context, these trends have been suggested to be due to Black patients experiencing delayed help-seeking, which results in the exacerbation of symptoms and increased need for urgent psychiatric interventions.

Related to this, research in Canada and elsewhere has found that Black individuals experiencing early psychosis, have fewer overall contacts on their care pathway[2] and are less likely to have had contact with general practitioners (GPs) prior to being referred to EIS.[1–3] Black individuals' increased likelihood of having pathways to care that involve emergency services and law enforcement, as well as their decreased likelihood of having GP involvement in pathways appear related: Black individuals may have negative attitudes towards primary care, as well as reduced access to family physicians when compared to other racial groups.[2, 5] Having access to a primary care provider could indicate a larger social network and greater organization of social supports available.[6]

Given these findings, and the identification of the goal "to ensure timely and equitable access to a continuum of safe quality care and supports." for diverse populations in Nova Scotia, including African Nova Scotians, there is a need for research outlining this community's mental health experiences and their experiences accessing mental health services.[7] In fulfillment of this need, the current study used a qualitative methodology to examine four domains relevant to African Nova Scotians' attitudes towards help seeking and mental illnesses: (a) perceptions and beliefs about psychosis and other mental illnesses among African Nova Scotian youth in the Halifax Regional Municipality (HRM); (b) perceptions and beliefs about help-seeking among African Nova Scotian youth in the HRM; (c) barriers, opportunities and facilitators experienced by African Nova Scotian youth seeking help for mental illness; and (d) preferred content and format of educational resources and 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.

There are 21,915 African Nova Scotians residing in Nova Scotia. They represent the largest racially visible community, constituting 2.4% of the total Nova Scotian population.[8] There are 48 African historical settlements across Nova Scotia. The geographic distribution of these settlements is indicated in Figure 1, created by the Nova Scotia Museum[9] (Figure 1).

Method

Setting and Participants

Six categories of participants (total $n = 75$) from four locations in the HRM were recruited to take part in focus groups: (1) youth in recovery, experiencing early psychosis, and their caregivers at the Nova Scotia Early Psychosis Program (NSEPP) ($n = 4$); (b) youth, caregivers, community leaders and service providers in Dartmouth North ($n- = 29$); (c) youth, caregivers, community leaders and service providers in The Prestons ($n = 25$); (d) youth, caregivers, community leaders and service providers in North End Halifax ($n = 17$) (Gottingen Street). Table 1 shows a detailed breakdown of participant characteristics.

African Nova Scotian youth in recovery at the NSEPP were recruited to share their lived experience with help-seeking, their knowledge of the factors which helped or hindered that process, and their perspective 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 illnesses, help-seeking, knowledge of psychosis, as well as their suggestions regarding the preferred format for youth education related to mental illnesses and help-seeking. Since African Nova Scotian families raising youth in the community often facilitate help-seeking, it was important to recruit them to obtain their perspective on mental illnesses and psychosis, stigma, help-seeking, level of knowledge about psychosis, and their perspectives on 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 in African Nova Scotian communities were recruited to obtain insight into their experiences providing mental health services to African Nova Scotian youth. As perspectives from 6 differing groups were of
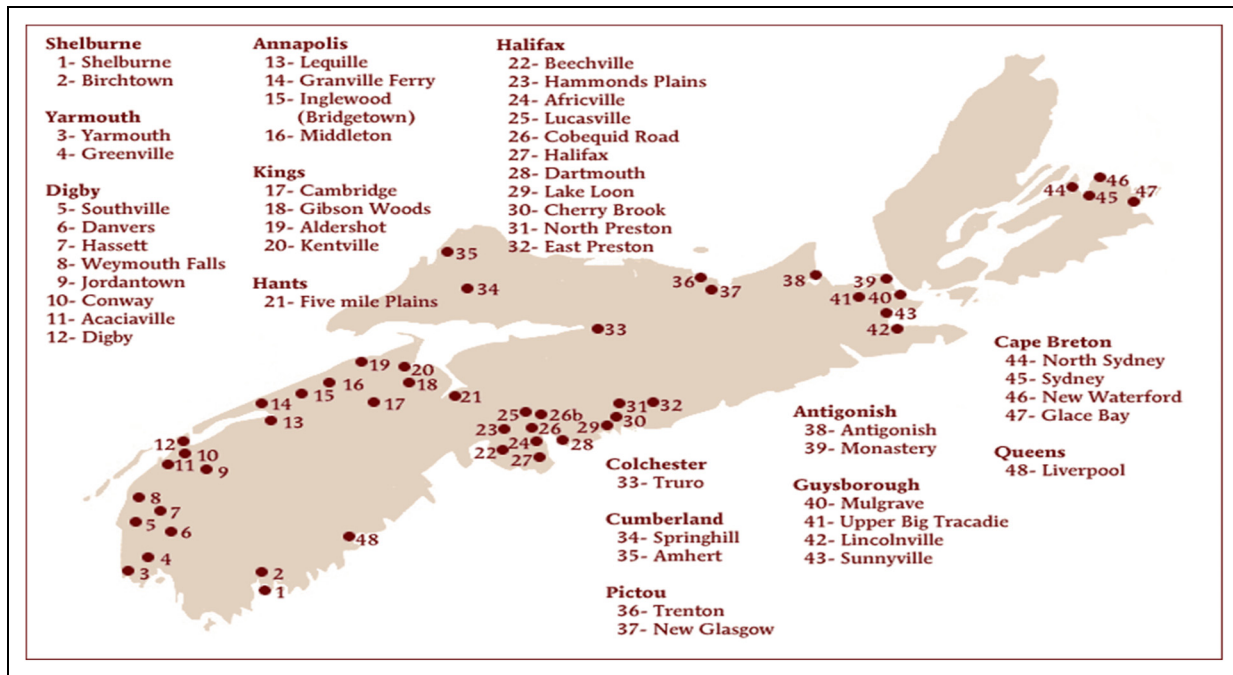
Figure 1. Geographic distribution of historic African Nova Scotian settlements.

Table 1. Sample Characteristics Breakdown by Location, Role and Gender, *n* = 75.

Location	Sample characteristics
Dartmouth North (*n* = 29)	Caregivers: (*n* = 7) (5 female; 2 male)
	Community leaders (church/community) (n = 8): (6 male; 2 female).
	Service providers (*n* = 7): (5 female; 2 male)
	Youth: (*n* = 7) (6 male; 1 female)
North End, Halifax (Gottingen Street) (*n* = 17)	Caregivers (*n* = 5): (5 female)
	Community leaders (church/community) (*n* = 6): (3 female; 3 male)
	Service providers (*n* = 2): (2 female)
	Youth (*n* = 4): (2 female; 2 male)
Nova Scotia Early Psychosis Program (*n* = 4)	Families (youth in recovery) (*n* = 1): (1 female)
	Youth in recovery (*n* = 3): (1 female; 2 male).
The Prestons (*n* = 25)	Community leaders (church/community) (*n* = 8): (4 female; 4 male)
	Service providers (*n* = 6): (6 female)

interest in this study, efforts were taken to recruit sufficient numbers of each group to reach data saturation and to obtain a rich and detailed perspective from a diverse range of relevant stakeholder groups.

To be eligible to participate in the study, youth in community focus groups were required to be between 18 and 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. Youth in recovery, family caregivers, 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 service providers were required to live in, work, or provide services in the African Nova Scotian community. Approval to conduct this project was obtained from the Dalhousie University research ethics board.

Data Collection and Analysis

Prior to interviews, eligible participants provided informed written consent to participate. Following this, they were placed into 1 of 14 focus groups, comprising a maximum of 8 participants. Focus groups were split by geographical location. Focus groups for the youth in recovery and caregivers for youth in recovery took place at the NSEPP. Focus groups for African Nova Scotian youth, caregivers, community leaders and service providers were conducted in their prospective locations. A semi-structured focus group guide

Table 2. Sample Analysis Template With Themes Used to Analyse Qualitative Data.

Themes for Analysis	Perceptions and beliefs about psychosis and other mental illnesses among African Nova Scotians	Perceptions and beliefs about help-seeking among African Nova Scotians	Content and format of educational resources and other educational activities
Participant categories			
Youth in recovery from psychosis			
Caregivers of youth recovering from psychosis			
Youth who may or may not have accessed mental health services			
Caregivers			
Community leaders			
Health and mental health service providers			

was used to facilitate the discussions, which were audio-taped and transcribed.

An interpretive, narrative approach guided the design of this study and was used to collect and analyse the data.[10, 11] This qualitative approach involves data collection methods that enable participants to articulate, define and give meaning to their experiences. Polkinghorne observes that narratives are the "primary scheme by means of which human existence is rendered meaningful" (p 11).[10] 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.[10] 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. The transcripts were then analysed based on these themes. 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.[12, 13] 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. 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.

Three investigators were responsible for analysing the data in the transcripts based on themes that arose from the 4 study domains listed earlier. Each of the 3 investigators were responsible for coding and analysing the transcripts for 2 of the 6 participant categories. Headings based on themes were included in a separate document and data (including relevant quotes) in the transcripts that reflected each of the themes for analysis were copied from the transcript and then pasted into that separate document, starting from theme 1 to theme 4. Once each investigator completed her/his analyses, their documents were combined into 1 master document that was used to write this article and future articles. Table 2, provides a sample of the analysis template and themes for analysis that were used.

Results

The following 4 themes based on the research objectives and focus group guide were prominently discussed by participants: (a) perceptions and beliefs about psychosis and other mental illnesses among African Nova Scotian youth in the HRM; (b) perceptions and beliefs about help-seeking among African Nova Scotian youth in the HRM; (c) barriers, opportunities and facilitators experienced by African Nova Scotian youth seeking help for mental illnesses; and (d) the preferred content and format of educational resources and other educational activities to educate youth, families and communities about early stage psychosis.

Perceptions and Beliefs About Psychosis and Other Mental Illnesses Among African Nova Scotian Youth in the HRM

When asked about their perceptions and beliefs about psychosis and other mental illnesses, youth shared that there was a high level of stigma including labelling of individuals with mental illnesses 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 illnesses, as well as denial of its existence. Patients living with psychosis shared that there is a tendency for African Nova Scotians to view mental illnesses as weaknesses, or as challenges that do not affect the Black community. One youth in recovery at the NSEPP commented:

> 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.

Additionally, family participants reported that a general lack of knowledge and understanding contributed to negative perceptions, lack of acceptance, and denial of mental illnesses. Community leaders and service providers had similar observations; Uncertainty that youth can recognize having mental health concerns was also voiced. While they described stigma and shame around mental health to be common, community leaders did express beliefs that stigma was decreasing. One community leader commented:

> 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.

Perceptions and Beliefs About Help-Seeking Among African Nova Scotian Youth in theHRM

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 illnesses. Multiple caregivers expressed concerns that there was a reluctance to seek help because of a lack of safe places to go. Related to this, caregivers also described mental health being neglected and help-seeking avoided out of fear that the police would become involved. One caregiver commented:

> 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, in the event, you know. 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's no safe places that we can go.

Community leaders expressed concerns that instead of seeking help, youth engaged in self-medication. Service providers described concerns that youth are often not knowledgeable about the appropriate treatments they should seek

out. Concerns were also raised by community leaders and service providers that a sole reliance on church/spirituality has impeded help-seeking among community members who perceived a religious/moral framework as more acceptable 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. 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.

Barriers, Opportunities and Facilitators Experienced by African Nova Scotian Youth in Seeking Help for Mental Illnesses

Participants identified the following barriers to help-seeking among African Nova Scotian youth: lack of access to Black service providers, lack of financial resources, lack of knowledge and understanding of mental illnesses, and a cultural emphasis on personal strength and self-reliance. A youth in recovery at the NSEPP, described difficulty accessing medications as a common challenge for African Nova Scotian Youth:

> But I think access to medication. 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 as well.

Reference was also made to the lack of comfort with and trust in the health system and health providers and long wait times. Community leaders indicated that the following barriers, facilitators and opportunities influence help-seeking among African Nova Scotian youth: the belief that mental illnesses can be addressed through church attendance and religion only; concerns that mentally ill people in the African Nova Scotian community tend to be addressed through negative interactions with police, rather than with the mental health system; the lack of Black and other racialized mental health professionals; the dismissiveness of health care professionals when African Nova Scotians seek out care for mental illnesses; denial that a loved one is suffering from a mental illness; and the lack of education about mental illnesses in the African Nova Scotian community. Participants identified the facilitators and opportunities for improved help seeking to be: existing relationships and organizations in the community that can support people with mental illnesses rather than relying on the health care system; educating church ministers and deacons on how to support people with mental illnesses; setting up a 311 African-Nova Scotian help line; and hiring a mental health

advocate for the African Nova Scotian community who can collaborate with mental health services. One caregiver echoed the above points suggesting that there was a lack of access to Black service providers and services within the community with whom youth feel safe and comfortable sharing their mental health concerns with:

> African-Nova Scotian communities need to have those people and those resources on site right there. And like [participant] said earlier, you know, 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. And it's very important that they do. 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.

Content and Format of Educational Resources and Other Educational Activities

Participants shared suggestions for the content and format of resources to educate youth and communities about early-stage psychosis, promote help-seeking and self-care, and reduce the stigma around mental illnesses. Youth recommended that education be delivered using virtual resources including Instagram, Twitter, videos, or through the creation of an app. They also suggested that brochures and pamphlets, educational sessions in schools and the community, and interactive group discussions be developed to engage African Nova Scotians. They suggested that the content should include information on the signs and symptoms of psychosis, stress and illness, stigma, grief, the role of trauma in illness onset, substance use and mental health, and how to support individuals in seeking help. Youth also recommended that the delivery of information include Black health professionals, pastors and other community leaders, and that presenters at educational sessions and other events on mental illness in the community be close in age to the youth. Obtaining the perspective of youth and using a peer-to-peer approach was considered important for one caregiver:

> 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.

Community leaders indicated that information on psychosis and help-seeking should be shared with the African Nova Scotian community in varied ways to maximize the reception of valuable information. Leaders suggested providing information through written material such as brochures and creative approaches such as plays, art, and videos. They emphasized the importance of making resources available locally by hosting gatherings that focus on mental health at community organizations. They also suggested creating a community forum where presentations focused on mental health are delivered, and participants can ask questions. Finally, leaders stressed the need for effective community outreach by health services, especially for those who do not have access to technology. A community leader suggested that a group comprised of African Nova Scotian mental health professionals, youth workers, and individuals from Nova Scotia Health 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 Nova Scotia Health 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.

Discussion

To our knowledge, this is the first qualitative study and perhaps the first study of any kind focusing on the mental health needs of African Nova Scotian youth. Narrative accounts from focus groups suggest several barriers to accessing care for this community. Perceptions and beliefs about mental illnesses among African Nova Scotian youth and the African Nova Scotian community, suggest that the stigma surrounding mental illnesses in this community is a significant barrier to help-seeking. In general, the African Nova Scotian community tends to avoid the topic of mental illness or deny its prevalence in the community. There was also considerable lack of knowledge and understanding of mental illnesses, which can be attributed to the lack of education on the topic in schools or in conversations in the home.

Beliefs about mental illness among African Nova Scotian youth greatly influence their attitudes about seeking help for and coping with mental illnesses. There is a general sentiment in the community that it is challenging to access safe spaces where people felt comfortable sharing their struggles and needs. In addition, a culture of self-reliance and strength among African Nova Scotians was suggested to discourage help-seeking behaviors. A fear of negative police involvement in their care also contributed to a reluctance to seek

treatment and a dismissal of the gravity of mental health concerns in the African Nova Scotian community. These findings reflect the findings in other studies. For example, Taylor and Kuo (2019) found that stigma and double stigma are significant factors influencing help-seeking behaviors for mental illness among African Americans, and that in both the United States and Canada, Black communities hold 3 main culturally determined beliefs about mental illness: Black people are not affected by mental illness; Black people must always show strength, regardless of the circumstances; and 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.[14] 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 forwarded as some of the most common reasons why African American women underutilize mental health services.[15] 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.[15]

For many African Nova Scotian youth in this study, 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 were discussed as impediments to help-seeking. And, while African Nova Scotian youth are becoming more willing to discuss mental illness, they often lack knowledge about appropriate and available treatments.

Participants also discussed the barriers to help-seeking among African Nova Scotian youth, including lack of access to Black service providers, lack of access to transportation, lack of financial resources, barriers accessing medication and medical coverage, and lack of knowledge and understanding about mental illnesses. Many participants also discussed a general lack of trust in the health system and a lack of comfort with health providers. Youth identified that the common dismissiveness of health care professionals when African Nova Scotians seek out care for mental illnesses, and the lack of education about mental illness in the African Nova Scotian community remained barriers to help-seeking.

The lack of cultural competency demonstrated by mental health professionals was also a significant barrier to youth seeking help. One community leader noted that 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:

> 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.

A youth pastor 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.

Participants suggested several potential opportunities for and facilitators of help-seeking. These included the relationships that exist in the community that can be used to further develop community resources to address mental illnesses instead of relying on the health care system, educating church ministers and other spiritual leaders about ways to support people with mental illnesses, setting up a 311 African-Nova Scotian help line, and hiring a mental health advocate for the African Nova Scotian community.

Conclusion

In conclusion, results from this study suggest that attitudes and perceptions towards mental illness and help-seeking

among the African Nova Scotian community pose barriers to accessing services. Although reasons for differential rates of unmet needs, decreased help-seeking and increased rates of accessing care via emergency services in Black Canadian communities remain complicated, this study was the first to identify how beliefs in the African Nova Scotian community about mental illness, and how perceptions towards health care may be relevant to these disparities. Results from focus groups provide researchers and health services with several actionable findings to attempt to address these disparities. Future research should aim to implement recommendations shared by participants in this study and to evaluate their effectiveness in improving outcomes in this population.

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