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Title

The African, Caribbean, & European (ACE) Pathways to Care Study: How stigma operates in defining differences in pathways to care for psychosis.

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Abstract

Objectives: An inductive qualitative approach was used to examine differences in entering into first-episode psychosis (FEP) programs between young people from African, Caribbean, and European origin.

Setting: Ontario, Canada.

Participants: 35 participants in total. 26 young people who experienced a first episode of psychosis and nine family members. Participants were part of the African, Caribbean, and European (ACE) Pathways to Care Study.

Results: Factors that influenced help-seeking delays across the three groups were: personal awareness of symptoms, family members' knowledge of psychotic symptoms, and knowledge of mental health services. Youth and their family members described how stigma plays a key role in pathways to care by stopping them from asking for help. The way in which stigma operated among the three groups, from feeling ashamed to feeling guilty for their mental illnesses, helped to explain differences in DUP between the groups. Guilt feelings emerged as a prominent theme among members from the African and Caribbean groups; and it was not discussed in the European focus group. Delay in entering into first-episode psychosis (FEP) programs was also influenced by the stigma perceived by young people in health care settings. This had an impact on the therapeutic relationships, disclosure of symptoms, and overall trust in the health care system.

Conclusions: The findings of this paper suggest that stigma, especially internalized stigma, may operate in different ways in European-, African-, and Caribbean-origin groups. This could explain the differences in the pathways to early intervention services for psychosis for these young people. These findings could inform the development of more equitable services for people in early stages of psychosis.

Keywords: First-episode Psychosis; Pathways to Care; Duration of Untreated Psychosis; Stigma; Ethnicity.

Strengths and limitations of this study

1. This paper reports a qualitative exploration of the reasons for differences in pathways to care and DUP between African-, Caribbean-, and European-origin groups.
2. The findings suggest that stigma, especially internalized stigma in African-, and Caribbean-origin groups, seems to explain differences in pathways to care between the three groups.
3. Delay in entering into first-episode psychosis programs was also influenced by the stigma perceived by young people in health care settings. This had an impact on the therapeutic relationships, disclosure of symptoms, and overall trust in the health care system.
4. Findings from this study could be sued anti-stigma initiatives and sensitivity training for key-players (e.g., general practitioners, emergency staff, police). Those initiatives should be developed through the lens of cultural knowledge of and beliefs about mental health problems.
5. The sample size in this study was relatively small; only limited inferences can be drawn for other groups.
6. The sample size was defined from the quantitative part of the study. We were not able to involve any family members of African origin as our original pool of participants was very small.

Introduction

Psychotic disorders affect 1–2% of the population and are associated with a significantly shorter life expectancy and an increased risk of self-harm and violent victimization [1-8]. Members of immigrant groups have been reported to be at an increased risk of psychosis. A number of factors are considered to be contributory, such as social deprivation and disorganization, separation from parents, and the experience of discrimination [9-13]. The Canadian literature has reported differences in the use of services by members of immigrant groups [15-16]. There are barriers to getting care for many immigrant groups [15]. Both the Canadian and international literature has investigated differences in pathways to care and service use, and outcomes for people of Caribbean- and African- origin with psychosis [14,15]. A longer duration of untreated psychosis (DUP) and more coercive care pathways have been reported in the African- and Caribbean-origin groups in Ontario [16]; both these factors are associated with poorer outcomes [9-15].

The African, Caribbean, and European (ACE) Pathways to Care Study investigated pathways to care and the duration of untreated psychosis (DUP) in African-, Caribbean-, and European-origin groups in Ontario, Canada. The study identified differences in the pathways to first-episode psychosis (FEP) programs between the three groups. The median DUP was seven months for the European group, nine months for the African group, and 16 months for the Caribbean group. Caribbean participants in the study had fewer health services/providers in their pathways to care, they more often accessed FEP programs from an in-patient admission, and they faced more obstacles in their access to specialized treatment for psychosis than the

European group. African group members in the study more often had an emergency department as first contact in their pathways [17].

Once disparities have been identified, understanding of the reasons why they may exist is necessary if we are to develop effective services. This paper reports a qualitative exploration of the reasons for differences in pathways to care and DUP in the ACE Study from the perspective of respondents to the study and their families. The aim was to understand differences in DUP between African-, Caribbean-, and European-origin groups. To do so, we explored young people's and their family members' journeys of seeking help for psychosis, investigating how people responded to early signs of psychosis as well as the roles that different people and services played in accessing specialized programs for psychosis.

Methods

This study used an inductive qualitative approach to examine differences in the routes to care between young people with lived experience of psychosis of African-, Caribbean-, and European-origin. Focus groups were used as a means of generating in-depth knowledge of pathways to care, exploring the interaction between individual socio-cultural positions, young people' experiences of seeking help, and group dynamics—as each participant's narrative is generated out of the journeys of others. By using focus groups we were able to examine how participants (1) interacted with each other; (2) produced and reproduced knowledge; and (3) articulated and/or defended their views [18].

Participant Recruitment

Ethics approval was obtained from the Research Ethics Board (REB) at the Centre for

Addiction and Mental Health, as well as from the REB at each participating hospital site of the ACE Study.

Our groups were based on the categories developed by the Toronto District School Board. Respondents were asked to choose which racial or ethnic group best reflected their identity (see Anderson et al. for more information) [17]. Participants who took part in the ACE Study's semi-structured interviews were asked if they were willing to be re-contacted. Only those who agreed were approached for the qualitative study. They were asked if they would take part in a two-hour focus group to discuss the results of the study. Participants' family members were also contacted and asked if they were willing to take part in a separate focus group.

Six focus groups with young people were envisaged: one male and one female group for each of the African-, Caribbean-, and European-origin groups. Three focus groups were organized for the family members, one for each of the African, Caribbean, and European groups. Because of difficulty recruiting for the African and Caribbean women's groups, we adjusted the study protocol and undertook individual in-depth interviews with young African and Caribbean women with lived experience of psychosis. The protocol change allowed us to have a small, but important, representation of women from these two groups.

Data collection

Focus groups were conducted by the first author, MF, who acted as focus group moderator, and research assistants who were trained in focus groups, transcribing, and qualitative data analysis for the purpose of this study. Focus group questions were designed to be conversational, open, and clear. They unfolded according to Krueger and Casey's recommendations: opening, introductory, transition, key, ending [18]. At the end of each focus group, the research team involved in the focus group completed 30–40 minutes of debriefing. During the focus groups, participants were presented with preliminary ACE Study quantitative data; we focused on the differences in DUP as well as pathways to care and asked participants to comment on them.

Focus groups and in-depth interviews were digitally recorded. The digital audio files were transcribed by the research assistants and reviewed for data accuracy. One research assistant transcribed a focus group and the other reviewed the work done. Finally, all material was also reviewed by MF. Focus group transcripts were then prepared to facilitate thematic analyses. All participant names were changed to pseudonyms to ensure confidentiality.

Traditional data saturation, that is, "collecting data until no new information is obtained," [19, p. 147] is often an object of controversy in qualitative research literature [19]. We used instead Morse's criterion of data saturation as "adequacy" of the data, which can be obtained through specific methodological choices. These methodological choices were (a) selecting and working with an ethnic- and gender-cohesive sample; (b) at the same time, working with three different ethnocultural groups so as to maximize and explore cultural contrasts in pathways to care—a gap in current literature; and (c) basing our sample on quantitative data analysis, which allowed focus-group member checks on the quantitative findings, as well as the possibility for rich, full, and complete understanding.

Finally, Lincoln and Guba [20] defined primary criteria to assess rigour and trustworthiness of the qualitative research process. Primary criteria—credibility, authenticity, criticality, and integrity—are necessary to all qualitative enquiry but they are insufficient in and of themselves. Trustworthiness was achieved within the study through the following criteria: *credibility* and *authenticity*, attained through multiple sources of data (e.g., pathways maps generated from semi-structured interviews, chart reviews, focus groups' data) as well as specific and different sample strategies being employed to generate rich and meaningful data; *criticality* and *integrity,* using team debriefing and analysis to ensure methodological effectiveness.

Analysis

Thematic analysis was employed to identify, analyze, and report patterns or themes within data [20]. Our thematic analysis was data driven, rather than theoretically driven, making use of an inductive approach, as the themes identified were strongly linked to the data themselves. We followed Braun and Clark's steps [21] of thematic analysis. We compared each participant's journey to care (shared during the focus group), the pathway depicted during a semi-structured interview, and the participant's medical chart. Further, we performed an analysis within each ethnic group, comparing and contrasting young people's narratives with those of family members, and a cross-ethnic-group analysis. As a result, in the study findings we describe themes that were common across all the narratives as well as the ones that were different between the three ethnic groups.

Results

Overview of the sample

A total of 35 people took part in the study; 26 young people with lived experiences of psychosis (origins: European = 17, African = 5, Caribbean = 4) and nine family members (origins: European = 6, African = 0, Caribbean = 3). Table 1 reports the socio-demographic information for young people with lived experiences of psychosis only –no socio-demographic information were collected for family members at the time of the focus group.

Findings are presented in two main sections: (1) *Understanding help seeking*, in which we first present commonality across the three groups, and then we investigate differences in DUP between African-, Caribbean-, and European-origin groups. In this section we unpack the role of stigma and how it operates early on in pathways to care. In this paper, stigma refers to a collection of negative attitudes, beliefs, and behaviours against people with mental disorders, which are manifested in rejection, avoidance, prejudice, and discrimination of people with mental illness conditions [22.24]. Stigma can be a barrier for people who experience mental health problems by making them reluctant to ask for help due to fear of prejudice, being labelled, and discrimination by others. Internalized stigma, or self-stigma, occurs when a person takes on those negative stereotypes and assumptions and applies them to themselves [23, 24]. Discrimination due to mental health stigma can take place in different circumstances/settings: education, employment, housing, and treatment. (2) *Understanding delay in entering first-episode psychosis (FEP) programs*, which explores the relationship between negative experiences, stigma, health care delivery, and illness/symptoms disclosure. The themes presented in this section are also common across the three groups. All young people's and family members' names used in this paper have been changed to ensure participants' confidentiality.

Understand help seeking

Common across the three groups: Knowledge, awareness, and mental health stigma

Consistent across all narratives, for both young people and family members, was that knowledge or lack of knowledge about symptoms of psychosis, mental illness, and services available to them was key to them recognizing the significance of changes in behaviour. Often this knowledge was based on family members' or friends' past experiences of mental illness.

> Maria: The one person who really helped me to realize what I'm going through, and that I need help, is my mother. She knows what I'm going through because she went through it with my father. She helps me a lot …
>
> (European youth focus group)

Young people who did not have any knowledge of signs or symptoms of psychosis were aware of personal changes but did not know that they were indicative of mental illness. In these cases, family members played a key role in the help-seeking process by taking them to the hospital.

> Benjamin: I was schizophrenic, and I didn't know what to do. I heard voices and stuff. I did some stuff that I couldn't remember, so some people took me in-
>
> Paul: I kept hearing … weird voices, but I didn't know what is. So, later on I came … my parents took me to the hospital …
>
> (African youth focus group)
>
> Steve: I didn't know that I needed help. I had no one around me who knew what was happening. … I was staying with a friend, my mom was occasionally stopping by … she saw certain signs in me, and she immediately drove me to [name of the hospital].
>
> (Caribbean youth focus group)

> June: I wouldn't have stayed in the emergency room, I wouldn't have gone by myself … I didn't know what was going on. … I didn't know *I was going crazy*, … I thought everybody was against me.
>
> (European youth focus group)

Young people and family members who did not have awareness or knowledge of the signs or symptoms of psychosis struggled the most to understand and/or make sense of the situations.

> Janine: I didn't know what this illness was. I thought it was just some kind of behaviours, being angry or strange like teenagers could possibly experience sometime … it was people from the outside who used to tell me ''No this more than just … you know teenager's crisis.'' Not knowing [the] symptoms … I just didn't know what was going on really.
>
> (Caribbean family members' focus group)

> Louise: My son was 17 when he had his psychotic break. I thought he was just being a typical rebellious teenager … he smoked pot. He didn't get violent. He was so scared and I didn't know what else to do with him. I took him to (name of general hospital) … after about 15 hours convincing them that I was not taking him home, they admitted him.
>
> (European family members' focus group)

Often, family members attributed the changes in their relatives' behaviour to growing up/going through adolescence, peer groups/wrong crowds, stress, and/or substance abuse in young adults. Family members often thought that what their relatives were experiencing was just a temporary phase in their relatives' lives without recognizing signs or symptoms of psychosis. Help seeking often occurred after doubting the early signs of psychosis and, most importantly, after feeling sadness and discomfort.

Along with knowledge and awareness of signs or symptoms of psychosis, the role that stigma played during the help-seeking process was also constantly present in the narratives.

Through the analysis conducted, it was possible to identify how individual and family perceptions of mental illness influenced the internalization of stigma. For example, young people involved in the study often distinguished between their rational understandings of the mental health problems, symptoms, and causes, and, at the same time, their feelings of being trapped in emotions such as shame.

> Karen: People are scared to look for help, and to …
>
> Maria: And to admit to themselves even ... [Karen: Yeah!] that "I have schizophrenia"… I never told anybody.
>
> June: I'm still ashamed of what I have.
>
> Samantha: Me too.
>
> (European youth focus group)

Participants described how, for fear of family members' and/or friends' reactions to their conditions, they tried to ignore the signs and symptoms by, for example, using marijuana, and attempted to hide their symptoms from others.

> Sandi: I was worried about what people around me might say … once you're in the hospital you can't really keep your secret anymore. There is a huge stigma about mental illness; people tend to like to avoid it.
>
> (European youth focus group)

Positive symptoms (e.g., hearing voices, bizarre behaviour, violence) were often catalysts to treatment initiation. Family members often struggled to recognize when their relative was no longer able to care for himself/herself or when he/she was asking for help as the symptoms of psychosis took over his/her ability to make decisions. This created quite a complex situation where family members felt threatened or worried about their safety and, at the same time, guilty when they had to call the emergency department, ambulance, or, unfortunately, the police. This was evident in family members' narratives.

> Natali: I have been there … I couldn't stop crying for days … when my daughter finally broke down at school ... being scary violent with us. … the first time she finally did get to the hospital that day [name of the hospital] … It was almost like a relief, she was safe and she was away from us … because we were scared. We were so afraid. [Sarah: (overlapping) Yes. Yes. Yeah.]
>
> (European family members' focus group)

Stigma was also closely connected to how much the person who experienced psychosis was considered responsible for his/her mental condition or was in control, or not, of his/her symptoms. Family members recognized that mental illness is not perceived the same as other health problems. Physical disorders, such as cancer, generate compassion in extended family members, whereas mental disorders bring reactions of distancing, blaming, and stigmatizing from members of the extended family.

> Natali: Unfortunately, I still see … my family members not so supportive. On the surface, they are, but I see them shy away from my son. I see the stigma, it is still so much there. If she was (clears throat) you know physically ill they would be right there.
>
> (European family members' focus group)

Overall, family members described how psychosis is hidden until it manifests through a person's behaviours. It is difficult to understand what is happening to the person as well as to assess if, when, and how to intervene.

<u>Differences in help seeking between the three groups: Internalized stigma as feeling shame versus feeling guilty for their own condition</u>

Participants of European origin internalized mental health stigma as shame about their symptoms (e.g., hearing voices, unpredictable or bizarre behaviours in front of family and friends, or irrational actions). They felt distress caused by the awareness of their past bizarre behaviours and a sense of humiliation for their conditions. In contrast, young people from African- and, even more, Caribbean-origin groups stressed their responsibility for their conditions, they felt that they committed something wrong (for having an mental illness), and a sense of failure for not being able to “snap out of it”—as a participant described during a focus group. In this sense, they seemed to internalize mental health stigma as guilt—there is shame and humiliation but also they felt that they had done something wrong

> Paul: … there was a lot of pressure to excel in school and succeed. I dabbled too much in, dabbled too much in drugs, that was my problem … that was really my fault. I have no one else to blame but myself … people expect you to just walk it off kind of thing. But you really, you really can’t, you can’t really walk off a mental illness … you can cope with it.
>
> (African youth focus group)
>
> Steve: Going through a mental illness totally flipped the way I view … everything! It’s also made me become more aware of how family members react, and why are they reacting that way. Eventually it is what got me onto the culture of it, my religion, and so forth. I can’t say exactly what it is about the Caribbean culture … but, I can tell, those two things definitely play a factor in it.
>
> (Caribbean youth focus group)

In the African and Caribbean focus groups, participants discussed the role that religion had in shaping their and their families’ perceptions of mental illness and feelings of guilt for their condition—this topic was not discussed in the European focus groups. In some cases, people described how they grew up thinking that mental illness was a sin or God’s punishment. Although they did not think in this way now, they saw how this perception influenced their understanding of early signs of psychosis, the focuses of their paranoid symptoms (in some cases), and, most importantly, their asking for help.

> Suzanne: Well, it made me feel badly because I thought, “Wow. You know, she’s so nervous [mother] about me going to the hospital for help.” It made me feel kind of ashamed that I needed help. And then, my mom called me CRAZY. She didn’t call me mentally ill. She said, you know, “Suzanne is little crazy”… she wasn’t using the right terminology, but that hurt my feelings. Yeah. I guess it made me a little bit reluctant to seek care later on. [Later on in the interview] … in the beginning my mom was like, “Suzanne you need to PRAY more. That’s the problem.” And, I’m like, “No mom, I need medication. I need some help.” Mom said, “It’s ‘cause you’re not praying enough and because you stopped going to church.” And now she’s like, “Suzanne, did you pray today?” And I’m like, “Mom, no I didn’t pray.” And she’s like, “I’m telling you you’ll get better, if you start praying.” She REALLY BELIEVES it. Sometimes I just tell her that I prayed just so she can get off my case. My brother often tell me that my life has gone in this direction because I stopped going to church. … It makes me feel bad. It’s not helpful me to get better.
>
> (Caribbean youth interview)

> Greg: I can’t say everybody but, A LOT of people in my family, and in the community … they become very superstitious. It’s a mind job with Catholicism first of all—and no offense to anybody here who’s Catholic, I am Catholic. Something simple as, as having a mental condition, is not simple in this world anymore, it becomes then, “that person needs to be exorcised, or that person’s got bad demons—”
>
> Steve: (overlapping) Oh, I’ve heard … I’ve heard that, I’ve heard that, to get rid of my voices I have to get an exorcism.
>
> Greg: Yeah.
>
> Steve: That’s what I heard from a friend.
>
> Greg: Like, my mom said that when she was uh, a kid, when she was like 5 or 6, she actually witnessed someone getting exorcised, because of voices in his head and stuff like that.
>
> (Caribbean youth focus group)

As described, African- and, even more, Caribbean-origin young people reported that their mental illnesses were taboos among members of their close or extended families. While young people of African origin had their families around to support their struggles, young people of Caribbean origin who attended the focus groups had no one or only a few close family members. The support networks that could assist them in seeking help were not available.

> Simone: When people in the Caribbean get to know that your child has this issue [mental illness] … the whole family is labelled … from the grandparent right the way down. The family is labelled and you are sort of ostracized. That's why many of us don't want to bring it up to the light … we are in denial that this is not happening to this family. … We, as parents, don't have the freedom to talk about it … because of the stigma that's still attached … we internalize it. When we internalize, we're stressed. We would love to know that there is somewhere that we can go and sit down and talk. We need to unload but we have no place to unload.
>
> (Caribbean family members' focus group)

African- and Caribbean-origin participants described how when they experienced early signs of psychosis they tried to control them and they felt guilty if they were not able to. Their sense of guilt was also connected with cultural interpretation of mental illness as sin, God's punishment, and a taboo illness heavily stigmatized—themes more present in the Caribbean-origin focus group and interviews.

Understanding delay in entering first-episode psychosis programs (FEP)

> Rachel: Now none of these people [university psychological service/psychiatrist] told me about any other resources. ... All I knew was [name of mental health hospital], which was, like, the last resort. … I was in the dark. And then I went to my family doctor, and she was the first person after like 3 months who told us that, "Oh, there's actually an inpatient program at [name of a general hospital], for if you're in an emergency—go there." … So then when I got really bad, I was in the inpatient at [name of a general hospital] and there, it was when I actually found out about a bunch of other resources …"
>
> (European youth focus group)

Participants often recognized changes in behaviours and thinking but they did not always attribute these to a mental illness; however they were active in seeking help, contacting community services (e.g., school or university health services) or their family doctors, if they had one. In reflecting on their pathways, they often felt upset, as early attempts to ask for help were dismissed by providers and/or information was not provided to them.

Negative experiences, stigma and care: First contact, therapeutic relationship, and disclosure of symptoms

Once in the system, groups' differences in the journeys to specialized treatment seemed less present. Before entering into early intervention programs, young people saw between four and six difference health providers/services (e.g., family doctor, emergency, police, detention centre, in-patient unit). As young people described, the care they received (or did not receive) and health care providers' attitudes towards mental illness influenced what they shared about their mental states (e.g., hearing voices, suicidal thoughts) and, overall, their trust in the system. From the first contact with a hospital, the majority of young people involved in the focus groups reported that, if it was a negative experience, it affected their therapeutic relationships, and, generally, their willingness to stay in the system and to return, if needed, a second time.

> Samantha: From my experience there's a lot of stigma and shame surrounding people who have substance abuse problems. Whenever I've been in treatment, there has not been an accepting atmosphere for me to discuss my issues or to make me feel like I'm actually going to get help.
>
> (European youth focus group)

> Steve: Well, I found, like, a number of them [mental health care providers] definitely helped. I feel that the majority of [hospital name] staff definitely does have that, but there are still the ones that can create that negative experience for you when you're already going through a negative experience. … It's funny … you're going through stuff,

> even though your mind's not in the right place, you still remember all the negativity. … [Andy: (overlapping) Yeah.] Yeah. Those are the things that I will always remember, about, [name of the hospital], and dealing with [the staff] at the first time. Like, although they were there to help me, it didn't seem like half had actually studied mental health at all.
>
> (Caribbean youth focus group)

During the focus groups and interviews, participants reported how their experiences of poor quality of care was due to health providers' negative attitudes and behaviours towards mental illness. Indeed, stigma does operate, albeit marginally, in mental health services, such as primary care (e.g., family doctors), emergency departments, in-patient units, out-patient units, and so on and, when present, it seems to be more hurtful than when experienced outside the health care system.

Eight young people who took part in the focus groups had police and detention centres as early contacts in their pathways to FEP treatment. Overall, police officers were perceived to be supportive, helpful, and understanding of the situations. Police officers have the duty to respond to an emergency call, accompany the person to the hospital emergency room, and stay with them until the hospital staff takes over.

> Linda: I did it twice. The first time, I went to the hospital was in an ambulance, and, the second time was … in a police car. I actually found the police were nice. Like, I was in handcuffs [laughter], but I found them to be really nice … they stayed with me until the doctors started seeing me. They didn't judge me, and I asked the one cop if he was married … he was like showing me pictures of his kids. He was just nice.
>
> (European youth focus group)

Three men of European origin had forensic services in their pathways. In these cases, the young men had to stay in detention for several days before they were able to see a judge. During the focus groups they described how they were exposed to verbal and physical violence as well as the trauma of experiencing psychotic episodes while in detention.

> Rob: Well, for me the cops were ok. But, then at the detention centre, I said something really dumb to the correctional officer and … I'm walking … he literally just POUNDS me, he beat the shit out of me. Right there on the ground. I wasn't shaken by it at all because I was psychotic, but like—I don't know, it was really weird. He literally took me from behind and just pounded me. I guess his superior comes in and takes him off me. I guess the cops are ok but the guys in the jail …
>
> Matt: Yeah, I had the same experience. One time, when I was psychotic, my mom called the police on me ... She meant for me to go to the hospital but I got charged by the police with a bunch of things. They sent me to JAIL, and I was completely psychotic … they didn't know what to do with me. They were physical with me, they injected me in the back of my neck with I don't know what medication. They just locked me in a jail cell for probably a month until I was transferred to a medical facility.
>
> (European youth focus group)

It was interesting to notice that men of European origin were able to share these experiences during the focus group, whereas men of African and Caribbean origin just mentioned police involvement in their pathways without elaborating on it. We realized the sensitivity of this topic which, combined with the sense of guilt, probably precluded any further disclosure.

In total, 10 youth had family doctors as first contact in their pathways. Among all focus groups, there was only one case in which referral was made to an FEP program directly by a general practitioner. The majority of them reported to have been misdiagnosed or had their symptoms dismissed by their family doctors.

> Benjamin: ... the family doctor doesn't, uh well, didn't work for me, he thought it was just anxiety, like … anxiety because of school … 'cause I was going into university.
>
> (African youth focus group)

In other cases, a young man and woman described how their family doctor focused only on their substance abuse problem and reprimanded them for their behaviours.

> Steve: I kind of did [went to see my family doctor at first], but, he turned me down flatly, 'cause I was smoking weed. I said, "I thinking, I'm suffering with depression." He asked me if I did drugs, I said that I did smoke weed quite often, and he said stop smoking the weed then "come back and I help you." I never heard about it after that. Next time, I saw him, I had to tell him that, yeah, I was diagnosed with schizophrenia. So, my general practitioner, unfortunately, wasn't able to do anything at the time.
>
> (Caribbean youth focus group)
>
> Jill: I recognized the symptoms but I didn't know the specifics of my diagnosis. I went to the family doctor and explained that I felt that I was being followed and everything. And then he told me, "Okay. You need to stop doing drugs," 'cause I was high on marijuana when it first happened … but [it happened] several time [before] and I just thought it was the pot.
>
> (African youth interview)

It may be difficult for general practitioners to diagnose psychosis early; however, participants felt that they had actively sought help but their requests were misunderstood or dismissed.

When admitted to emergency units or in-patient services, participants described the following negative experiences: being labelled, feeling like a number, feeling no longer a person but an illness, being judged for behaviours/symptoms, and/or being treated like a child.

> Matt: I don't know, how it makes sense, but [hospital staff] were almost like TOO nice … I don't know the word, like, treating you like you're a child … talking down to you. It was NICE, but it didn't make me feel better … other people were nice but, at the same time … made you feel like an equal. I felt like that was important.

> Steve: I think maybe the word you were looking for was “pity.” Like we were treated with PITY [Matt: Yeah.] Yeah. I think that, people think that people with schizophrenia are somehow STUPIDER or something … I don’t think people with schizophrenia are stupid at all.
>
> (European youth focus group)
>
> Robin: They treat you like a number [mumbles of agreement].
>
> Samantha: When I went to the hospital last time ... I was going through a panic attack when I FIRST found out I had schizophrenia, and they, the nurse was like, “Yeah, you’re just faking it, you’re perfectly fine, nothing’s wrong with you.’”
>
> Robin: Yeah.
>
> Samantha: It really, made me not like being in the hospital. I did not want to go back there ever.
>
> Natali: I agree. I think they treat you more like a number. And I think, being treated like a PERSON instead of a number or a case because, if you’re just a case, you’re like “I’m schizophrenic”… you’re not a person, anymore [mumbles of agreement].
>
> (European youth focus group)

According to young people, all of these factors influenced the therapeutic relationship with services and providers and, in particular, affected young people’s disclosures of symptoms—as described.

Discussion

Differences in pathways to care and the duration of untreated psychosis have been reported in some studies of ethnic minority groups. The reasons for these differences are unclear. In this paper, the authors focused on participants’ narrative accounts to investigate the social and cultural contexts of help seeking. In doing so, we were able to further investigate differences between the groups as well as how a number of factors, including stigma, influenced both help seeking and access to specialized programs. We developed preliminary hypotheses about the link between internalized stigma, cultural beliefs about mental illness, and help seeking. At the same time, we discussed how interactions with health care settings shape the experience of asking for help, influencing future engagement with health providers and/or willingness to disclose symptoms.

In our attempt to understand differences in the pathways to care and DUP between African-, Caribbean-, and European-origin groups, we found similarities to other studies that broadly explore help seeking among young people in FEP programs [25,26] and their families [27,29] without focusing on ethnicity. As with our findings, other qualitative works described long and difficult periods from the realization of signs and symptoms of psychosis to the initiation of help seeking [27-31]. Family members' knowledge of mental illness and services available to them was important in dealing with the situations. However, as other studies described, family members often mistook early signs of psychosis—especially in the prodromal phase of the illness—for mood changes due to adolescence, social withdrawal, stress, or drugs [25-29]. At the same time, even if the young people who took part in our study, recognized changes in themselves, they did not attribute these changes to mental illness—as was also described in other studies [25,29,31]. Moreover, as we discussed, because of the associated stigma, young people and family members engaged in denial, avoidance, and hiding of early symptoms of psychosis.[25-31]

In *Stigma*, Goffman [22] defined and discussed stigma as *discredited* versus *discreditable*; in the first case, a visible and physical mark defines stigma, where, in the second, no visible or physical mark is present—as is the case with the stigma of mental illness. More recently, further theories have been developed and used to understand the relationship between stigma and mental illness (see Link & Phelan [23], and Corrigan [24]). In all of these theories, stigma is based on signs that define who is different, stereotypes about the person or group, marginalization, avoidance, discrimination, fear of what or who is different—where normality and abnormality or similarity and difference are defined by socio-cultural norms and beliefs. Furthermore, internalized stigma seems more distractive and harmful for the affected person's health and, broadly, for his/her sense of self [32].

Several studies investigate stigma and mental illness [32,33]. Stigma about mental illness is prevalent in the general public but, unfortunately, occurs in health and mental health settings as well [32,33]. Work done in the Canadian context recognizes the role of stigma in seeking help for mental illness in immigrant and refugee groups in Canada. The *Improving mental health services for immigrant, refugee, ethno-cultural and racialized groups: Issues and options for service development* report describes how immigrants, refugees, and racialized groups are less likely to ask about mental health systems because of possible stigma and this leads to people either not getting treatment or to a delay in getting treatment [15]. Other studies describe the specific needs and issues that immigrant groups are facing in relation to mental health services in urban settings in Canada [34,35]. These studies, which were conducted with West Indian immigrants in Montreal, focus on cultural beliefs in non-medical interventions as the preferred form of treatment for mental illness (e.g., prayer or traditional folk medicine) or on the perception of primary care (e.g., doctors often prescribing pharmaceutical medications, or lack of time from physicians in early encounters that deterred the use of current health services) [34,35].

There are similarities but also differences with our findings compared to other studies. This paper describes how stigma operated on young people and family members of African, Caribbean, and European origin and how it influenced the help-seeking process. Although all young participants internalized stigma as shame, and they feared lifelong discrimination for their mental health conditions, those of African and Caribbean origin also internalized a sense of guilt for their conditions. As mentioned, Caribbean young people described the role of cultural beliefs about mental illness and of religion in delay in getting treatment. African and Caribbean young people were able to distinguish the difference between their own beliefs about mental illness and those of their cultural groups. They were critical of traditional cultural beliefs, that see mental illness as a sin for which praying to God is a solution. However, the stigma has been internalized as guilt, which influenced their decisions to seek help. It could be that young people of Caribbean origin waited longer to ask for help as a way to protect their families from being labelled with a taboo illness; future studies are needed to verify this hypothesis. As family members of Caribbean origin described, there is a desire and need to find a space and place to bring to light these issues: "We need to unload but we have no place to unload."

Although the analysis presented in this paper helps in the understanding of some of the differences in DUP between African-, Caribbean-, and European-origin immigrants, we recognize that this work has some limitations, listed in Table 2. We were able to ask to both young people and family members for possible strategies which could be used to support people in the help-seeking process and for ideas about how the system of care could be improved (see Table 3). All participants described the importance of anti-stigma initiatives in different settings (e.g., schools, universities, primary care services/providers) and targeted to different groups. Based on our findings, such initiatives should be developed through the lens of ethnocultural knowledge of and beliefs about mental health problems.

Conclusion

The findings of this study suggest that stigma, especially internalized stigma, operates in different ways in European-, African-, and Caribbean-origin individuals and that this could explain the differences in the pathways to early intervention services for psychosis for these young people. These findings could inform the development of targeted anti-stigma campaigns as well as the implementation of more equitable services for people in early stages of psychosis. To do so, trust needs to be redefined and gained between ethnocultural groups and mental health researchers/providers both in research and in clinical practice. Implementing a community-based participatory framework could help to achieve this goal.

Contributorship statement KM contributed to the conception of the study. MF, NF, KA, and KM developed the qualitative study protocol and materials. MF and NF implemented the focus groups and MF implemented the individual interviews. MF performed data analysis, assisted by NF, than they presented findings to all the authors in different stages of the process. MF wrote the manuscript and it was than revised by KM. All authors reviewed and approved the final manuscript.

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Table 1

Variable	**n**	**(%)**
Sex		
Male	13	(50.0)
Female	13	(50.0)
Education		
>High school	8	(30.77)
≤High school	18	(69.23)
Born in Canada		
Yes	18	(69.23)
No	8	(30.77)
English Spoken at home		
Yes	18	(69.23)
No	6	(23.08)
English and other	2	(7.69)
Relationship Status		
Single	24	(92.31)
Married	0	(0.00)
Cohabiting	1	(3.85)
Separated/Divorced	1	(3.85)
Sexual Orientation		
Heterosexual	22	(84.62)
Homosexual	1	(3.85)
Bisexual	2	(7.69)

Other	1	(3.85)
Parents Born in Canada		
Both	5	(19.23)
Father Only	4	(15.38)
Mother Only	2	(7.69)
Not born in Canada	15	(57.69)

Table 2

7. The sample size in this study was relatively small; only limited inferences can be drawn for other groups.

8. The sample size was defined from the quantitative part of the study. We were not able to involve any family members of African origin as our original pool of participants was very small.

9. There are many different ways to group people from different ethnic groups and races. Our classification was subjective, based on self-identification. At the same time, arbitrary choices were made for the analysis of the quantitative part of the study—focus groups were based on these decisions. We acknowledge that this did not necessarily reflect the fluidity of ethnic differences and diversity of identities represented by the participants.

Table 3

1. Universal and selected prevention interventions in school are needed:
    - Education in school settings,
    - Early detection efforts should focus on identifying the full spectrum of psychotic symptoms. As youth described, withdrawal, and, broadly, negative symptoms, often occur before the psychosis develops. However, those symptoms are often questioned and neglected by family members and health providers;
2. Anti-stigma initiatives are needed and should be developed through the lens of cultural knowledge of and beliefs about mental health problems;
3. Increased family involvement should be encouraged;

4. Self-referral to early intervention services may be beneficial and the possibility for a triage model should be explored;
5. Sensitivity training should be offered for general practitioners and emergency staff on recognition, mental illness/gender bias resources, and services;
6. Sensitivity training should be offered for police and detention centre staff.

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The African, Caribbean, & European (ACE) Pathways to Care Study: A qualitative exploration of similarities and differences between African-, Caribbean-, and European-origin groups in pathways to care for psychosis.

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Title

The African, Caribbean, & European (ACE) Pathways to Care Study: A qualitative exploration of similarities and differences between African-, Caribbean-, and European-origin groups in pathways to care for psychosis.

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Abstract

Objectives: This paper reports on a qualitative exploration of the reasons for differences in pathways to care and duration of untreated psychosis (DUP) in the African, Caribbean, and European (ACE) Pathways to Care Study from the perspective of respondents to the study and their families. The aim was to understand differences in DUP between African-, Caribbean-, and European-origin groups.

Setting: Ontario, Canada.

Participants: Thirty-four participants in total. Twenty-five young people who had experienced a first episode of psychosis and nine family members. Participants were part of the ACE Pathways to Care Study.

Design: We implemented six focus groups. Among the young people there was one male and one female European-origin group, a male African-origin group, a male Caribbean-origin group; for family-member, a European-origin group a Caribbean-origin group. Furthermore, we implemented four in-depth interviews with two young African-, one Caribbean-, one European-origin women with lived experience of psychosis.

Results: Factors that influenced help-seeking delays across the three groups were: personal awareness of symptoms, family members' knowledge of psychotic symptoms, and knowledge of mental health services. Youth and their family members described how stigma played a key role in pathways to care by stopping them from asking for help. The way in which stigma operated on the three groups' members, from feeling ashamed to feeling guilty for their mental illnesses, helped to explain differences in DUP between the groups. Guilt feelings emerged as a prominent theme among members from the African and Caribbean groups and it was not discussed in the European focus group. Delay in entering into first-episode psychosis (FEP) programs was also influenced by the stigma perceived by young people in health care settings. This had an impact on the therapeutic relationships, disclosure of symptoms, and overall trust in the health care system.

Conclusions: The findings of this paper suggest that stigma, especially internalized stigma, may operate in different ways in European-, African-, and Caribbean-origin groups. This could explain the differences in the pathways to early intervention services for psychosis for these young people. These findings could inform the development of more equitable services for people in early stages of psychosis.

Keywords: First-episode Psychosis; Pathways to Care; Duration of Untreated Psychosis; Stigma; Ethnicity.

Key messages

1. The findings suggest that stigma, especially internalized stigma in African-, and Caribbean-origin groups, seems to explain differences in pathways to care between the three groups.
2. Delay in entering into first-episode psychosis programs was also influenced by the stigma perceived by young people in health care settings. This had an impact on the therapeutic relationships, disclosure of symptoms, and overall trust in the health care system.
3. Findings from this study could be used anti-stigma initiatives and sensitivity training for key-players (e.g., general practitioners, emergency staff, police). Such initiatives should be developed through the lens of cultural knowledge of and beliefs about mental health problems.

Strengths and limitations of this study

1. Use qualitative methodology to explore similarity and differences in pathways to care and DUP between African-, Caribbean-, and European-origin groups.

2. Young people who experienced a first episode of psychosis and their family members were invited to review ACE Study quantitative findings and elaborate on them.

3. Young people and their family members were invited to comment on possible strategies and ideas about how the system of care could be improved

4. The sample size in this study was relatively small; only limited inferences can be drawn for other groups.

5. The sample size was defined from the quantitative part of the study. We were not able to involve any family members of African origin as our original pool of participants was very small.

Introduction

Psychotic disorders affect 1–2% of the population and are associated with a significantly shorter life expectancy and an increased risk of self-harm and violent victimization [1-8]. Members of immigrant groups have been reported to be at an increased risk of psychosis. A number of factors are considered to be contributory, such as social deprivation and disorganization, separation from parents, and the experience of discrimination [9-14]. The Canadian literature has reported differences in the use of services by members of immigrant groups [15,16]. There are barriers to getting care for many immigrant groups [15]. Both the Canadian and international literature have investigated differences in pathways to care and service use and outcomes for people of Caribbean and African origin with psychosis [13, 16]. A longer duration of untreated psychosis (DUP) and more coercive care pathways (e.g., compulsory admission, police and criminal justice system involvement before admission) have been reported in the African- and Caribbean-origin groups in Ontario [16]; both these factors are associated with poorer outcomes [12,13].

The African, Caribbean, and European (ACE) Pathways to Care Study investigated pathways to care and the duration of untreated psychosis (DUP) in African-, Caribbean-, and European-origin groups in Ontario, Canada. The study identified differences between the three groups in the pathways to first-episode psychosis (FEP) programs. The median DUP was seven months for the European group, nine months for the African group, and 16 months for the Caribbean group. Caribbean participants in the study had fewer health services/providers in their pathways to care, they more often accessed FEP programs from an in-patient admission, and they faced more obstacles in their access to specialized treatment for psychosis than the European group. African group members in the study more often had an emergency department as first contact in their pathways [17].

Once disparities have been identified, understanding of the reasons why they may exist is necessary if we are to develop effective services. This paper reports a qualitative exploration of the reasons for differences in pathways to care and DUP in the ACE Study from the perspective of respondents to the study and their families. The aim was to understand differences in DUP between African-, Caribbean-, and European-origin groups. To do so, we explored young people's and their family members' journeys of seeking help for psychosis, investigating how people responded to early signs of psychosis as well as the roles that different people and services played in accessing specialized programs for psychosis.

Methods

This study used an inductive qualitative approach to examine differences in the routes to care between young people with lived experience of psychosis of African-, Caribbean-, and European-origin. In this exploratory and inductive qualitative study, the data analysis and interpretation developed from patterns originated in empirical data rather than a deductive process where an existing theory, or a hypothesis, guides the data analysis and interpretation process.

Focus groups were used as a means of generating in-depth knowledge of pathways to care, exploring the interaction between individual socio-cultural positions, young people's experiences of seeking help, and group dynamics—as each participant's narrative is generated out of the journeys of others. By using focus groups we were able to examine how participants (1) interacted with each other; (2) produced and reproduced knowledge; and (3) articulated and/or defended their views [18].

Ethical considerations

Ethics approval was obtained from the Research Ethics Board (REB) at the Centre for Addiction and Mental Health, as well as from the REB at each participating hospital site of the ACE Study. The approved REB consent form was reviewed at the beginning of each focus group and interview. The consent form emphasized costs and benefits of taking part in the study, its voluntary nature, and each participant's ability to his/her participation at any time. Confidentiality procedures and data management information were described within the consent form and reviewed before the beginning of each focus group and interview. During each focus group we informed focus group participants that, while we can promise that their identity will be kept confidential, we could not stop or prevent participants who were in the group from sharing things that should be confidential.

Participant Recruitment

Our groups were based on the categories developed by the Toronto District School Board. Respondents were asked to choose which racial or ethnic group best reflected their identity (see Anderson et al. for more information) [17]. Participants who took part in the ACE Study's semi-structured interviews were asked if they were willing to be re-contacted. Only those who agreed were approached for the qualitative study. They were asked if they would take part in a two-hour focus group to discuss the results of the study. Participants' family members were also contacted and asked if they were willing to take part in a separate focus group. One hundred and nine quantitative interview participants were contacted to take part in a focus group or an interview. Of these, 31 declined participation, 38 could not be reached, and 40 agreed to take part in the focus group or an individual interview and, due to scheduling issues, only 25 of these individuals could attend a focus group or an interview.

Four focus groups with young people were implemented: one male group for each of the African-, Caribbean-, and European-origin groups as well as one female European-origin groups (African = 3 male, Caribbean = 3 male, European= 7 male and women 8 male). Two focus groups were organized for the family members, one for each of the Caribbean, and European groups (European = 6, Caribbean = 3). Because of difficulty recruiting for the African and Caribbean women's groups, we adjusted the study protocol and undertook individual in-depth interviews, for total of two interviews with African women, and one interview with a Caribbean woman with lived experience of psychosis. The protocol change allowed us to have a small, but important, representation of women from these two groups. Furthermore, we were able to conduct an interview with a young woman of European origin who, due to anxiety problems, did not feel comfortable attending the focus group session.

Data collection

Focus groups were conducted by the first author, MF, who acted as focus group moderator, and research assistants who were trained in focus groups, transcribing, and qualitative data analysis for the purpose of this study. Focus group questions were designed to be conversational, open, and clear. They unfolded according to Krueger and Casey‘s recommendations [18]: opening, introductory, key, ending (see Table 1). At the end of each focus group, the research team involved in the focus group completed 30–40 minutes of debriefing. During the focus groups, participants were presented with preliminary ACE Study quantitative data; we focused on the differences in DUP as well as pathways to care and asked participants to comment on them.

Focus groups and in-depth interviews were digitally recorded. The digital audio files were transcribed by the research assistants and reviewed for data accuracy. One research assistant transcribed a focus group recording and the other reviewed the work done. Finally, all material was also reviewed by MF. Focus group transcripts were then prepared to facilitate thematic analysis. All participant names were changed to pseudonyms to ensure confidentiality.

Traditional data saturation, that is, “collecting data until no new information is obtained,” [19, p. 147] is often an object of controversy in qualitative research literature [19]. As Morse described: “The *quantity* of the data in a category is not theoretically important to the process of saturation. Richness of the data is driven from detailed description, not the number of time something is stated. Frequency counts are out” [19, p. 148]. We used instead Morse’s criterion of data saturation as “adequacy” of the data, which can be obtained through specific methodological choices. These methodological choices were (a) selecting and working with an ethnic- and gender-cohesive sample; (b) at the same time, working with three different ethnocultural groups so as to maximize and explore cultural contrasts in pathways to care—a gap in current literature; and (c) basing our sample on quantitative data analysis, which allowed focus-group-member checks on the quantitative findings, as well as the possibility for rich, full, and complete understanding.

Analysis

Thematic analysis was employed to identify, analyze, and report patterns or themes within data [20]. Our thematic analysis was data driven, rather than theoretically driven, making use of an inductive approach, as the themes identified were strongly linked to the data themselves. We followed Braun and Clark's steps of thematic analysis [21] by: (1) familiarizing ourselves with our data (transcribing data, reviewing transcriptions for accuracy, reading transcriptions over and over, and noting initial ideas); (2) generating initial codes and searching for themes (collating codes into potential themes); (3) reviewing and redefining themes (exploring how strong the identified themes are by assisting the relationship between first [code] and second [theme] level of analysis, generating a thematic map of the analysis); and (4) further unpacking the analysis through the writing process (identifying themes and initial stigma concepts was further explored through a review of existing models of mental health stigma).

We compared each participant's journey to care (shared during the focus group), the pathway depicted during a semi-structured interview, and the participant's medical chart. Further, we performed an analysis within each ethnic group, comparing and contrasting young people's narratives with those of family members, and a cross-ethnic-group analysis. As a result, in the study findings we describe themes that were common across all the narratives as well as the ones that were different between the three ethnic groups. All young people's and family members' names used in this paper have been changed to ensure participants' confidentiality.

Rigour

Lincoln and Guba [20] defined primary criteria to assess rigour and trustworthiness of the qualitative research process. Primary criteria—credibility, authenticity, criticality, and integrity—are necessary to all qualitative enquiry but they are insufficient in and of themselves. Trustworthiness was achieved within the study through the following criteria: *credibility* and *authenticity*, attained through multiple sources of data (e.g., pathways maps generated from semi-structured interviews, chart reviews, focus groups' data) as well as specific and different sample strategies being employed to generate rich and meaningful data; *criticality* and *integrity,* using team debriefing and analysis to ensure methodological effectiveness.

Results

Overview of the sample

A total of 34 people took part in the study; 25 young people with lived experiences of psychosis (origins: European = 16, African = 5, Caribbean = 4) and nine family members (origins: European = 6, African = 0, Caribbean = 3). Table 2 reports the socio-demographic information for young people with lived experiences of psychosis only—no socio-demographic information was collected for family members at the time of the focus group.

Findings are presented in two main sections: (1) *Understanding help seeking*, in which we first present commonality across the three groups, and then we investigate differences in DUP between African-, Caribbean-, and European-origin groups. In this section we unpack the role of stigma and how it operates early on in pathways to care. In this paper, stigma refers to a collection of negative attitudes, beliefs about, and behaviours directed at people with mental disorders, which are manifested in rejection and avoidance of, and prejudice and discrimination against people with mental illness conditions [22-24]. Stigma can be a barrier for people who experience mental health problems by making them reluctant to ask for help due to fear of prejudice, being labelled, and discrimination by others. Internalized stigma, or self-stigma, occurs when a person takes on those negative stereotypes and assumptions and applies them to themselves [23, 24]. Discrimination due to mental health stigma can take place in different circumstances/settings: education, employment, housing, and treatment. (2) *Understanding delay in entering first-episode psychosis (FEP) programs*, in which we explore the relationship between negative experiences, stigma, health care delivery, and illness/symptoms disclosure. The themes presented in this section are also common across the three groups.

Understanding help seeking

Common across the three groups: Knowledge, awareness, and mental health stigma

Consistent across all narratives, for both young people and family members, was that knowledge or lack of knowledge about symptoms of psychosis, mental illness, and services available to them was key to them recognizing the significance of changes in behaviour. Often this knowledge was based on family members' or friends' past experiences of mental illness.

> Maria: The one person who really helped me to realize what I'm going through, and that I need help, is my mother. She knows what I'm going through because she went through it with my father. She helps me a lot. ...
>
> (European youth focus group)

Young people who did not have any knowledge of signs or symptoms of psychosis were aware of personal changes but did not know that they were indicative of mental illness. In these cases, family members played a key role in the help-seeking process by taking them to the hospital.

> Benjamin: I was schizophrenic, and I didn't know what to do. I heard voices and stuff. I did some stuff that I couldn't remember, so some people took me in …
>
> Paul: I kept hearing … weird voices, but I didn't know what is. So, later on I came … my parents took me to the hospital …
>
> (African youth focus group)
>
> Steve: I didn't know that I needed help. I had no one around me who knew what was happening. … I was staying with a friend, my mom was occasionally stopping by … she saw certain signs in me, and she immediately drove me to [name of the hospital].
>
> (Caribbean youth focus group)
>
> June: I wouldn't have stayed in the emergency room, I wouldn't have gone by myself … I didn't know what was going on. … I didn't know *I was going crazy*, … I thought everybody was against me.
>
> (European youth focus group)

Young people and family members who did not have awareness or knowledge of the signs or symptoms of psychosis, struggled the most to understand and/or make sense of the situations.

> Janine: I didn't know what this illness was. I thought it was just some kind of behaviours, being angry or strange like teenagers could possibly experience sometime … it was people from the outside who used to tell me ''No, this more than just … you know teenager's crisis.'' Not knowing [the] symptoms … I just didn't know what was going on really.

> (Caribbean family members' focus group)

> Louise: My son was 17 when he had his psychotic break. I thought he was just being a typical rebellious teenager … he smoked pot. He didn't get violent. He was so scared and I didn't know what else to do with him. I took him to [name of general hospital] … after about 15 hours convincing them that I was not taking him home, they admitted him.
>
> (European family members' focus group)

Often, family members attributed the changes in their relatives' behaviours to growing up/going through adolescence, peer groups/wrong crowds, stress, and/or substance abuse in young adults. Family members often thought that what their relatives were experiencing was just a temporary phase in their relatives' lives without recognizing signs or symptoms of psychosis. Help seeking often occurred after doubting the early signs of psychosis and, most importantly, after feeling sadness and discomfort.

Along with knowledge and awareness of signs or symptoms of psychosis, the role that stigma played during the help-seeking process was also constantly present in the narratives. Through the analysis conducted, it was possible to identify how individual and family perceptions of mental illness influenced the internalization of stigma. For example, young people involved in the study often distinguished between their rational understandings of the mental health problems, symptoms, and causes, and, at the same time, their feelings of being trapped in emotions such as shame.

> Karen: People are scared to look for help, and to …
>
> Maria: And to admit to themselves even ... [Karen: Yeah!] that "I have schizophrenia"… I never told anybody.
>
> June: I'm still ashamed of what I have.

> Samantha: Me too.
>
> (European youth focus group)

Participants described how, for fear of family members' and/or friends' reactions to their conditions, they tried to ignore the signs and symptoms by, for example, using marijuana, and attempted to hide their symptoms from others.

> Sandi: I was worried about what people around me might say … once you're in the hospital you can't really keep your secret anymore. There is a huge stigma about mental illness; people tend to like to avoid it.
>
> (European youth focus group)

Positive symptoms (e.g., hearing voices, bizarre behaviour, violence) were often catalysts to treatment initiation. Family members often struggled to recognize when their relative was no longer able to care for himself/herself or when he/she was asking for help as the symptoms of psychosis took over his/her ability to make decisions. This created quite a complex situation where family members felt threatened or worried about their safety and, at the same time, guilty when they had to call the emergency department, ambulance, or, unfortunately, the police. This was evident in family members' narratives.

> Natali: I have been there … I couldn't stop crying for days … when my daughter finally broke down at school ... being scary violent with us. … the first time she finally did get to the hospital that day [name of the hospital] … It was almost like a relief, she was safe and she was away from us … because we were scared. We were so afraid. [Sarah: (overlapping) Yes. Yes. Yeah.]
>
> (European family members' focus group)

Stigma was also closely connected to how much the person who experienced psychosis was considered responsible for his/her mental condition or was in control, or not, of his/her symptoms. Family members recognized that mental illness is not perceived the same as other health problems. Physical disorders, such as cancer, generate compassion in extended family members, whereas mental disorders bring reactions of distancing, blaming, and stigmatizing from members of the extended family.

> Natali: Unfortunately, I still see … my family members not so supportive. On the surface, they are, but I see them shy away from my son. I see the stigma, it is still so much there. If he was (clears throat) you know physically ill they would be right there.
>
> (European family members' focus group)

Overall, family members described how psychosis is hidden until it manifests through a person's behaviours. It is difficult to understand what is happening to the person as well as to assess if, when, and how to intervene.

Differences in help seeking between the three groups: Internalized stigma as feeling shame versus feeling guilty for their own condition

Participants of European origin internalized mental health stigma as shame about their symptoms (e.g., hearing voices, unpredictable or bizarre behaviours in front of family and friends, or irrational actions). They felt distress caused by the awareness of their past bizarre behaviours and a sense of humiliation for their conditions. In contrast, young people from African- and, even more, Caribbean-origin groups stressed their responsibility for their conditions, they felt that they had done something wrong (for having an mental illness), and they felt a sense of failure for not being able to "snap out of it"—as a participant described during a focus group. In this sense, they seemed to internalize mental health stigma as guilt—there is shame and humiliation but also they felt that they had done something wrong.

> Paul: … there was a lot of pressure to excel in school and succeed. I dabbled too much in, dabbled too much in drugs, that was my problem … that was really my fault. I have no one else to blame but myself … people expect you to just walk it off kind of thing. But you really, you really can't, you can't really walk off a mental illness … you can cope with it.
>
> (African youth focus group)
>
> Steve: Going through a mental illness totally flipped the way I view … everything! It's also made me become more aware of how family members react, and why are they reacting that way. Eventually it is what got me onto the culture of it, my religion, and so forth. I can't say exactly what it is about the Caribbean culture … but, I can tell, those two things definitely play a factor in it.
>
> (Caribbean youth focus group)

In the African and Caribbean focus groups, participants discussed the role that religion had in shaping their and their families' perceptions of mental illness and feelings of guilt for their condition—this topic was not discussed in the European focus groups. In some cases, people described how they grew up thinking that mental illness was a sin or God's punishment. Although they did not think in this way now, they saw how this perception influenced their understanding of early signs of psychosis, the focuses of their paranoid symptoms (in some cases), and, most importantly, their asking for help.

> Suzanne: Well, it made me feel badly because I thought, "Wow. You know, she's so nervous [mother] about me going to the hospital for help." It made me feel kind of ashamed that I needed help. … I guess it made me a little bit reluctant to seek care later on. [Later on in the interview] … in the beginning my mom was like, "Suzanne you need to PRAY more. That's the problem." And, I'm like, "No mom, I need medication. I need some help." … Sometimes I just tell her that I prayed just so she can get off my case. My brother often tell me that my life has gone in this direction because I stopped going to church. … It makes me feel bad. It's not helpful me to get better.
>
> (Caribbean youth interview)

> Greg: I can't say everybody but, A LOT of people in my family, and in the community … they become very superstitious. It's a mind job with Catholicism first of all—and no

> offense to anybody here who's Catholic, I am Catholic. Something simple as, as having a mental condition, is not simple in this world anymore, it becomes then, "that person needs to be exorcised, or that person's got bad demons—"
>
> Steve: (overlapping) Oh, I've heard … I've heard that, I've heard that, to get rid of my voices I have to get an exorcism.
>
> Greg: Yeah.
>
> Steve: That's what I heard from a friend.
>
> Greg: Like, my mom said that when she was uh, a kid, when she was like 5 or 6, she actually witnessed someone getting exorcised, because of voices in his head and stuff like that.
>
> (Caribbean youth focus group)

As described, African- and, even more, Caribbean-origin young people reported that their mental illnesses were taboos among members of their close or extended families. While young people of African origin had their families around to support their struggles, young people of Caribbean origin who attended the focus groups had no one or only a few close family members. The support networks that could assist them in seeking help were not available.

> Simone: When people in the Caribbean get to know that your child has this issue [mental illness] … the whole family is labelled … from the grandparent right the way down. The family is labelled and you are sort of ostracized. That's why many of us don't want to bring it up to the light … we are in denial that this is not happening to this family. … We, as parents, don't have the freedom to talk about it … because of the stigma that's still attached … we internalize it. When we internalize, we're stressed. We would love to know that there is somewhere that we can go and sit down and talk. We need to unload but we have no place to unload.
>
> (Caribbean family members' focus group)

African- and Caribbean-origin participants described how when they experienced early signs of psychosis, they tried to control them and they felt guilty if they were not able to. Their sense of guilt was also connected with cultural interpretation of mental illness as sin, God's punishment, and a taboo illness heavily stigmatized—themes more present in the Caribbean-origin focus group and interviews.

Understanding delay in entering first-episode psychosis programs (FEP)

> Rachel: Now none of these people [university psychological service/psychiatrist] told me about any other resources. ... All I knew was [name of mental health hospital], which was, like, the last resort. … I was in the dark. And then I went to my family doctor, and she was the first person after like 3 months who told us that, "Oh, there's actually an in-patient program at [name of a general hospital], for if you're in an emergency—go there." … So then when I got really bad, I was in the in-patient at [name of a general hospital] and there, it was when I actually found out about a bunch of other resources …"
>
> (European youth focus group)

Participants often recognized changes in behaviours and thinking but they did not always attribute these to a mental illness; however they were active in seeking help, contacting community services (e.g., school or university health services) or their family doctors, if they had one. In reflecting on their pathways, they often felt upset, as early attempts to ask for help were dismissed by providers and/or information was not provided to them.

<u>Negative experiences, stigma and care: First contact, therapeutic relationship, and disclosure of symptoms</u>

Once in the system, groups' differences in the journeys to specialized treatment seemed less present. Before entering into early intervention programs, young people saw between four and six difference health providers/services (e.g., family doctor, emergency, police, detention centre, in-patient unit). As young people described, the care they received (or did not receive) and health care providers' attitudes towards mental illness influenced what they shared about their mental states (e.g., hearing voices, suicidal thoughts) and, overall, their trust in the system. From the first contact with a hospital, the majority of young people involved in the focus groups reported that, if it was a negative experience, it affected their therapeutic relationships, and, generally, their willingness to stay in the system and to return, if needed, a second time.

> Samantha: From my experience there's a lot of stigma and shame surrounding people who have substance abuse problems. Whenever I've been in treatment, there has not been an accepting atmosphere for me to discuss my issues or to make me feel like I'm actually going to get help.
>
> (European youth focus group)

> Steve: Well, I found, like, a number of them [mental health care providers] definitely helped. I feel that the majority of [hospital name] staff definitely does have that, but there are still the ones that can create that negative experience for you when you're already going through a negative experience. … It's funny … you're going through stuff, even though your mind's not in the right place, you still remember all the negativity. … [Andy: (overlapping) Yeah.] Yeah. Those are the things that I will always remember, about [name of the hospital] and dealing with [the staff] at the first time. Like, although they were there to help me, it didn't seem like half had actually studied mental health at all.
>
> (Caribbean youth focus group)

During the focus groups and interviews, participants reported how their experiences of poor quality of care was due to health providers' negative attitudes and behaviours towards mental illness. Indeed, stigma does operate, albeit marginally, in mental health services, such as primary care (e.g., family doctors), emergency departments, in-patient units, out-patient units, and so on and, when present, it seems to be more hurtful than when experienced outside the health care system.

Eight young people who took part in the focus groups had police and detention centres as early contacts in their pathways to FEP treatment. Overall, police officers were perceived to be supportive, helpful, and understanding of the situations. Police officers have the duty to respond to an emergency call, accompany the person to the hospital emergency room, and stay with them until the hospital staff takes over.

> Linda: I did it twice. The first time, I went to the hospital was in an ambulance, and, the second time was … in a police car. I actually found the police were nice. Like, I was in handcuffs [laughter], but I found them to be really nice … they stayed with me until the doctors started seeing me. They didn't judge me, and I asked the one cop if he was married … he was like showing me pictures of his kids. He was just nice.
>
> (European youth focus group)

Three men of European origin had forensic services in their pathways. In these cases, the young men had to stay in detention for several days before they were able to see a judge. During the focus groups they described how they were exposed to verbal and physical violence as well as the trauma of experiencing psychotic episodes while in detention.

> Rob: Well, for me the cops were ok. But, then at the detention centre, I said something really dumb to the correctional officer and … I'm walking … he literally just POUNDS me, he beat the shit out of me. Right there on the ground. I wasn't shaken by it at all because I was psychotic, but like—I don't know, it was really weird. He literally took me from behind and just pounded me. I guess his superior comes in and takes him off me. I guess the cops are ok but the guys in the jail …
>
> Matt: Yeah, I had the same experience. One time, when I was psychotic, my mom called the police on me ... She meant for me to go to the hospital but I got charged by the police with a bunch of things. They sent me to JAIL, and I was completely psychotic … they didn't know what to do with me. They were physical with me, they injected me in the back of my neck with I don't know what medication. They just locked me in a jail cell for probably a month until I was transferred to a medical facility.
>
> (European youth focus group)

It was interesting to notice that men of European origin were able to share these experiences during the focus group, whereas men of African and Caribbean origin just mentioned police involvement in their pathways without elaborating on it. We realized the sensitivity of this topic which, combined with the sense of guilt, probably precluded any further disclosure.

In total, 10 youth had family doctors as first contact in their pathways. Among all focus groups, there was only one case in which referral was made to an FEP program directly by a general practitioner. The majority of them reported to have been misdiagnosed or had their symptoms dismissed by their family doctors.

> Benjamin: ... the family doctor doesn't, uh well, didn't work for me, he thought it was just anxiety, like … anxiety because of school … 'cause I was going into university.
>
> (African youth focus group)

In other cases, a young man and woman described how their family doctors focused only on their substance abuse problems and reprimanded them for their behaviours.

> Steve: I kind of did [went to see my family doctor at first], but, he turned me down flatly, 'cause I was smoking weed. I said, "I thinking, I'm suffering with depression." He asked me if I did drugs, I said that I did smoke weed quite often, and he said stop smoking the weed then "come back and I help you." I never heard about it after that. Next time, I saw him, I had to tell him that, yeah, I was diagnosed with schizophrenia. So, my general practitioner, unfortunately, wasn't able to do anything at the time.
>
> (Caribbean youth focus group)
>
> Jill: I recognized the symptoms but I didn't know the specifics of my diagnosis. I went to the family doctor and explained that I felt that I was being followed and everything. And then he told me, "Okay. You need to stop doing drugs," 'cause I was high on marijuana when it first happened … but [it happened] several time [before] and I just thought it was the pot.
>
> (African youth interview)

It may be difficult for general practitioners to diagnose psychosis early; however, participants felt that they had actively sought help but their requests were misunderstood or dismissed.

When admitted to emergency units or in-patient services, participants described the following negative experiences: being labelled, feeling like a number, feeling no longer a person but an illness, being judged for behaviours/symptoms, and/or being treated like a child.

> Matt: I don't know, how it makes sense, but [hospital staff] were almost like TOO nice … I don't know the word, like, treating you like you're a child … talking down to you. It was NICE, but it didn't make me feel better … other people were nice but, at the same time … made you feel like an equal. I felt like that was important.
>
> Steve: I think maybe the word you were looking for was "pity." Like we were treated with PITY [Matt: Yeah.] Yeah. I think that, people think that people with schizophrenia are somehow STUPIDER or something … I don't think people with schizophrenia are stupid at all.
>
> (European youth focus group)
>
> Robin: They treat you like a number [mumbles of agreement].
>
> Samantha: When I went to the hospital last time ... I was going through a panic attack when I FIRST found out I had schizophrenia, and they, the nurse was like, "Yeah, you're just faking it, you're perfectly fine, nothing's wrong with you.'"
>
> Robin: Yeah.
>
> Samantha: It really, made me not like being in the hospital. I did not want to go back there ever.
>
> Natali: I agree. I think they treat you more like a number. And I think, being treated like a PERSON instead of a number or a case because, if you're just a case, you're like "I'm schizophrenic"… you're not a person, anymore [mumbles of agreement].
>
> (European youth focus group)

According to young people, all of these factors influenced the therapeutic relationship with services and providers and, in particular, affected young people's disclosures of symptoms—as described.

Discussion

Differences in pathways to care and the duration of untreated psychosis have been reported in some studies of ethnic minority groups [13, 16]. The reasons for these differences are unclear [25]. In this paper, the authors focused on participants' narrative accounts to investigate the social and cultural contexts of help seeking. In doing so, we were able to further investigate differences between the groups as well as how a number of factors, including stigma, influenced both help seeking and access to specialized programs. We developed preliminary hypotheses about the link between internalized stigma, cultural beliefs about mental illness, and help seeking. At the same time, we discussed how interactions with health care settings shape the experience of asking for help, influencing future engagement with health providers and/or willingness to disclose symptoms.

In our attempt to understand differences in the pathways to care and DUP between African-, Caribbean-, and European-origin groups, we found similarities to other studies that broadly explore help seeking among young people in FEP programs [26, 27] and their families [28-33] without focusing on ethnicity. As with our findings, other qualitative works described long and difficult periods from the realization of signs and symptoms of psychosis to the initiation of help seeking [28-31]. As other studies reported, family members described how the role of caregiver was emotionally draining [32] due to their inability to understand and cope with the changes in their family members, feelings of guilt after calling the police, as well as frustration of their inability to navigate the health care system and/or lack of involvement in the treatment program [33]. Family members’ knowledge of mental illness and services available to them was important in dealing with the situations. However, as other studies described, they often mistook early signs of psychosis—especially in the prodromal phase of the illness—for mood changes due to adolescence, social withdrawal, stress, or drugs [26-30]. At the same time, even if the young people who took part in our study recognized changes in themselves, they did not attribute these changes to mental illness—as was also described in other studies [26, 30]. Moreover, as we discussed, because of the associated stigma, young people and family members engaged in denial, avoidance, and hiding of early symptoms of psychosis which prevented them from seeking help [26-34].

In *Stigma*, Goffman [22] defined and discussed stigma as *discredited* versus *discreditable*; in the first case, a visible and physical mark defines stigma, where, in the second, no visible or physical mark is present—as is the case with the stigma of mental illness. More recently, further theories have been developed and used to understand the relationship between stigma and mental illness (see Link & Phelan [23], and Corrigan [24]). In all of these theories, stigma is based on signs that define who is different, stereotypes about the person or group, marginalization, avoidance, discrimination, fear of what or who is different—where normality and abnormality or similarity and difference are defined by socio-cultural norms and beliefs. Furthermore, internalized stigma seems more distractive and harmful to the affected person’s health and, broadly, to his/her sense of self [35].

Several studies investigate stigma and mental illness [33, 35, 36]. Stigma about mental illness is prevalent in the general public but, unfortunately, occurs in health and mental health settings as well [36]. Work done in the Canadian context recognizes the role of stigma in seeking help for mental illness in immigrant and refugee groups in Canada. The *Improving mental health services for immigrant, refugee, ethno-cultural and racialized groups: Issues and options for service development* report describes how immigrants, refugees, and racialized groups are less likely to ask about mental health systems because of possible stigma and this leads either to people not getting treatment or to a delay in getting treatment [15]. Other studies describe the specific needs and issues that immigrant groups are facing in relation to mental health services in urban settings in Canada [37, 38]. These studies, which were conducted with West Indian immigrants in Montreal, focus on cultural beliefs in non-medical interventions as the preferred form of treatment for mental illness (e.g., prayer or traditional folk medicine) or on the perception of primary care (e.g., doctors often prescribing pharmaceutical medications, or lack of time from physicians in early encounters that deterred the use of current health services) [37, 38].

There are similarities but also differences with our findings compared to other studies. This paper describes how stigma operated on young people and family members of African, Caribbean, and European origin and how it influenced the help-seeking process. Although all young participants internalized stigma as shame, fearing lifelong discrimination for their mental health conditions, which often prevented them from disclosing their symptoms to others and ask for professional help, those of African and Caribbean origin also internalized a sense of guilt for their conditions, holding them back from talking about their problems as well as pushing them to try to overcome their symptoms alone.

As mentioned, Caribbean young people described the role of cultural beliefs about mental illness and of religion in delay in getting treatment. African and Caribbean young people were able to distinguish the difference between their own beliefs about mental illness and those of their cultural groups. They were critical of traditional cultural beliefs, that see mental illness as a sin for which praying to God is a solution. However, the stigma has been internalized as guilt, which influenced their decisions to seek help. It could be that young people of Caribbean origin waited longer to ask for help as a way to protect their families from being labelled with a taboo illness; future studies are needed to verify this hypothesis. As family members of Caribbean origin described, there is a desire and need to find a space and place to bring to light these issues: "We need to unload but we have no place to unload."

Although the analysis presented in this paper helps in the understanding of some of the differences in DUP between African-, Caribbean-, and European-origin immigrants, we recognize that this work has some limitations First, the sample size in this study was relatively small; only limited inferences can be drawn for other groups. Second, as described, the sample size was defined from the quantitative part of the study. We were not able to involve any family members of African origin as our original pool of participants was very small. Finally, there are many different ways to group people from different ethnic groups and races. Our classification was subjective, based on self-identification. At the same time, arbitrary choices were made for the analysis of the quantitative part of the study—focus groups were based on these decisions. We acknowledge that this did not necessarily reflect the fluidity of ethnic differences and diversity of identities represented by the participants.

We were able to ask both young people and family members for possible strategies which could be used to support people in the help-seeking process and for ideas about how the system of care could be improved (see Table 3). All participants described the importance of anti-stigma initiatives in different settings (e.g., schools, universities, primary care services/providers) and targeted to different groups. Anti-stigma initiatives could challenge wrong beliefs and stereotypes around mental illness and, in particular, psychosis and raise awareness about psychosis signs and symptoms to promote problem recognition. This could empower young people as well as adults around them to promptly intervene if needed. Furthermore, more knowledge about systems of care, early intervention programs, treatment options, and positive prognosis promoted by early intervention can help young people and family members to initiate help seeking and to better navigate the system. At the same time, sensitivity training should be offered for general practitioners and emergency-room staff to promote self-awareness on mental illness bias, the impact of stigma toward mental illness in access to care and/or therapeutic relationships, and general information on early intervention programs, resources, and services. Based on our findings, anti-stigma initiatives should be developed through the lens of ethnocultural knowledge of and beliefs about mental health problems.

Conclusion

The findings of this study suggest that stigma, especially internalized stigma, operates in different ways in European-, African-, and Caribbean-origin individuals and that this could explain the differences in the pathways to early intervention services for psychosis for these young people. These findings could inform the development of targeted anti-stigma campaigns as well as the implementation of more equitable services for people in early stages of psychosis. To do so, trust needs to be redefined and gained between ethnocultural groups and mental health researchers/providers both in research and in clinical practice. Implementing a community-based participatory framework could help to achieve this goal.

Contributorship statement KM contributed to the conception of the study. MF, NF, KA, and KM developed the qualitative study protocol and materials. MF and NF implemented the focus groups and MF implemented the individual interviews. MF performed data analysis, assisted by NF; they presented findings to all the authors in different stages of the process. MF wrote the manuscript and it was than revised by KM. All authors reviewed and approved the final manuscript.

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Table 1

Focus Group and Interview Questions: **Young people**	**Focus Group and Interview Questions:** **Family members**
Opening question: Tell us your name and why you decided to participate in this focus group? **Introductory:** 2. How long have you been in the program? And, if you feel like sharing it, how did you come into contact with the first-episode psychosis services?	**Opening question:** Tell us your name and why you decided to participate in this focus group? **Introductory:** 2. If you feel like sharing it, how did [the person who refered you to the focus group, he/she can be your son/daughter, etc.] come into contact with mental health services the first time?

Key questions: Based on all interviews that we conducted so far we were able to identify that: First, the help-seeking process is very complex, as you can see, many people, places, circumstances and factors are involved; Why do they think this happens? Second, we were able to identify some of the key people involved in this journey and we would like to know more from you about their roles. NOTE: For each provider we explore what was helpful and/or less helpful or frustrating. Specific question based on the analysis done (e.g., The Caribbean population have really long delays–why do they think this happens?)	**Key questions:** Based on all interviews that we conducted so far we were able to identify that: First, the help-seeking process is very complex, as you can see, many people, places, circumstances and factors are involved; Why do they think this happens? Second, we were able to identify some of the key people involved in this journey, you already mentioned some of them, we would like to know more from you about their roles. NOTE: For each provider we explore what was helpful and/or less helpful or frustrating.
Ending questions: We want to know how to improve the services. What can be done to better help people that experience early symptoms of psychosis to have access to treatment? Is there anything that we missed?	**Ending questions:** We want to know how to improve the services. What can be done to better help people that experience early symptoms of psychosis to have access to treatment? Is there anything you want to say that we did not ask or you did not talk about today that you want to add?

Table 2

Variables	N	(%)
Sex		
Male	13	(52)
Female	12	(48)
Education		
>High school	8	(32)
≤High school	17	(68)

Born in Canada		
Yes	17	(68)
No	8	(32)
English Spoken at home		
Yes	18	(72)
No	5	(20)
English and other	2	(8)
Sexual Orientation		
Heterosexual	21	(84)
Homosexual	1	(4)
Bisexual	2	(8)
Other	1	(4)
Relationship Status		
Single	23	(92)
Married	0	(0)
Cohabiting	1	(4)
Separated/Divorced	1	(4)
Parents Born in Canada		
Both	5	(20)
Father Only	4	(16)
Mother Only	2	(8)
Not born in Canada	14	(56)

Table 3

1. Universal and selected prevention interventions in school are needed:
    - Education in school settings,
    - Early detection efforts should focus on identifying the full spectrum of psychotic symptoms. As youth described, withdrawal and, broadly, negative symptoms, often occur before the psychosis develops. However, these symptoms are often questioned and neglected by family members and health providers;
2. Anti-stigma initiatives are needed and should be developed through the lens of cultural knowledge of and beliefs about mental health problems;
3. Increased family involvement should be encouraged;
4. Self-referral to early intervention services may be beneficial and the possibility for a triage model should be explored;

5. Sensitivity training should be offered for general practitioners and emergency staff on recognition, mental illness/gender bias resources, and services;

6. Sensitivity training should be offered for police and detention center staff.

Title

The African, Caribbean, & European (ACE) Pathways to Care Study: A qualitative exploration of similarities and differences between African-, Caribbean-, and European-origin groups in pathways to care for psychosis.

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Abstract

Objectives: This paper reports on a qualitative exploration of the reasons for differences in pathways to care and duration of untreated psychosis (DUP) in the African, Caribbean, and European (ACE) Pathways to Care Study from the perspective of respondents to the study and their families. The aim was to understand differences in DUP between African-, Caribbean-, and European-origin groups.

Setting: Ontario, Canada.

Participants: Thirty-four participants in total. Twenty-five young people who had experienced a first episode of psychosis and nine family members. Participants were part of the ACE Pathways to Care Study.

Design: We implemented six focus groups. Among the young people there was one male and one female European-origin group, a male African-origin group, a male Caribbean-origin group; for family-member, a European-origin group a Caribbean-origin group. Furthermore, we implemented four in-depth interviews with two young African-, one Caribbean-, one European-origin women with lived experience of psychosis.

Results: Factors that influenced help-seeking delays across the three groups were: personal awareness of symptoms, family members' knowledge of psychotic symptoms, and knowledge of mental health services. Youth and their family members described how stigma played a key role in pathways to care by stopping them from asking for help. The way in which stigma operated on the three groups' members, from feeling ashamed to feeling guilty for their mental illnesses, helped to explain differences in DUP between the groups. Guilt feelings emerged as a prominent theme among members from the African and Caribbean groups and it was not discussed in the European focus group. Delay in entering into first-episode psychosis (FEP) programs was also influenced by the stigma perceived by young people in health care settings. This had an impact on the therapeutic relationships, disclosure of symptoms, and overall trust in the health care system.

Conclusions: The findings of this paper suggest that stigma, especially internalized stigma, may operate in different ways in European-, African-, and Caribbean-origin groups. This could

explain the differences in the pathways to early intervention services for psychosis for these young people. These findings could inform the development of more equitable services for people in early stages of psychosis.

Keywords: First-episode Psychosis; Pathways to Care; Duration of Untreated Psychosis; Stigma; Ethnicity.

Key messages

1. The findings suggest that stigma, especially internalized stigma in African-, and Caribbean-origin groups, seems to explain differences in pathways to care between the three groups.
2. Delay in entering into first-episode psychosis programs was also influenced by the stigma perceived by young people in health care settings. This had an impact on the therapeutic relationships, disclosure of symptoms, and overall trust in the health care system.
3. Findings from this study could be used anti-stigma initiatives and sensitivity training for key-players (e.g., general practitioners, emergency staff, police). Such initiatives should be developed through the lens of cultural knowledge of and beliefs about mental health problems.

Strengths and limitations of this study

1. Use qualitative methodology to explore similarity and differences in pathways to care and DUP between African-, Caribbean-, and European-origin groups.

2. Young people who experienced a first episode of psychosis and their family members were invited to review ACE Study quantitative findings and elaborate on them.

3. Young people and their family members were invited to comment on possible strategies and ideas about how the system of care could be improved

4. The sample size in this study was relatively small; only limited inferences can be drawn for other groups.

5. The sample size was defined from the quantitative part of the study. We were not able to involve any family members of African origin as our original pool of participants was very small.

Introduction

Psychotic disorders affect 1–2% of the population and are associated with a significantly shorter life expectancy and an increased risk of self-harm and violent victimization [1-8]. Members of immigrant groups have been reported to be at an increased risk of psychosis. A number of factors are considered to be contributory, such as social deprivation and disorganization, separation from parents, and the experience of discrimination [9-14]. The Canadian literature has reported differences in the use of services by members of immigrant groups [15,16]. There are barriers to getting care for many immigrant groups [15]. Both the Canadian and international literature have investigated differences in pathways to care and service use and outcomes for people of Caribbean and African origin with psychosis [13, 16]. A longer duration of untreated psychosis (DUP) and more coercive care pathways (e.g., compulsory admission, police and criminal justice system involvement before admission) have been reported in the African- and Caribbean-origin groups in Ontario [16]; both these factors are associated with poorer outcomes [12,13].

The African, Caribbean, and European (ACE) Pathways to Care Study investigated pathways to care and the duration of untreated psychosis (DUP) in African-, Caribbean-, and European-origin groups in Ontario, Canada. The study identified differences between the three groups in the pathways to first-episode psychosis (FEP) programs. The median DUP was seven months for the European group, nine months for the African group, and 16 months for the Caribbean group. Caribbean participants in the study had fewer health services/providers in their pathways to care, they more often accessed FEP programs from an in-patient admission, and they faced more obstacles in their access to specialized treatment for psychosis than the European group. African group members in the study more often had an emergency department as first contact in their pathways [17].

Once disparities have been identified, understanding of the reasons why they may exist is necessary if we are to develop effective services. This paper reports a qualitative exploration of the reasons for differences in pathways to care and DUP in the ACE Study from the perspective of respondents to the study and their families. The aim was to understand differences in DUP between African-, Caribbean-, and European-origin groups. To do so, we explored young people’s and their family members’ journeys of seeking help for psychosis, investigating how people responded to early signs of psychosis as well as the roles that different people and services played in accessing specialized programs for psychosis.

Methods

This study used an inductive qualitative approach to examine differences in the routes to care between young people with lived experience of psychosis of African-, Caribbean-, and European-origin. In this exploratory and inductive qualitative study, the data analysis and interpretation developed from patterns originated in empirical data rather than a deductive process where an existing theory, or a hypothesis, guides the data analysis and interpretation process.

Focus groups were used as a means of generating in-depth knowledge of pathways to care, exploring the interaction between individual socio-cultural positions, young people's experiences of seeking help, and group dynamics—as each participant's narrative is generated out of the journeys of others. By using focus groups we were able to examine how participants (1) interacted with each other; (2) produced and reproduced knowledge; and (3) articulated and/or defended their views [18].

Ethical considerations

Ethics approval was obtained from the Research Ethics Board (REB) at the Centre for Addiction and Mental Health, as well as from the REB at each participating hospital site of the ACE Study. The approved REB consent form was reviewed at the beginning of each focus group and interview. The consent form emphasized costs and benefits of taking part in the study, its voluntary nature, and each participant's ability to his/her participation at any time. Confidentiality procedures and data management information were described within the consent form and reviewed before the beginning of each focus group and interview. During each focus group we informed focus group participants that, while we can promise that their identity will be kept confidential, we could not stop or prevent participants who were in the group from sharing things that should be confidential.

Participant Recruitment

Our groups were based on the categories developed by the Toronto District School Board. Respondents were asked to choose which racial or ethnic group best reflected their identity (see Anderson et al. for more information) [17]. Participants who took part in the ACE Study's semi-structured interviews were asked if they were willing to be re-contacted. Only those who agreed were approached for the qualitative study. They were asked if they would take part in a two-hour focus group to discuss the results of the study. Participants' family members were also contacted and asked if they were willing to take part in a separate focus group. One hundred and nine quantitative interview participants were contacted to take part in a focus group or an interview. Of these, 31 declined participation, 38 could not be reached, and 40 agreed to take part in the focus group or an individual interview and, due to scheduling issues, only 25 of these individuals could attend a focus group or an interview.

Four focus groups with young people were implemented: one male group for each of the African-, Caribbean-, and European-origin groups as well as one female European-origin groups (African = 3 male, Caribbean = 3 male, European= 7 male and women 8 male). Two focus groups were organized for the family members, one for each of the Caribbean, and European groups (European = 6, Caribbean = 3). Because of difficulty recruiting for the African and Caribbean women's groups, we adjusted the study protocol and undertook individual in-depth interviews, for total of two interviews with African women, and one interview with a Caribbean woman with lived experience of psychosis. The protocol change allowed us to have a small, but important, representation of women from these two groups. Furthermore, we were able to conduct an interview with a young woman of European origin who, due to anxiety problems, did not feel comfortable attending the focus group session.

Data collection

Focus groups were conducted by the first author, MF, who acted as focus group moderator, and research assistants who were trained in focus groups, transcribing, and qualitative data analysis for the purpose of this study. Focus group questions were designed to be conversational, open, and clear. They unfolded according to Krueger and Casey's recommendations [18]: opening, introductory, key, ending (see Table 1). At the end of each focus group, the research team involved in the focus group completed 30–40 minutes of debriefing. During the focus groups, participants were presented with preliminary ACE Study quantitative data; we focused on the differences in DUP as well as pathways to care and asked participants to comment on them.

Focus groups and in-depth interviews were digitally recorded. The digital audio files were transcribed by the research assistants and reviewed for data accuracy. One research assistant transcribed a focus group recording and the other reviewed the work done. Finally, all material was also reviewed by MF. Focus group transcripts were then prepared to facilitate thematic analysis. All participant names were changed to pseudonyms to ensure confidentiality.

Traditional data saturation, that is, "collecting data until no new information is obtained," [19, p. 147] is often an object of controversy in qualitative research literature [19]. As Morse described: "The *quantity* of the data in a category is not theoretically important to the process of saturation. Richness of the data is driven from detailed description, not the number of time something is stated. Frequency counts are out" [19, p. 148]. We used instead Morse's criterion of data saturation as "adequacy" of the data, which can be obtained through specific methodological choices. These methodological choices were (a) selecting and working with an ethnic- and gender-cohesive sample; (b) at the same time, working with three different ethnocultural groups so as to maximize and explore cultural contrasts in pathways to care—a gap in current literature; and (c) basing our sample on quantitative data analysis, which allowed focus-group-member checks on the quantitative findings, as well as the possibility for rich, full, and complete understanding.

Analysis

Thematic analysis was employed to identify, analyze, and report patterns or themes within data [20]. Our thematic analysis was data driven, rather than theoretically driven, making use of an inductive approach, as the themes identified were strongly linked to the data themselves. We followed Braun and Clark's steps of thematic analysis [21] by: (1) familiarizing ourselves with our data (transcribing data, reviewing transcriptions for accuracy, reading transcriptions over and over, and noting initial ideas); (2) generating initial codes and searching for themes (collating codes into potential themes); (3) reviewing and redefining themes (exploring how strong the identified themes are by assisting the relationship between first [code] and second [theme] level of analysis, generating a thematic map of the analysis); and (4) further unpacking the analysis through the writing process (identifying themes and initial stigma concepts was further explored through a review of existing models of mental health stigma).

We compared each participant's journey to care (shared during the focus group), the pathway depicted during a semi-structured interview, and the participant's medical chart. Further, we performed an analysis within each ethnic group, comparing and contrasting young people's narratives with those of family members, and a cross-ethnic-group analysis. As a result, in the study findings we describe themes that were common across all the narratives as well as the ones that were different between the three ethnic groups. All young people's and family members' names used in this paper have been changed to ensure participants' confidentiality.

Rigour

Lincoln and Guba [20] defined primary criteria to assess rigour and trustworthiness of the qualitative research process. Primary criteria—credibility, authenticity, criticality, and integrity—are necessary to all qualitative enquiry but they are insufficient in and of themselves. Trustworthiness was achieved within the study through the following criteria: *credibility* and *authenticity*, attained through multiple sources of data (e.g., pathways maps generated from semi-structured interviews, chart reviews, focus groups' data) as well as specific and different sample strategies being employed to generate rich and meaningful data; *criticality* and *integrity,* using team debriefing and analysis to ensure methodological effectiveness.

Results

Overview of the sample

A total of 34 people took part in the study; 25 young people with lived experiences of psychosis (origins: European = 16, African = 5, Caribbean = 4) and nine family members (origins: European = 6, African = 0, Caribbean = 3). Table 2 reports the socio-demographic information for young people with lived experiences of psychosis only—no socio-demographic information was collected for family members at the time of the focus group.

Findings are presented in two main sections: (1) *Understanding help seeking*, in which we first present commonality across the three groups, and then we investigate differences in DUP between African-, Caribbean-, and European-origin groups. In this section we unpack the role of stigma and how it operates early on in pathways to care. In this paper, stigma refers to a collection of negative attitudes, beliefs about, and behaviours directed at people with mental disorders, which are manifested in rejection and avoidance of, and prejudice and discrimination against people with mental illness conditions [22-24]. Stigma can be a barrier for people who experience mental health problems by making them reluctant to ask for help due to fear of prejudice, being labelled, and discrimination by others. Internalized stigma, or self-stigma, occurs when a person takes on those negative stereotypes and assumptions and applies them to themselves [23, 24]. Discrimination due to mental health stigma can take place in different circumstances/settings: education, employment, housing, and treatment. (2) *Understanding delay in entering first-episode psychosis (FEP) programs*, in which we explore the relationship between negative experiences, stigma, health care delivery, and illness/symptoms disclosure. The themes presented in this section are also common across the three groups.

Understanding help seeking

Common across the three groups: Knowledge, awareness, and mental health stigma

Consistent across all narratives, for both young people and family members, was that knowledge or lack of knowledge about symptoms of psychosis, mental illness, and services available to them was key to them recognizing the significance of changes in behaviour. Often this knowledge was based on family members' or friends' past experiences of mental illness.

> Maria: The one person who really helped me to realize what I'm going through, and that I need help, is my mother. She knows what I'm going through because she went through it with my father. She helps me a lot. ...
>
> (European youth focus group)

Young people who did not have any knowledge of signs or symptoms of psychosis were aware of personal changes but did not know that they were indicative of mental illness. In these cases, family members played a key role in the help-seeking process by taking them to the hospital.

> Benjamin: I was schizophrenic, and I didn't know what to do. I heard voices and stuff. I did some stuff that I couldn't remember, so some people took me in …
>
> Paul: I kept hearing … weird voices, but I didn't know what is. So, later on I came … my parents took me to the hospital …
>
> (African youth focus group)
>
> Steve: I didn't know that I needed help. I had no one around me who knew what was happening. … I was staying with a friend, my mom was occasionally stopping by … she saw certain signs in me, and she immediately drove me to [name of the hospital].
>
> (Caribbean youth focus group)
>
> June: I wouldn't have stayed in the emergency room, I wouldn't have gone by myself … I didn't know what was going on. … I didn't know *I was going crazy*, … I thought everybody was against me.
>
> (European youth focus group)

Young people and family members who did not have awareness or knowledge of the signs or symptoms of psychosis, struggled the most to understand and/or make sense of the situations.

> Janine: I didn't know what this illness was. I thought it was just some kind of behaviours, being angry or strange like teenagers could possibly experience sometime … it was people from the outside who used to tell me ''No, this more than just … you know teenager's crisis.'' Not knowing [the] symptoms … I just didn't know what was going on really.

> (Caribbean family members' focus group)
>
> Louise: My son was 17 when he had his psychotic break. I thought he was just being a typical rebellious teenager … he smoked pot. He didn't get violent. He was so scared and I didn't know what else to do with him. I took him to [name of general hospital] … after about 15 hours convincing them that I was not taking him home, they admitted him.
>
> (European family members' focus group)

Often, family members attributed the changes in their relatives' behaviours to growing up/going through adolescence, peer groups/wrong crowds, stress, and/or substance abuse in young adults. Family members often thought that what their relatives were experiencing was just a temporary phase in their relatives' lives without recognizing signs or symptoms of psychosis. Help seeking often occurred after doubting the early signs of psychosis and, most importantly, after feeling sadness and discomfort.

Along with knowledge and awareness of signs or symptoms of psychosis, the role that stigma played during the help-seeking process was also constantly present in the narratives. Through the analysis conducted, it was possible to identify how individual and family perceptions of mental illness influenced the internalization of stigma. For example, young people involved in the study often distinguished between their rational understandings of the mental health problems, symptoms, and causes, and, at the same time, their feelings of being trapped in emotions such as shame.

> Karen: People are scared to look for help, and to …
>
> Maria: And to admit to themselves even ... [Karen: Yeah!] that "I have schizophrenia"… I never told anybody.
>
> June: I'm still ashamed of what I have.

> Samantha: Me too.
>
> (European youth focus group)

Participants described how, for fear of family members' and/or friends' reactions to their conditions, they tried to ignore the signs and symptoms by, for example, using marijuana, and attempted to hide their symptoms from others.

> Sandi: I was worried about what people around me might say … once you're in the hospital you can't really keep your secret anymore. There is a huge stigma about mental illness; people tend to like to avoid it.
>
> (European youth focus group)

Positive symptoms (e.g., hearing voices, bizarre behaviour, violence) were often catalysts to treatment initiation. Family members often struggled to recognize when their relative was no longer able to care for himself/herself or when he/she was asking for help as the symptoms of psychosis took over his/her ability to make decisions. This created quite a complex situation where family members felt threatened or worried about their safety and, at the same time, guilty when they had to call the emergency department, ambulance, or, unfortunately, the police. This was evident in family members' narratives.

> Natali: I have been there … I couldn't stop crying for days … when my daughter finally broke down at school ... being scary violent with us. … the first time she finally did get to the hospital that day [name of the hospital] … It was almost like a relief, she was safe and she was away from us … because we were scared. We were so afraid. [Sarah: (overlapping) Yes. Yes. Yeah.]
>
> (European family members' focus group)

Stigma was also closely connected to how much the person who experienced psychosis was considered responsible for his/her mental condition or was in control, or not, of his/her symptoms. Family members recognized that mental illness is not perceived the same as other health problems. Physical disorders, such as cancer, generate compassion in extended family members, whereas mental disorders bring reactions of distancing, blaming, and stigmatizing from members of the extended family.

> Natali: Unfortunately, I still see … my family members not so supportive. On the surface, they are, but I see them shy away from my son. I see the stigma, it is still so much there. If he was (clears throat) you know physically ill they would be right there.
>
> (European family members' focus group)

Overall, family members described how psychosis is hidden until it manifests through a person's behaviours. It is difficult to understand what is happening to the person as well as to assess if, when, and how to intervene.

Differences in help seeking between the three groups: Internalized stigma as feeling shame versus feeling guilty for their own condition

Participants of European origin internalized mental health stigma as shame about their symptoms (e.g., hearing voices, unpredictable or bizarre behaviours in front of family and friends, or irrational actions). They felt distress caused by the awareness of their past bizarre behaviours and a sense of humiliation for their conditions. In contrast, young people from African- and, even more, Caribbean-origin groups stressed their responsibility for their conditions, they felt that they had done something wrong (for having an mental illness), and they felt a sense of failure for not being able to "snap out of it"—as a participant described during a focus group. In this sense, they seemed to internalize mental health stigma as guilt—there is shame and humiliation but also they felt that they had done something wrong.

> Paul: … there was a lot of pressure to excel in school and succeed. I dabbled too much in, dabbled too much in drugs, that was my problem … that was really my fault. I have no one else to blame but myself … people expect you to just walk it off kind of thing. But you really, you really can't, you can't really walk off a mental illness … you can cope with it.
>
> (African youth focus group)
>
> Steve: Going through a mental illness totally flipped the way I view … everything! It's also made me become more aware of how family members react, and why are they reacting that way. Eventually it is what got me onto the culture of it, my religion, and so forth. I can't say exactly what it is about the Caribbean culture … but, I can tell, those two things definitely play a factor in it.
>
> (Caribbean youth focus group)

In the African and Caribbean focus groups, participants discussed the role that religion had in shaping their and their families' perceptions of mental illness and feelings of guilt for their condition—this topic was not discussed in the European focus groups. In some cases, people described how they grew up thinking that mental illness was a sin or God's punishment. Although they did not think in this way now, they saw how this perception influenced their understanding of early signs of psychosis, the focuses of their paranoid symptoms (in some cases), and, most importantly, their asking for help.

> Suzanne: Well, it made me feel badly because I thought, "Wow. You know, she's so nervous [mother] about me going to the hospital for help." It made me feel kind of ashamed that I needed help. … I guess it made me a little bit reluctant to seek care later on. [Later on in the interview] … in the beginning my mom was like, "Suzanne you need to PRAY more. That's the problem." And, I'm like, "No mom, I need medication. I need some help." … Sometimes I just tell her that I prayed just so she can get off my case. My brother often tell me that my life has gone in this direction because I stopped going to church. … It makes me feel bad. It's not helpful me to get better.
>
> (Caribbean youth interview)
>
> Greg: I can't say everybody but, A LOT of people in my family, and in the community … they become very superstitious. It's a mind job with Catholicism first of all—and no

> offense to anybody here who's Catholic, I am Catholic. Something simple as, as having a mental condition, is not simple in this world anymore, it becomes then, "that person needs to be exorcised, or that person's got bad demons—"
>
> Steve: (overlapping) Oh, I've heard … I've heard that, I've heard that, to get rid of my voices I have to get an exorcism.
>
> Greg: Yeah.
>
> Steve: That's what I heard from a friend.
>
> Greg: Like, my mom said that when she was uh, a kid, when she was like 5 or 6, she actually witnessed someone getting exorcised, because of voices in his head and stuff like that.
>
> (Caribbean youth focus group)

As described, African- and, even more, Caribbean-origin young people reported that their mental illnesses were taboos among members of their close or extended families. While young people of African origin had their families around to support their struggles, young people of Caribbean origin who attended the focus groups had no one or only a few close family members. The support networks that could assist them in seeking help were not available.

> Simone: When people in the Caribbean get to know that your child has this issue [mental illness] … the whole family is labelled … from the grandparent right the way down. The family is labelled and you are sort of ostracized. That's why many of us don't want to bring it up to the light … we are in denial that this is not happening to this family. … We, as parents, don't have the freedom to talk about it … because of the stigma that's still attached … we internalize it. When we internalize, we're stressed. We would love to know that there is somewhere that we can go and sit down and talk. We need to unload but we have no place to unload.
>
> (Caribbean family members' focus group)

African- and Caribbean-origin participants described how when they experienced early signs of psychosis, they tried to control them and they felt guilty if they were not able to. Their sense of guilt was also connected with cultural interpretation of mental illness as sin, God's punishment, and a taboo illness heavily stigmatized—themes more present in the Caribbean-origin focus group and interviews.

Understanding delay in entering first-episode psychosis programs (FEP)

> Rachel: Now none of these people [university psychological service/psychiatrist] told me about any other resources. ... All I knew was [name of mental health hospital], which was, like, the last resort. … I was in the dark. And then I went to my family doctor, and she was the first person after like 3 months who told us that, "Oh, there's actually an in-patient program at [name of a general hospital], for if you're in an emergency—go there." … So then when I got really bad, I was in the in-patient at [name of a general hospital] and there, it was when I actually found out about a bunch of other resources …"
>
> (European youth focus group)

Participants often recognized changes in behaviours and thinking but they did not always attribute these to a mental illness; however they were active in seeking help, contacting community services (e.g., school or university health services) or their family doctors, if they had one. In reflecting on their pathways, they often felt upset, as early attempts to ask for help were dismissed by providers and/or information was not provided to them.

Negative experiences, stigma and care: First contact, therapeutic relationship, and disclosure of symptoms

Once in the system, groups' differences in the journeys to specialized treatment seemed less present. Before entering into early intervention programs, young people saw between four and six difference health providers/services (e.g., family doctor, emergency, police, detention centre, in-patient unit). As young people described, the care they received (or did not receive) and health care providers' attitudes towards mental illness influenced what they shared about their mental states (e.g., hearing voices, suicidal thoughts) and, overall, their trust in the system. From the first contact with a hospital, the majority of young people involved in the focus groups reported that, if it was a negative experience, it affected their therapeutic relationships, and, generally, their willingness to stay in the system and to return, if needed, a second time.

> Samantha: From my experience there's a lot of stigma and shame surrounding people who have substance abuse problems. Whenever I've been in treatment, there has not been an accepting atmosphere for me to discuss my issues or to make me feel like I'm actually going to get help.
>
> (European youth focus group)

> Steve: Well, I found, like, a number of them [mental health care providers] definitely helped. I feel that the majority of [hospital name] staff definitely does have that, but there are still the ones that can create that negative experience for you when you're already going through a negative experience. … It's funny … you're going through stuff, even though your mind's not in the right place, you still remember all the negativity. … [Andy: (overlapping) Yeah.] Yeah. Those are the things that I will always remember, about [name of the hospital] and dealing with [the staff] at the first time. Like, although they were there to help me, it didn't seem like half had actually studied mental health at all.
>
> (Caribbean youth focus group)

During the focus groups and interviews, participants reported how their experiences of poor quality of care was due to health providers' negative attitudes and behaviours towards mental illness. Indeed, stigma does operate, albeit marginally, in mental health services, such as primary care (e.g., family doctors), emergency departments, in-patient units, out-patient units, and so on and, when present, it seems to be more hurtful than when experienced outside the health care system.

Eight young people who took part in the focus groups had police and detention centres as early contacts in their pathways to FEP treatment. Overall, police officers were perceived to be supportive, helpful, and understanding of the situations. Police officers have the duty to respond to an emergency call, accompany the person to the hospital emergency room, and stay with them until the hospital staff takes over.

> Linda: I did it twice. The first time, I went to the hospital was in an ambulance, and, the second time was … in a police car. I actually found the police were nice. Like, I was in handcuffs [laughter], but I found them to be really nice … they stayed with me until the doctors started seeing me. They didn't judge me, and I asked the one cop if he was married … he was like showing me pictures of his kids. He was just nice.
>
> (European youth focus group)

Three men of European origin had forensic services in their pathways. In these cases, the young men had to stay in detention for several days before they were able to see a judge. During the focus groups they described how they were exposed to verbal and physical violence as well as the trauma of experiencing psychotic episodes while in detention.

> Rob: Well, for me the cops were ok. But, then at the detention centre, I said something really dumb to the correctional officer and … I'm walking … he literally just POUNDS me, he beat the shit out of me. Right there on the ground. I wasn't shaken by it at all because I was psychotic, but like—I don't know, it was really weird. He literally took me from behind and just pounded me. I guess his superior comes in and takes him off me. I guess the cops are ok but the guys in the jail …
>
> Matt: Yeah, I had the same experience. One time, when I was psychotic, my mom called the police on me ... She meant for me to go to the hospital but I got charged by the police with a bunch of things. They sent me to JAIL, and I was completely psychotic … they didn't know what to do with me. They were physical with me, they injected me in the back of my neck with I don't know what medication. They just locked me in a jail cell for probably a month until I was transferred to a medical facility.
>
> (European youth focus group)

It was interesting to notice that men of European origin were able to share these experiences during the focus group, whereas men of African and Caribbean origin just mentioned police involvement in their pathways without elaborating on it. We realized the sensitivity of this topic which, combined with the sense of guilt, probably precluded any further disclosure.

In total, 10 youth had family doctors as first contact in their pathways. Among all focus groups, there was only one case in which referral was made to an FEP program directly by a general practitioner. The majority of them reported to have been misdiagnosed or had their symptoms dismissed by their family doctors.

> Benjamin: ... the family doctor doesn't, uh well, didn't work for me, he thought it was just anxiety, like … anxiety because of school … 'cause I was going into university.
>
> (African youth focus group)

In other cases, a young man and woman described how their family doctors focused only on their substance abuse problems and reprimanded them for their behaviours.

> Steve: I kind of did [went to see my family doctor at first], but, he turned me down flatly, 'cause I was smoking weed. I said, "I thinking, I'm suffering with depression." He asked me if I did drugs, I said that I did smoke weed quite often, and he said stop smoking the weed then "come back and I help you." I never heard about it after that. Next time, I saw him, I had to tell him that, yeah, I was diagnosed with schizophrenia. So, my general practitioner, unfortunately, wasn't able to do anything at the time.
>
> (Caribbean youth focus group)
>
> Jill: I recognized the symptoms but I didn't know the specifics of my diagnosis. I went to the family doctor and explained that I felt that I was being followed and everything. And then he told me, "Okay. You need to stop doing drugs," 'cause I was high on marijuana when it first happened … but [it happened] several time [before] and I just thought it was the pot.
>
> (African youth interview)

It may be difficult for general practitioners to diagnose psychosis early; however, participants felt that they had actively sought help but their requests were misunderstood or dismissed.

When admitted to emergency units or in-patient services, participants described the following negative experiences: being labelled, feeling like a number, feeling no longer a person but an illness, being judged for behaviours/symptoms, and/or being treated like a child.

> Matt: I don't know, how it makes sense, but [hospital staff] were almost like TOO nice … I don't know the word, like, treating you like you're a child … talking down to you. It was NICE, but it didn't make me feel better … other people were nice but, at the same time … made you feel like an equal. I felt like that was important.
>
> Steve: I think maybe the word you were looking for was "pity." Like we were treated with PITY [Matt: Yeah.] Yeah. I think that, people think that people with schizophrenia are somehow STUPIDER or something … I don't think people with schizophrenia are stupid at all.
>
> (European youth focus group)
>
> Robin: They treat you like a number [mumbles of agreement].
>
> Samantha: When I went to the hospital last time … I was going through a panic attack when I FIRST found out I had schizophrenia, and they, the nurse was like, "Yeah, you're just faking it, you're perfectly fine, nothing's wrong with you.'"
>
> Robin: Yeah.
>
> Samantha: It really, made me not like being in the hospital. I did not want to go back there ever.
>
> Natali: I agree. I think they treat you more like a number. And I think, being treated like a PERSON instead of a number or a case because, if you're just a case, you're like "I'm schizophrenic"… you're not a person, anymore [mumbles of agreement].
>
> (European youth focus group)

According to young people, all of these factors influenced the therapeutic relationship with services and providers and, in particular, affected young people's disclosures of symptoms—as described.

Discussion

Differences in pathways to care and the duration of untreated psychosis have been reported in some studies of ethnic minority groups [13, 16]. The reasons for these differences are unclear [25]. In this paper, the authors focused on participants' narrative accounts to investigate the social and cultural contexts of help seeking. In doing so, we were able to further investigate differences between the groups as well as how a number of factors, including stigma, influenced both help seeking and access to specialized programs. We developed preliminary hypotheses about the link between internalized stigma, cultural beliefs about mental illness, and help seeking. At the same time, we discussed how interactions with health care settings shape the experience of asking for help, influencing future engagement with health providers and/or willingness to disclose symptoms.

In our attempt to understand differences in the pathways to care and DUP between African-, Caribbean-, and European-origin groups, we found similarities to other studies that broadly explore help seeking among young people in FEP programs [26, 27] and their families [28-33] without focusing on ethnicity. As with our findings, other qualitative works described long and difficult periods from the realization of signs and symptoms of psychosis to the initiation of help seeking [28-31]. As other studies reported, family members described how the role of caregiver was emotionally draining [32] due to their inability to understand and cope with the changes in their family members, feelings of guilt after calling the police, as well as frustration of their inability to navigate the health care system and/or lack of involvement in the treatment program [33]. Family members' knowledge of mental illness and services available to them was important in dealing with the situations. However, as other studies described, they often mistook early signs of psychosis—especially in the prodromal phase of the illness—for mood changes due to adolescence, social withdrawal, stress, or drugs [26-30]. At the same time, even if the young people who took part in our study recognized changes in themselves, they did not attribute these changes to mental illness—as was also described in other studies [26, 30]. Moreover, as we discussed, because of the associated stigma, young people and family members engaged in denial, avoidance, and hiding of early symptoms of psychosis which prevented them from seeking help [26-34].

In *Stigma*, Goffman [22] defined and discussed stigma as *discredited* versus *discreditable*; in the first case, a visible and physical mark defines stigma, where, in the second, no visible or physical mark is present—as is the case with the stigma of mental illness. More recently, further theories have been developed and used to understand the relationship between stigma and mental illness (see Link & Phelan [23], and Corrigan [24]). In all of these theories, stigma is based on signs that define who is different, stereotypes about the person or group, marginalization, avoidance, discrimination, fear of what or who is different—where normality and abnormality or similarity and difference are defined by socio-cultural norms and beliefs. Furthermore, internalized stigma seems more distractive and harmful to the affected person's health and, broadly, to his/her sense of self [35].

Several studies investigate stigma and mental illness [33, 35, 36]. Stigma about mental illness is prevalent in the general public but, unfortunately, occurs in health and mental health settings as well [36]. Work done in the Canadian context recognizes the role of stigma in seeking help for mental illness in immigrant and refugee groups in Canada. The *Improving mental health services for immigrant, refugee, ethno-cultural and racialized groups: Issues and options for service development* report describes how immigrants, refugees, and racialized groups are less likely to ask about mental health systems because of possible stigma and this leads either to people not getting treatment or to a delay in getting treatment [15]. Other studies describe the specific needs and issues that immigrant groups are facing in relation to mental health services in urban settings in Canada [37, 38]. These studies, which were conducted with West Indian immigrants in Montreal, focus on cultural beliefs in non-medical interventions as the preferred form of treatment for mental illness (e.g., prayer or traditional folk medicine) or on the perception of primary care (e.g., doctors often prescribing pharmaceutical medications, or lack of time from physicians in early encounters that deterred the use of current health services) [37, 38].

There are similarities but also differences with our findings compared to other studies. This paper describes how stigma operated on young people and family members of African, Caribbean, and European origin and how it influenced the help-seeking process. Although all young participants internalized stigma as shame, fearing lifelong discrimination for their mental health conditions, which often prevented them from disclosing their symptoms to others and ask for professional help, those of African and Caribbean origin also internalized a sense of guilt for their conditions, holding them back from talking about their problems as well as pushing them to try to overcome their symptoms alone.

As mentioned, Caribbean young people described the role of cultural beliefs about mental illness and of religion in delay in getting treatment. African and Caribbean young people were able to distinguish the difference between their own beliefs about mental illness and those of their cultural groups. They were critical of traditional cultural beliefs, that see mental illness as a sin for which praying to God is a solution. However, the stigma has been internalized as guilt, which influenced their decisions to seek help. It could be that young people of Caribbean origin waited longer to ask for help as a way to protect their families from being labelled with a taboo illness; future studies are needed to verify this hypothesis. As family members of Caribbean origin described, there is a desire and need to find a space and place to bring to light these issues: "We need to unload but we have no place to unload."

Although the analysis presented in this paper helps in the understanding of some of the differences in DUP between African-, Caribbean-, and European-origin immigrants, we recognize that this work has some limitations First, the sample size in this study was relatively small; only limited inferences can be drawn for other groups. Second, as described, the sample size was defined from the quantitative part of the study. We were not able to involve any family members of African origin as our original pool of participants was very small. Finally, there are many different ways to group people from different ethnic groups and races. Our classification was subjective, based on self-identification. At the same time, arbitrary choices were made for the analysis of the quantitative part of the study—focus groups were based on these decisions. We acknowledge that this did not necessarily reflect the fluidity of ethnic differences and diversity of identities represented by the participants.

We were able to ask both young people and family members for possible strategies which could be used to support people in the help-seeking process and for ideas about how the system of care could be improved (see Table 3). All participants described the importance of anti-stigma initiatives in different settings (e.g., schools, universities, primary care services/providers) and targeted to different groups. Anti-stigma initiatives could challenge wrong beliefs and stereotypes around mental illness and, in particular, psychosis and raise awareness about psychosis signs and symptoms to promote problem recognition. This could empower young people as well as adults around them to promptly intervene if needed. Furthermore, more knowledge about systems of care, early intervention programs, treatment options, and positive prognosis promoted by early intervention can help young people and family members to initiate help seeking and to better navigate the system. At the same time, sensitivity training should be offered for general practitioners and emergency-room staff to promote self-awareness on mental illness bias, the impact of stigma toward mental illness in access to care and/or therapeutic relationships, and general information on early intervention programs, resources, and services. Based on our findings, anti-stigma initiatives should be developed through the lens of ethnocultural knowledge of and beliefs about mental health problems.

Conclusion

The findings of this study suggest that stigma, especially internalized stigma, operates in different ways in European-, African-, and Caribbean-origin individuals and that this could explain the differences in the pathways to early intervention services for psychosis for these young people. These findings could inform the development of targeted anti-stigma campaigns as well as the implementation of more equitable services for people in early stages of psychosis. To do so, trust needs to be redefined and gained between ethnocultural groups and mental health researchers/providers both in research and in clinical practice. Implementing a community-based participatory framework could help to achieve this goal.

Contributorship statement KM contributed to the conception of the study. MF, NF, KA, and KM developed the qualitative study protocol and materials. MF and NF implemented the focus groups and MF implemented the individual interviews. MF performed data analysis, assisted by NF; they presented findings to all the authors in different stages of the process. MF wrote the manuscript and it was than revised by KM. All authors reviewed and approved the final manuscript.

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Table 1

Focus Group and Interview Questions: **Young people**	**Focus Group and Interview Questions:** **Family members**
Opening question: Tell us your name and why you decided to participate in this focus group? **Introductory:** 2. How long have you been in the program? And, if you feel like sharing it, how did you come into contact with the first-episode psychosis services?	**Opening question:** Tell us your name and why you decided to participate in this focus group? **Introductory:** 2. If you feel like sharing it, how did [the person who refered you to the focus group, he/she can be your son/daughter, etc.] come into contact with mental health services the first time?

Key questions: Based on all interviews that we conducted so far we were able to identify that: First, the help-seeking process is very complex, as you can see, many people, places, circumstances and factors are involved; Why do they think this happens? Second, we were able to identify some of the key people involved in this journey and we would like to know more from you about their roles. NOTE: For each provider we explore what was helpful and/or less helpful or frustrating. Specific question based on the analysis done (e.g., The Caribbean population have really long delays–why do they think this happens?)	**Key questions:** Based on all interviews that we conducted so far we were able to identify that: First, the help-seeking process is very complex, as you can see, many people, places, circumstances and factors are involved; Why do they think this happens? Second, we were able to identify some of the key people involved in this journey, you already mentioned some of them, we would like to know more from you about their roles. NOTE: For each provider we explore what was helpful and/or less helpful or frustrating.
Ending questions: We want to know how to improve the services. What can be done to better help people that experience early symptoms of psychosis to have access to treatment? Is there anything that we missed?	**Ending questions:** We want to know how to improve the services. What can be done to better help people that experience early symptoms of psychosis to have access to treatment? Is there anything you want to say that we did not ask or you did not talk about today that you want to add?

Table 2

Variables	**N**	**(%)**
Sex		
Male	13	(52)
Female	12	(48)
Education		
>High school	8	(32)
≤High school	17	(68)

Born in Canada		
Yes	17	(68)
No	8	(32)
English Spoken at home		
Yes	18	(72)
No	5	(20)
English and other	2	(8)
Sexual Orientation		
Heterosexual	21	(84)
Homosexual	1	(4)
Bisexual	2	(8)
Other	1	(4)
Relationship Status		
Single	23	(92)
Married	0	(0)
Cohabiting	1	(4)
Separated/Divorced	1	(4)
Parents Born in Canada		
Both	5	(20)
Father Only	4	(16)
Mother Only	2	(8)
Not born in Canada	14	(56)

Table 3

1. Universal and selected prevention interventions in school are needed:
    - Education in school settings,
    - Early detection efforts should focus on identifying the full spectrum of psychotic symptoms. As youth described, withdrawal and, broadly, negative symptoms, often occur before the psychosis develops. However, these symptoms are often questioned and neglected by family members and health providers;
2. Anti-stigma initiatives are needed and should be developed through the lens of cultural knowledge of and beliefs about mental health problems;
3. Increased family involvement should be encouraged;
4. Self-referral to early intervention services may be beneficial and the possibility for a triage model should be explored;

5. Sensitivity training should be offered for general practitioners and emergency staff on recognition, mental illness/gender bias resources, and services;

6. Sensitivity training should be offered for police and detention center staff.