

BMJ Open

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Journal:	<i>BMJ Open</i>
Manuscript ID:	bmjopen-2014-006562
Article Type:	Research
Date Submitted by the Author:	08-Sep-2014
Complete List of Authors:	Ferrari, Manuela; Centre for Addiction and Mental Health (CAMH), Social Aetiology of Mental Illness (SAMI) Training Program -CIHR Strategic Training; York University, School of Health Policy and Management Flora, Nina; Centre for Addiction and Mental Health (CAMH), Anderson, Kelly; Western University, Department of Epidemiology & Biostatistics Tuck, Andrew; Centre for Addiction and Mental Health (CAMH), Archie, Suzanne; McMaster University, Department of Psychiatry and Behavioural Neurosciences Kidd, Sean; Centre for Addiction and Mental Health (CAMH), McKenzie, Kwame; Centre for Addiction and Mental Health (CAMH),
Primary Subject Heading:	Mental health
Secondary Subject Heading:	Qualitative research, Health services research
Keywords:	Schizophrenia & psychotic disorders < PSYCHIATRY, QUALITATIVE RESEARCH, Child & adolescent psychiatry < PSYCHIATRY

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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.

Manuela Ferrari,^a Nina Flora,^a Kelly K. Anderson,^b Andrew Tuck,^a Suzanne Archie,^c Sean Kidd,^{a,d} & Kwame McKenzie^{a,d} on behalf of the ACE Project Team

^a *Social and Epidemiological Research, Centre for Addiction and Mental Health (CAMH)*

Toronto, Ontario, Canada

^b *Department of Epidemiology & Biostatistics, Western University, London, Ontario, Canada*

^c *Department of Psychiatry and Behavioural Neurosciences, McMaster University*

Hamilton, Ontario, Canada

^d *Department of Psychiatry, University of Toronto*

Toronto, Ontario, Canada

Correspondence:

Manuela Ferrari, PhD

Social and Epidemiological Research

Centre for Addiction and Mental Health (CAMH)

455 Spadina Avenue, Suite 300

Toronto, ON M5S 2G8 CANADA

Phone: (416)535-8501 ext. 77614 Fax: (416) 979-0564

E-mail: manuela.ferrari@camh.ca

Word count : 6,433

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 used to inform 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

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3 European group. African group members in the study more often had an emergency
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5 department as first contact in their pathways [17].
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9 Once disparities have been identified, understanding of the reasons why they may exist
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11 is necessary if we are to develop effective services. This paper reports a qualitative exploration
12
13 of the reasons for differences in pathways to care and DUP in the ACE Study from the
14
15 perspective of respondents to the study and their families. The aim was to understand
16
17 differences in DUP between African-, Caribbean-, and European-origin groups. To do so, we
18
19 explored young people's and their family members' journeys of seeking help for psychosis,
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21 investigating how people responded to early signs of psychosis as well as the roles that
22
23 different people and services played in accessing specialized programs for psychosis.
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29 **Methods**

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31
32 This study used an inductive qualitative approach to examine differences in the routes
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34 to care between young people with lived experience of psychosis of African-, Caribbean-, and
35
36 European-origin. Focus groups were used as a means of generating in-depth knowledge of
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38 pathways to care, exploring the interaction between individual socio-cultural positions, young
39
40 people' experiences of seeking help, and group dynamics—as each participant's narrative is
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42 generated out of the journeys of others. By using focus groups we were able to examine how
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44 participants (1) interacted with each other; (2) produced and reproduced knowledge; and (3)
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46 articulated and/or defended their views [18].
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53 *Participant Recruitment*

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

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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

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3 be conversational, open, and clear. They unfolded according to Krueger and Casey's
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5 recommendations: opening, introductory, transition, key, ending [18]. At the end of each focus
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7 group, the research team involved in the focus group completed 30–40 minutes of debriefing.
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10 During the focus groups, participants were presented with preliminary ACE Study quantitative
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12 data; we focused on the differences in DUP as well as pathways to care and asked participants
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14 to comment on them.
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19 Focus groups and in-depth interviews were digitally recorded. The digital audio files
20
21 were transcribed by the research assistants and reviewed for data accuracy. One research
22
23 assistant transcribed a focus group and the other reviewed the work done. Finally, all material
24
25 was also reviewed by MF. Focus group transcripts were then prepared to facilitate thematic
26
27 analyses. All participant names were changed to pseudonyms to ensure confidentiality.
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33 Traditional data saturation, that is, “collecting data until no new information is
34
35 obtained,” [19, p. 147] is often an object of controversy in qualitative research literature [19].
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37 We used instead Morse's criterion of data saturation as “adequacy” of the data, which can be
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39 obtained through specific methodological choices. These methodological choices were (a)
40
41 selecting and working with an ethnic- and gender-cohesive sample; (b) at the same time,
42
43 working with three different ethnocultural groups so as to maximize and explore cultural
44
45 contrasts in pathways to care—a gap in current literature; and (c) basing our sample on
46
47 quantitative data analysis, which allowed focus-group member checks on the quantitative
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49 findings, as well as the possibility for rich, full, and complete understanding.
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56 Finally, Lincoln and Guba [20] defined primary criteria to assess rigour and
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3 trustworthiness of the qualitative research process. Primary criteria—credibility, authenticity,
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6 criticality, and integrity—are necessary to all qualitative enquiry but they are insufficient in and
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9 of themselves. Trustworthiness was achieved within the study through the following criteria:
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11 *credibility* and *authenticity*, attained through multiple sources of data (e.g., pathways maps
12
13 generated from semi-structured interviews, chart reviews, focus groups' data) as well as
14
15 specific and different sample strategies being employed to generate rich and meaningful data;
16
17
18 *criticality* and *integrity*, using team debriefing and analysis to ensure methodological
19
20 effectiveness.
21

22 23 24 *Analysis*

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28 Thematic analysis was employed to identify, analyze, and report patterns or themes
29
30 within data [20]. Our thematic analysis was data driven, rather than theoretically driven,
31
32 making use of an inductive approach, as the themes identified were strongly linked to the data
33
34 themselves. We followed Braun and Clark's steps [21] of thematic analysis. We compared each
35
36 participant's journey to care (shared during the focus group), the pathway depicted during a
37
38 semi-structured interview, and the participant's medical chart. Further, we performed an
39
40 analysis within each ethnic group, comparing and contrasting young people's narratives with
41
42 those of family members, and a cross-ethnic-group analysis. As a result, in the study findings we
43
44 describe themes that were common across all the narratives as well as the ones that were
45
46 different between the three ethnic groups.
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52 53 54 55 **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'

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3 confidentiality.

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7 *Understand help seeking*

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

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12 Consistent across all narratives, for both young people and family members, was that
13 knowledge or lack of knowledge about symptoms of psychosis, mental illness, and services
14 available to them was key to them recognizing the significance of changes in behaviour. Often
15 this knowledge was based on family members' or friends' past experiences of mental illness.
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24 Maria: The one person who really helped me to realize what I'm going through, and that I
25 need help, is my mother. She knows what I'm going through because she went through it
26 with my father. She helps me a lot ...
27

28 (European youth focus group)
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32 Young people who did not have any knowledge of signs or symptoms of psychosis were
33 aware of personal changes but did not know that they were indicative of mental illness. In
34 these cases, family members played a key role in the help-seeking process by taking them to
35 the hospital.
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43 Benjamin: I was schizophrenic, and I didn't know what to do. I heard voices and stuff. I did
44 some stuff that I couldn't remember, so some people took me in-

45
46 Paul: I kept hearing ... weird voices, but I didn't know what is. So, later on I came ... my
47 parents took me to the hospital ...
48

49 (African youth focus group)
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52 Steve: I didn't know that I needed help. I had no one around me who knew what was
53 happening. ... I was staying with a friend, my mom was occasionally stopping by ... she saw
54 certain signs in me, and she immediately drove me to [name of the hospital].
55

56 (Caribbean youth focus group)
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3 June: I wouldn't have stayed in the emergency room, I wouldn't have gone by myself ... I
4 didn't know what was going on. ... I didn't know *I was going crazy*, ... I thought everybody
5 was against me.
6

7
8 (European youth focus group)
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12 Young people and family members who did not have awareness or knowledge of the signs or
13 symptoms of psychosis struggled the most to understand and/or make sense of the situations.
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18 Janine: I didn't know what this illness was. I thought it was just some kind of behaviours,
19 being angry or strange like teenagers could possibly experience sometime ... it was people
20 from the outside who used to tell me "No this more than just ... you know teenager's
21 crisis." Not knowing [the] symptoms ... I just didn't know what was going on really.
22

23
24 (Caribbean family members' focus group)
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28 Louise: My son was 17 when he had his psychotic break. I thought he was just being a
29 typical rebellious teenager ... he smoked pot. He didn't get violent. He was so scared and I
30 didn't know what else to do with him. I took him to (name of general hospital) ... after
31 about 15 hours convincing them that I was not taking him home, they admitted him.
32

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34 (European family members' focus group)
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38 Often, family members attributed the changes in their relatives' behaviour to growing up/going
39 through adolescence, peer groups/wrong crowds, stress, and/or substance abuse in young
40 adults. Family members often thought that what their relatives were experiencing was just a
41 temporary phase in their relatives' lives without recognizing signs or symptoms of psychosis.
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43 Help seeking often occurred after doubting the early signs of psychosis and, most importantly,
44 after feeling sadness and discomfort.
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54 Along with knowledge and awareness of signs or symptoms of psychosis, the role that
55 stigma played during the help-seeking process was also constantly present in the narratives.
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3 Through the analysis conducted, it was possible to identify how individual and family
4 perceptions of mental illness influenced the internalization of stigma. For example, young
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6 people involved in the study often distinguished between their rational understandings of the
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8 mental health problems, symptoms, and causes, and, at the same time, their feelings of being
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10 trapped in emotions such as shame.
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17 Karen: People are scared to look for help, and to ...

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19 Maria: And to admit to themselves even ... [Karen: Yeah!] that “I have schizophrenia”... I
20 never told anybody.
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22 June: I’m still ashamed of what I have.
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24 Samantha: Me too.
25

26 (European youth focus group)
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31 Participants described how, for fear of family members’ and/or friends’ reactions to their
32 conditions, they tried to ignore the signs and symptoms by, for example, using marijuana, and
33 attempted to hide their symptoms from others.
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37 Sandi: I was worried about what people around me might say ... once you’re in the
38 hospital you can’t really keep your secret anymore. There is a huge stigma about mental
39 illness; people tend to like to avoid it.
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42 (European youth focus group)
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47 Positive symptoms (e.g., hearing voices, bizarre behaviour, violence) were often
48 catalysts to treatment initiation. Family members often struggled to recognize when their
49 relative was no longer able to care for himself/herself or when he/she was asking for help as
50 the symptoms of psychosis took over his/her ability to make decisions. This created quite a
51 complex situation where family members felt threatened or worried about their safety and, at
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3 the same time, guilty when they had to call the emergency department, ambulance, or,
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6 unfortunately, the police. This was evident in family members' narratives.
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10 Natali: I have been there ... I couldn't stop crying for days ... when my daughter finally
11 broke down at school ... being scary violent with us. ... the first time she finally did get to
12 the hospital that day [name of the hospital] ... It was almost like a relief, she was safe and
13 she was away from us ... because we were scared. We were so afraid. [Sarah:
14 (overlapping) Yes. Yes. Yeah.]
15

16 (European family members' focus group)
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21 Stigma was also closely connected to how much the person who experienced psychosis was
22 considered responsible for his/her mental condition or was in control, or not, of his/her
23 symptoms. Family members recognized that mental illness is not perceived the same as other
24 health problems. Physical disorders, such as cancer, generate compassion in extended family
25 members, whereas mental disorders bring reactions of distancing, blaming, and stigmatizing
26 from members of the extended family.
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33 Natali: Unfortunately, I still see ... my family members not so supportive. On the surface,
34 they are, but I see them shy away from my son. I see the stigma, it is still so much there. If
35 she was (clears throat) you know physically ill they would be right there.
36

37 (European family members' focus group)
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42 Overall, family members described how psychosis is hidden until it manifests through a
43 person's behaviours. It is difficult to understand what is happening to the person as well as to
44 assess if, when, and how to intervene.
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50 Differences in help seeking between the three groups: Internalized stigma as feeling shame
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52 versus feeling guilty for their own condition
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56 Participants of European origin internalized mental health stigma as shame about their
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3 symptoms (e.g., hearing voices, unpredictable or bizarre behaviours in front of family and
4 friends, or irrational actions). They felt distress caused by the awareness of their past bizarre
5 behaviours and a sense of humiliation for their conditions. In contrast, young people from
6 African- and, even more, Caribbean-origin groups stressed their responsibility for their
7 conditions, they felt that they committed something wrong (for having an mental illness), and a
8 sense of failure for not being able to “snap out of it”—as a participant described during a focus
9 group. In this sense, they seemed to internalize mental health stigma as guilt—there is shame
10 and humiliation but also they felt that they had done something wrong
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24 Paul: ... there was a lot of pressure to excel in school and succeed. I dabbled too much in,
25 dabbled too much in drugs, that was my problem ... that was really my fault. I have no
26 one else to blame but myself ... people expect you to just walk it off kind of thing. But you
27 really, you really can't, you can't really walk off a mental illness ... you can cope with it.
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29

30 (African youth focus group)
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32 Steve: Going through a mental illness totally flipped the way I view ... everything! It's also
33 made me become more aware of how family members react, and why are they reacting
34 that way. Eventually it is what got me onto the culture of it, my religion, and so forth. I
35 can't say exactly what it is about the Caribbean culture ... but, I can tell, those two things
36 definitely play a factor in it.
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39 (Caribbean youth focus group)
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44 In the African and Caribbean focus groups, participants discussed the role that religion
45 had in shaping their and their families' perceptions of mental illness and feelings of guilt for
46 their condition—this topic was not discussed in the European focus groups. In some cases,
47 people described how they grew up thinking that mental illness was a sin or God's punishment.
48 Although they did not think in this way now, they saw how this perception influenced their
49 understanding of early signs of psychosis, the focuses of their paranoid symptoms (in some
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3 cases), and, most importantly, their asking for help.
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7 Suzanne: Well, it made me feel badly because I thought, “Wow. You know, she’s so
8 nervous [mother] about me going to the hospital for help.” It made me feel kind of
9 ashamed that I needed help. And then, my mom called me CRAZY. She didn’t call me
10 mentally ill. She said, you know, “Suzanne is little crazy”... she wasn’t using the right
11 terminology, but that hurt my feelings. Yeah. I guess it made me a little bit reluctant to
12 seek care later on. [Later on in the interview] ... in the beginning my mom was like,
13 “Suzanne you need to PRAY more. That’s the problem.” And, I’m like, “No mom, I need
14 medication. I need some help.” Mom said, “It’s ‘cause you’re not praying enough and
15 because you stopped going to church.” And now she’s like, “Suzanne, did you pray
16 today?” And I’m like, “Mom, no I didn’t pray.” And she’s like, “I’m telling you you’ll get
17 better, if you start praying.” She REALLY BELIEVES it. Sometimes I just tell her that I
18 prayed just so she can get off my case. My brother often tell me that my life has gone in
19 this direction because I stopped going to church. ... It makes me feel bad. It’s not helpful
20 me to get better.
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25 (Caribbean youth interview)
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29 Greg: I can’t say everybody but, A LOT of people in my family, and in the community ...
30 they become very superstitious. It’s a mind job with Catholicism first of all—and no
31 offense to anybody here who’s Catholic, I am Catholic. Something simple as, as having a
32 mental condition, is not simple in this world anymore, it becomes then, “that person
33 needs to be exorcised, or that person’s got bad demons—”
34
35

36 Steve: (overlapping) Oh, I’ve heard ... I’ve heard that, I’ve heard that, to get rid of my
37 voices I have to get an exorcism.
38
39

40 Greg: Yeah.
41

42 Steve: That’s what I heard from a friend.
43

44 Greg: Like, my mom said that when she was uh, a kid, when she was like 5 or 6, she
45 actually witnessed someone getting exorcised, because of voices in his head and stuff like
46 that.
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49 (Caribbean youth focus group)
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53 As described, African- and, even more, Caribbean-origin young people reported that their
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55 mental illnesses were taboos among members of their close or extended families. While young
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3 people of African origin had their families around to support their struggles, young people of
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5 Caribbean origin who attended the focus groups had no one or only a few close family
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7 members. The support networks that could assist them in seeking help were not available.
8
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11 Simone: When people in the Caribbean get to know that your child has this issue [mental
12 illness] ... the whole family is labelled ... from the grandparent right the way down. The
13 family is labelled and you are sort of ostracized. That's why many of us don't want to
14 bring it up to the light ... we are in denial that this is not happening to this family. ... We,
15 as parents, don't have the freedom to talk about it ... because of the stigma that's still
16 attached ... we internalize it. When we internalize, we're stressed. We would love to know
17 that there is somewhere that we can go and sit down and talk. We need to unload but we
18 have no place to unload.
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22 (Caribbean family members' focus group)
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27 African- and Caribbean-origin participants described how when they experienced early
28 signs of psychosis they tried to control them and they felt guilty if they were not able to. Their
29 sense of guilt was also connected with cultural interpretation of mental illness as sin, God's
30 punishment, and a taboo illness heavily stigmatized—themes more present in the Caribbean-
31 origin focus group and interviews.
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36 37 *Understanding delay in entering first-episode psychosis programs (FEP)* 38 39

40 Rachel: Now none of these people [university psychological service/psychiatrist] told me
41 about any other resources. ... All I knew was [name of mental health hospital], which was,
42 like, the last resort. ... I was in the dark. And then I went to my family doctor, and she was
43 the first person after like 3 months who told us that, "Oh, there's actually an inpatient
44 program at [name of a general hospital], for if you're in an emergency—go there." ... So
45 then when I got really bad, I was in the inpatient at [name of a general hospital] and
46 there, it was when I actually found out about a bunch of other resources ..."
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50 (European youth focus group)
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54 Participants often recognized changes in behaviours and thinking but they did not always
55 attribute these to a mental illness; however they were active in seeking help, contacting
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3 community services (e.g., school or university health services) or their family doctors, if they
4 had one. In reflecting on their pathways, they often felt upset, as early attempts to ask for help
5 were dismissed by providers and/or information was not provided to them.
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11 Negative experiences, stigma and care: First contact, therapeutic relationship, and disclosure of
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17 Once in the system, groups' differences in the journeys to specialized treatment seemed
18 less present. Before entering into early intervention programs, young people saw between four
19 and six difference health providers/services (e.g., family doctor, emergency, police, detention
20 centre, in-patient unit). As young people described, the care they received (or did not receive)
21 and health care providers' attitudes towards mental illness influenced what they shared about
22 their mental states (e.g., hearing voices, suicidal thoughts) and, overall, their trust in the
23 system. From the first contact with a hospital, the majority of young people involved in the
24 focus groups reported that, if it was a negative experience, it affected their therapeutic
25 relationships, and, generally, their willingness to stay in the system and to return, if needed, a
26 second time.
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43 Samantha: From my experience there's a lot of stigma and shame surrounding people
44 who have substance abuse problems. Whenever I've been in treatment, there has not
45 been an accepting atmosphere for me to discuss my issues or to make me feel like I'm
46 actually going to get help.
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49 (European youth focus group)
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53 Steve: Well, I found, like, a number of them [mental health care providers] definitely
54 helped. I feel that the majority of [hospital name] staff definitely does have that, but
55 there are still the ones that can create that negative experience for you when you're
56 already going through a negative experience. ... It's funny ... you're going through stuff,
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3 even though your mind's not in the right place, you still remember all the negativity. ...
4 [Andy: (overlapping) Yeah.] Yeah. Those are the things that I will always remember,
5 about, [name of the hospital], and dealing with [the staff] at the first time. Like, although
6 they were there to help me, it didn't seem like half had actually studied mental health at
7 all.
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10 (Caribbean youth focus group)
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15 During the focus groups and interviews, participants reported how their experiences of
16 poor quality of care was due to health providers' negative attitudes and behaviours towards
17 mental illness. Indeed, stigma does operate, albeit marginally, in mental health services, such
18 as primary care (e.g., family doctors), emergency departments, in-patient units, out-patient
19 units, and so on and, when present, it seems to be more hurtful than when experienced outside
20 the health care system.
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33 Eight young people who took part in the focus groups had police and detention centres
34 as early contacts in their pathways to FEP treatment. Overall, police officers were perceived to
35 be supportive, helpful, and understanding of the situations. Police officers have the duty to
36 respond to an emergency call, accompany the person to the hospital emergency room, and stay
37 with them until the hospital staff takes over.
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46 Linda: I did it twice. The first time, I went to the hospital was in an ambulance, and, the
47 second time was ... in a police car. I actually found the police were nice. Like, I was in
48 handcuffs [laughter], but I found them to be really nice ... they stayed with me until the
49 doctors started seeing me. They didn't judge me, and I asked the one cop if he was
50 married ... he was like showing me pictures of his kids. He was just nice.
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53 (European youth focus group)
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3 Three men of European origin had forensic services in their pathways. In these cases, the young
4
5 men had to stay in detention for several days before they were able to see a judge. During the
6
7 focus groups they described how they were exposed to verbal and physical violence as well as
8
9 the trauma of experiencing psychotic episodes while in detention.
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14 Rob: Well, for me the cops were ok. But, then at the detention centre, I said something
15 really dumb to the correctional officer and ... I'm walking ... he literally just POUNDS me,
16 he beat the shit out of me. Right there on the ground. I wasn't shaken by it at all because I
17 was psychotic, but like—I don't know, it was really weird. He literally took me from
18 behind and just pounded me. I guess his superior comes in and takes him off me. I guess
19 the cops are ok but the guys in the jail ...
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23 Matt: Yeah, I had the same experience. One time, when I was psychotic, my mom called
24 the police on me ... She meant for me to go to the hospital but I got charged by the police
25 with a bunch of things. They sent me to JAIL, and I was completely psychotic ... they didn't
26 know what to do with me. They were physical with me, they injected me in the back of
27 my neck with I don't know what medication. They just locked me in a jail cell for probably
28 a month until I was transferred to a medical facility.
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31 (European youth focus group)
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35 It was interesting to notice that men of European origin were able to share these experiences
36 during the focus group, whereas men of African and Caribbean origin just mentioned police
37 involvement in their pathways without elaborating on it. We realized the sensitivity of this topic
38 which, combined with the sense of guilt, probably precluded any further disclosure.
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46 In total, 10 youth had family doctors as first contact in their pathways. Among all focus
47 groups, there was only one case in which referral was made to an FEP program directly by a
48 general practitioner. The majority of them reported to have been misdiagnosed or had their
49 symptoms dismissed by their family doctors.
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3 Benjamin: ... the family doctor doesn't, uh well, didn't work for me, he thought it was just
4 anxiety, like ... anxiety because of school ... 'cause I was going into university.
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7 (African youth focus group)
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11 In other cases, a young man and woman described how their family doctor focused only on
12 their substance abuse problem and reprimanded them for their behaviours.
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17 Steve: I kind of did [went to see my family doctor at first], but, he turned me down flatly,
18 'cause I was smoking weed. I said, "I thinking, I'm suffering with depression." He asked me
19 if I did drugs, I said that I did smoke weed quite often, and he said stop smoking the weed
20 then "come back and I help you." I never heard about it after that. Next time, I saw him, I
21 had to tell him that, yeah, I was diagnosed with schizophrenia. So, my general
22 practitioner, unfortunately, wasn't able to do anything at the time.
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24

25 (Caribbean youth focus group)
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28 Jill: I recognized the symptoms but I didn't know the specifics of my diagnosis. I went to
29 the family doctor and explained that I felt that I was being followed and everything. And
30 then he told me, "Okay. You need to stop doing drugs," 'cause I was high on marijuana
31 when it first happened ... but [it happened] several time [before] and I just thought it was
32 the pot.
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35 (African youth interview)
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39 It may be difficult for general practitioners to diagnose psychosis early; however, participants
40 felt that they had actively sought help but their requests were misunderstood or dismissed.
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44 When admitted to emergency units or in-patient services, participants described the
45 following negative experiences: being labelled, feeling like a number, feeling no longer a person
46
47 but an illness, being judged for behaviours/symptoms, and/or being treated like a child.
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52 Matt: I don't know, how it makes sense, but [hospital staff] were almost like TOO nice ... I
53 don't know the word, like, treating you like you're a child ... talking down to you. It was
54 NICE, but it didn't make me feel better ... other people were nice but, at the same time ...
55 made you feel like an equal. I felt like that was important.
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3 Steve: I think maybe the word you were looking for was “pity.” Like we were treated with
4 PITY [Matt: Yeah.] Yeah. I think that, people think that people with schizophrenia are
5 somehow STUPIDER or something ... I don’t think people with schizophrenia are stupid at
6 all.
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8

9 (European youth focus group)

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11 Robin: They treat you like a number [mumbles of agreement].
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13 Samantha: When I went to the hospital last time ... I was going through a panic attack
14 when I FIRST found out I had schizophrenia, and they, the nurse was like, “Yeah, you’re
15 just faking it, you’re perfectly fine, nothing’s wrong with you.”
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17

18 Robin: Yeah.
19

20 Samantha: It really, made me not like being in the hospital. I did not want to go back
21 there ever.
22

23 Natali: I agree. I think they treat you more like a number. And I think, being treated like
24 a PERSON instead of a number or a case because, if you’re just a case, you’re like “I’m
25 schizophrenic”... you’re not a person, anymore [mumbles of agreement].
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28 (European youth focus group)
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34 According to young people, all of these factors influenced the therapeutic relationship
35 with services and providers and, in particular, affected young people’s disclosures of
36 symptoms—as described.
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40 41 42 Discussion

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45 Differences in pathways to care and the duration of untreated psychosis have been
46 reported in some studies of ethnic minority groups. The reasons for these differences are
47 unclear. In this paper, the authors focused on participants’ narrative accounts to investigate the
48 social and cultural contexts of help seeking. In doing so, we were able to further investigate
49 differences between the groups as well as how a number of factors, including stigma,
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3 influenced both help seeking and access to specialized programs. We developed preliminary
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5 hypotheses about the link between internalized stigma, cultural beliefs about mental illness,
6
7 and help seeking. At the same time, we discussed how interactions with health care settings
8
9 shape the experience of asking for help, influencing future engagement with health providers
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11 and/or willingness to disclose symptoms.
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17 In our attempt to understand differences in the pathways to care and DUP between
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19 African-, Caribbean-, and European-origin groups, we found similarities to other studies that
20
21 broadly explore help seeking among young people in FEP programs [25,26] and their families
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23 [27,29] without focusing on ethnicity. As with our findings, other qualitative works described
24
25 long and difficult periods from the realization of signs and symptoms of psychosis to the
26
27 initiation of help seeking [27-31]. Family members' knowledge of mental illness and services
28
29 available to them was important in dealing with the situations. However, as other studies
30
31 described, family members often mistook early signs of psychosis—especially in the prodromal
32
33 phase of the illness—for mood changes due to adolescence, social withdrawal, stress, or drugs
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35 [25-29]. At the same time, even if the young people who took part in our study, recognized
36
37 changes in themselves, they did not attribute these changes to mental illness—as was also
38
39 described in other studies [25,29,31]. Moreover, as we discussed, because of the associated
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41 stigma, young people and family members engaged in denial, avoidance, and hiding of early
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43 symptoms of psychosis.²⁵⁻³¹
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53 In *Stigma*, Goffman [22] defined and discussed stigma as *discredited* versus
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55 *discreditable*; in the first case, a visible and physical mark defines stigma, where, in the second,
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3 no visible or physical mark is present—as is the case with the stigma of mental illness. More
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5 recently, further theories have been developed and used to understand the relationship
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7 between stigma and mental illness (see Link & Phelan [23], and Corrigan [24]). In all of these
8
9 theories, stigma is based on signs that define who is different, stereotypes about the person or
10
11 group, marginalization, avoidance, discrimination, fear of what or who is different—where
12
13 normality and abnormality or similarity and difference are defined by socio-cultural norms and
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15 beliefs. Furthermore, internalized stigma seems more distractive and harmful for the affected
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17 person’s health and, broadly, for his/her sense of self [32].
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25 Several studies investigate stigma and mental illness [32,33]. Stigma about mental
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27 illness is prevalent in the general public but, unfortunately, occurs in health and mental health
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29 settings as well [32,33]. Work done in the Canadian context recognizes the role of stigma in
30
31 seeking help for mental illness in immigrant and refugee groups in Canada. The *Improving*
32
33 *mental health services for immigrant, refugee, ethno-cultural and racialized groups: Issues and*
34
35 *options for service development* report describes how immigrants, refugees, and racialized
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37 groups are less likely to ask about mental health systems because of possible stigma and this
38
39 leads to people either not getting treatment or to a delay in getting treatment [15]. Other
40
41 studies describe the specific needs and issues that immigrant groups are facing in relation to
42
43 mental health services in urban settings in Canada [34,35]. These studies, which were
44
45 conducted with West Indian immigrants in Montreal, focus on cultural beliefs in non-medical
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47 interventions as the preferred form of treatment for mental illness (e.g., prayer or traditional
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49 folk medicine) or on the perception of primary care (e.g., doctors often prescribing
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3 pharmaceutical medications, or lack of time from physicians in early encounters that deterred
4 the use of current health services) [34,35].
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9
10 There are similarities but also differences with our findings compared to other studies.
11 This paper describes how stigma operated on young people and family members of African,
12 Caribbean, and European origin and how it influenced the help-seeking process. Although all
13 young participants internalized stigma as shame, and they feared lifelong discrimination for
14 their mental health conditions, those of African and Caribbean origin also internalized a sense
15 of guilt for their conditions. As mentioned, Caribbean young people described the role of
16 cultural beliefs about mental illness and of religion in delay in getting treatment. African and
17 Caribbean young people were able to distinguish the difference between their own beliefs
18 about mental illness and those of their cultural groups. They were critical of traditional cultural
19 beliefs, that see mental illness as a sin for which praying to God is a solution. However, the
20 stigma has been internalized as guilt, which influenced their decisions to seek help. It could be
21 that young people of Caribbean origin waited longer to ask for help as a way to protect their
22 families from being labelled with a taboo illness; future studies are needed to verify this
23 hypothesis. As family members of Caribbean origin described, there is a desire and need to find
24 a space and place to bring to light these issues: “We need to unload but we have no place to
25 unload.”
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51 Although the analysis presented in this paper helps in the understanding of some of the
52 differences in DUP between African-, Caribbean-, and European-origin immigrants, we
53 recognize that this work has some limitations, listed in Table 2. We were able to ask to both
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3 young people and family members for possible strategies which could be used to support
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5 people in the help-seeking process and for ideas about how the system of care could be
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7 improved (see Table 3). All participants described the importance of anti-stigma initiatives in
8
9 different settings (e.g., schools, universities, primary care services/providers) and targeted to
10
11 different groups. Based on our findings, such initiatives should be developed through the lens
12
13 of ethnocultural knowledge of and beliefs about mental health problems.
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20 **Conclusion**

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23 The findings of this study suggest that stigma, especially internalized stigma, operates in
24
25 different ways in European-, African-, and Caribbean-origin individuals and that this could
26
27 explain the differences in the pathways to early intervention services for psychosis for these
28
29 young people. These findings could inform the development of targeted anti-stigma campaigns
30
31 as well as the implementation of more equitable services for people in early stages of
32
33 psychosis. To do so, trust needs to be redefined and gained between ethnocultural groups and
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35 mental health researchers/providers both in research and in clinical practice. Implementing a
36
37 community-based participatory framework could help to achieve this goal.
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45 **Contributorship statement** KM contributed to the conception of the study. MF, NF, KA, and KM
46 developed the qualitative study protocol and materials. MF and NF implemented the focus
47 groups and MF implemented the individual interviews. MF performed data analysis, assisted by
48 NF, than they presented findings to all the authors in different stages of the process. MF wrote
49 the manuscript and it was than revised by KM. All authors reviewed and approved the final
50 manuscript.
51

52
53 **Competing interests** The authors have no conflicts of interest with respect to the publication of
54 this manuscript.
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3 **Funding** This study was funded by a Canadian Institutes of Health Research (CIHR) Operating
4 Grant (Grant #220976).
5
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7 **Data sharing** No additional data available.
8

9
10 **ACE Project Team:**

11 Kelly K. Anderson,^a Suzanne Archie,^b Philippe-Edouard Boursiquot,^b Julie Buffett,^b Denise
12 Canso,^a Manuela Ferrari,^a Nina Flora,^a Lew Golding,^a Hayley Hamilton,^{a,c} Asante Haughton,^a
13 Sean Kidd,^{a,c} Laurence Kirmayer,^d Steve Lurie,^e Kwame McKenzie,^{a,c} Marianne Noh,^a Samuel
14 Noh,^{a,c} Karen O'Connor,^e Jennifer Parlee,^a Syb Pongracic,^a Delia Reuben,^a Rebecka T. Sheffield,^b
15 Laura Simich,^c Taryn Tang,^c Andrew Tuck^a
16
17

18
19 ^a Social and Epidemiological Research, Centre for Addiction and Mental Health (CAMH) Toronto,
20 Ontario, Canada

21 ^b Department of Psychiatry and Behavioural Neurosciences, McMaster University
22 Hamilton, Ontario, Canada

23 ^c Department of Psychiatry, University of Toronto
24 Toronto Ontario, Canada

25 ^d Division of Social and Transcultural Psychiatry, McGill University
26 Montreal Quebec, Canada

27 ^e Canadian Mental Health Association (CMHA), Toronto Branch
28 Toronto Ontario, Canada
29
30
31

32 Team gratefully acknowledge the clinical staff from the participating early intervention
33 programs for their involvement in study recruitment. We also appreciate the contribution and
34 support of the Toronto Early Intervention in Psychosis Network.
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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;

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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.

For peer review only

BMJ Open

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.

Journal:	<i>BMJ Open</i>
Manuscript ID:	bmjopen-2014-006562.R1
Article Type:	Research
Date Submitted by the Author:	12-Nov-2014
Complete List of Authors:	Ferrari, Manuela; Centre for Addiction and Mental Health (CAMH), Social Aetiology of Mental Illness (SAMI) Training Program -CIHR Strategic Training; York University, School of Health Policy and Management Flora, Nina; Centre for Addiction and Mental Health (CAMH), Anderson, Kelly; Western University, Department of Epidemiology & Biostatistics Tuck, Andrew; Centre for Addiction and Mental Health (CAMH), Archie, Suzanne; McMaster University, Department of Psychiatry and Behavioural Neurosciences Kidd, Sean; Centre for Addiction and Mental Health (CAMH), McKenzie, Kwame; Centre for Addiction and Mental Health (CAMH),
Primary Subject Heading:	Mental health
Secondary Subject Heading:	Qualitative research, Health services research
Keywords:	Schizophrenia & psychotic disorders < PSYCHIATRY, QUALITATIVE RESEARCH, Child & adolescent psychiatry < PSYCHIATRY

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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.

Manuela Ferrari,^a Nina Flora,^a Kelly K. Anderson,^b Andrew Tuck,^a Suzanne Archie,^c Sean Kidd,^{a,d} & Kwame McKenzie^{a,d} on behalf of the ACE Project Team

^a*Social and Epidemiological Research, Centre for Addiction and Mental Health (CAMH)*

Toronto, Ontario, Canada

^b*Department of Epidemiology & Biostatistics, Western University, London, Ontario, Canada*

^c*Department of Psychiatry and Behavioural Neurosciences, McMaster University*

Hamilton, Ontario, Canada

^d*Department of Psychiatry, University of Toronto*

Toronto, Ontario, Canada

Correspondence:

Manuela Ferrari, PhD

Social and Epidemiological Research

Centre for Addiction and Mental Health (CAMH)

455 Spadina Avenue, Suite 300

Toronto, ON M5S 2G8 CANADA

Phone: (416)535-8501 ext. 77614 Fax: (416) 979-0564

E-mail: manuela.ferrari@camh.ca

Word count : 6,433

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

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2
3 explain the differences in the pathways to early intervention services for psychosis for these
4 young people. These findings could inform the development of more equitable services for
5 people in early stages of psychosis.
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11 **Keywords:** First-episode Psychosis; Pathways to Care; Duration of Untreated Psychosis; Stigma;
12 Ethnicity.
13

14 **Key messages**

- 15 1. The findings suggest that stigma, especially internalized stigma in African-, and Caribbean-
16 origin groups, seems to explain differences in pathways to care between the three groups.
17
- 18 2. Delay in entering into first-episode psychosis programs was also influenced by the stigma
19 perceived by young people in health care settings. This had an impact on the therapeutic
20 relationships, disclosure of symptoms, and overall trust in the health care system.
21
- 22 3. Findings from this study could be used anti-stigma initiatives and sensitivity training for
23 key-players (e.g., general practitioners, emergency staff, police). Such initiatives should be
24 developed through the lens of cultural knowledge of and beliefs about mental health
25 problems.
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32 **Strengths and limitations of this study**

- 33 1. Use qualitative methodology to explore similarity and differences in pathways to care
34 and DUP between African-, Caribbean-, and European-origin groups.
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36
- 37 2. Young people who experienced a first episode of psychosis and their family members
38 were invited to review ACE Study quantitative findings and elaborate on them.
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41
- 42 3. Young people and their family members were invited to comment on possible strategies
43 and ideas about how the system of care could be improved
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- 49 4. The sample size in this study was relatively small; only limited inferences can be drawn
50 for other groups.
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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].

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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

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3 months for the European group, nine months for the African group, and 16 months for the
4
5 Caribbean group. Caribbean participants in the study had fewer health services/providers in
6
7 their pathways to care, they more often accessed FEP programs from an in-patient admission,
8
9 and they faced more obstacles in their access to specialized treatment for psychosis than the
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11 European group. African group members in the study more often had an emergency
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13 department as first contact in their pathways [17].
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18 Once disparities have been identified, understanding of the reasons why they may exist
19
20 is necessary if we are to develop effective services. This paper reports a qualitative exploration
21
22 of the reasons for differences in pathways to care and DUP in the ACE Study from the
23
24 perspective of respondents to the study and their families. The aim was to understand
25
26 differences in DUP between African-, Caribbean-, and European-origin groups. To do so, we
27
28 explored young people's and their family members' journeys of seeking help for psychosis,
29
30 investigating how people responded to early signs of psychosis as well as the roles that
31
32 different people and services played in accessing specialized programs for psychosis.
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39 **Methods**

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42 This study used an inductive qualitative approach to examine differences in the routes
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44 to care between young people with lived experience of psychosis of African-, Caribbean-, and
45
46 European-origin. In this exploratory and inductive qualitative study, the data analysis and
47
48 interpretation developed from patterns originated in empirical data rather than a deductive
49
50 process where an existing theory, or a hypothesis, guides the data analysis and interpretation
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60 process.

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3 Focus groups were used as a means of generating in-depth knowledge of pathways to
4 care, exploring the interaction between individual socio-cultural positions, young people's
5 experiences of seeking help, and group dynamics—as each participant's narrative is generated
6 out of the journeys of others. By using focus groups we were able to examine how participants
7
8 (1) interacted with each other; (2) produced and reproduced knowledge; and (3) articulated
9 and/or defended their views [18].
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19 *Ethical considerations*

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

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49 Our groups were based on the categories developed by the Toronto District School
50 Board. Respondents were asked to choose which racial or ethnic group best reflected their
51 identity (see Anderson et al. for more information) [17]. Participants who took part in the ACE
52 Study's semi-structured interviews were asked if they were willing to be re-contacted. Only
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3 those who agreed were approached for the qualitative study. They were asked if they would
4 take part in a two-hour focus group to discuss the results of the study. Participants' family
5 members were also contacted and asked if they were willing to take part in a separate focus
6 group. One hundred and nine quantitative interview participants were contacted to take part in
7 a focus group or an interview. Of these, 31 declined participation, 38 could not be reached, and
8 40 agreed to take part in the focus group or an individual interview and, due to scheduling
9 issues, only 25 of these individuals could attend a focus group or an interview.
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22 Four focus groups with young people were implemented: one male group for each of
23 the African-, Caribbean-, and European-origin groups as well as one female European-origin
24 groups (African = 3 male, Caribbean = 3 male, European= 7 male and women 8 male). Two focus
25 groups were organized for the family members, one for each of the Caribbean, and European
26 groups (European = 6, Caribbean = 3). Because of difficulty recruiting for the African and
27 Caribbean women's groups, we adjusted the study protocol and undertook individual in-depth
28 interviews, for total of two interviews with African women, and one interview with a Caribbean
29 woman with lived experience of psychosis. The protocol change allowed us to have a small, but
30 important, representation of women from these two groups. Furthermore, we were able to
31 conduct an interview with a young woman of European origin who, due to anxiety problems,
32 did not feel comfortable attending the focus group session.
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50 *Data collection*

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53 Focus groups were conducted by the first author, MF, who acted as focus group
54 moderator, and research assistants who were trained in focus groups, transcribing, and
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3 qualitative data analysis for the purpose of this study. Focus group questions were designed to
4
5 be conversational, open, and clear. They unfolded according to Krueger and Casey's
6
7 recommendations [18]: opening, introductory, key, ending (see Table 1). At the end of each
8
9 focus group, the research team involved in the focus group completed 30–40 minutes of
10
11 debriefing. During the focus groups, participants were presented with preliminary ACE Study
12
13 quantitative data; we focused on the differences in DUP as well as pathways to care and asked
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15 participants to comment on them.
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21 Focus groups and in-depth interviews were digitally recorded. The digital audio files
22
23 were transcribed by the research assistants and reviewed for data accuracy. One research
24
25 assistant transcribed a focus group recording and the other reviewed the work done. Finally, all
26
27 material was also reviewed by MF. Focus group transcripts were then prepared to facilitate
28
29 thematic analysis. All participant names were changed to pseudonyms to ensure confidentiality.
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35 Traditional data saturation, that is, “collecting data until no new information is
36
37 obtained,” [19, p. 147] is often an object of controversy in qualitative research literature [19].
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39 As Morse described: “The *quantity* of the data in a category is not theoretically important to the
40
41 process of saturation. Richness of the data is driven from detailed description, not the number
42
43 of time something is stated. Frequency counts are out” [19, p. 148]. We used instead Morse's
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45 criterion of data saturation as “adequacy” of the data, which can be obtained through specific
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47 methodological choices. These methodological choices were (a) selecting and working with an
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49 ethnic- and gender-cohesive sample; (b) at the same time, working with three different
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51 ethnocultural groups so as to maximize and explore cultural contrasts in pathways to care—a
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3 gap in current literature; and (c) basing our sample on quantitative data analysis, which allowed
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5 focus-group-member checks on the quantitative findings, as well as the possibility for rich, full,
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7 and complete understanding.
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10 11 12 13 14 15 *Analysis*

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18 Thematic analysis was employed to identify, analyze, and report patterns or themes
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20 within data [20]. Our thematic analysis was data driven, rather than theoretically driven,
21
22 making use of an inductive approach, as the themes identified were strongly linked to the data
23
24 themselves. We followed Braun and Clark's steps of thematic analysis [21] by: (1) familiarizing
25
26 ourselves with our data (transcribing data, reviewing transcriptions for accuracy, reading
27
28 transcriptions over and over, and noting initial ideas); (2) generating initial codes and searching
29
30 for themes (collating codes into potential themes); (3) reviewing and redefining themes
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32 (exploring how strong the identified themes are by assisting the relationship between first
33
34 [code] and second [theme] level of analysis, generating a thematic map of the analysis); and (4)
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36 further unpacking the analysis through the writing process (identifying themes and initial
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38 stigma concepts was further explored through a review of existing models of mental health
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40 stigma).
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49 We compared each participant's journey to care (shared during the focus group), the
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51 pathway depicted during a semi-structured interview, and the participant's medical chart.
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53 Further, we performed an analysis within each ethnic group, comparing and contrasting young
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55 people's narratives with those of family members, and a cross-ethnic-group analysis. As a
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3 result, in the study findings we describe themes that were common across all the narratives as
4
5 well as the ones that were different between the three ethnic groups. All young people's and
6
7 family members' names used in this paper have been changed to ensure participants'
8
9 confidentiality.
10

11 12 13 *Rigour*

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17 Lincoln and Guba [20] defined primary criteria to assess rigour and trustworthiness of
18
19 the qualitative research process. Primary criteria—credibility, authenticity, criticality, and
20
21 integrity—are necessary to all qualitative enquiry but they are insufficient in and of themselves.
22
23 Trustworthiness was achieved within the study through the following criteria: *credibility* and
24
25 *authenticity*, attained through multiple sources of data (e.g., pathways maps generated from
26
27 semi-structured interviews, chart reviews, focus groups' data) as well as specific and different
28
29 sample strategies being employed to generate rich and meaningful data; *criticality* and
30
31 *integrity*, using team debriefing and analysis to ensure methodological effectiveness.
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37 38 **Results**

39 40 *Overview of the sample*

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43 A total of 34 people took part in the study; 25 young people with lived experiences of
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45 psychosis (origins: European = 16, African = 5, Caribbean = 4) and nine family members (origins:
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47 European = 6, African = 0, Caribbean = 3). Table 2 reports the socio-demographic information
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49 for young people with lived experiences of psychosis only—no socio-demographic information
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51 was collected for family members at the time of the focus group.
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56 Findings are presented in two main sections: (1) *Understanding help seeking*, in which
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3 we first present commonality across the three groups, and then we investigate differences in
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6 DUP between African-, Caribbean-, and European-origin groups. In this section we unpack the
7
8 role of stigma and how it operates early on in pathways to care. In this paper, stigma refers to a
9
10 collection of negative attitudes, beliefs about, and behaviours directed at people with mental
11
12 disorders, which are manifested in rejection and avoidance of, and prejudice and discrimination
13
14 against people with mental illness conditions [22-24]. Stigma can be a barrier for people who
15
16 experience mental health problems by making them reluctant to ask for help due to fear of
17
18 prejudice, being labelled, and discrimination by others. Internalized stigma, or self-stigma,
19
20 occurs when a person takes on those negative stereotypes and assumptions and applies them
21
22 to themselves [23, 24]. Discrimination due to mental health stigma can take place in different
23
24 circumstances/settings: education, employment, housing, and treatment. (2) *Understanding*
25
26 *delay in entering first-episode psychosis (FEP) programs*, in which we explore the relationship
27
28 between negative experiences, stigma, health care delivery, and illness/symptoms disclosure.
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30 The themes presented in this section are also common across the three groups.
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Understanding help seeking

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

45 Consistent across all narratives, for both young people and family members, was that
46
47 knowledge or lack of knowledge about symptoms of psychosis, mental illness, and services
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49 available to them was key to them recognizing the significance of changes in behaviour. Often
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51 this knowledge was based on family members' or friends' past experiences of mental illness.
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3 Maria: The one person who really helped me to realize what I'm going through, and that I
4 need help, is my mother. She knows what I'm going through because she went through it
5 with my father. She helps me a lot. ...
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7

8 (European youth focus group)
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11
12 Young people who did not have any knowledge of signs or symptoms of psychosis were
13 aware of personal changes but did not know that they were indicative of mental illness. In
14 these cases, family members played a key role in the help-seeking process by taking them to
15 the hospital.
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23 Benjamin: I was schizophrenic, and I didn't know what to do. I heard voices and stuff. I did
24 some stuff that I couldn't remember, so some people took me in ...
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26 Paul: I kept hearing ... weird voices, but I didn't know what is. So, later on I came ... my
27 parents took me to the hospital ...
28

29 (African youth focus group)
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32 Steve: I didn't know that I needed help. I had no one around me who knew what was
33 happening. ... I was staying with a friend, my mom was occasionally stopping by ... she saw
34 certain signs in me, and she immediately drove me to [name of the hospital].
35

36 (Caribbean youth focus group)
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39 June: I wouldn't have stayed in the emergency room, I wouldn't have gone by myself ... I
40 didn't know what was going on. ... I didn't know *I was going crazy*, ... I thought everybody
41 was against me.
42

43 (European youth focus group)
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47 Young people and family members who did not have awareness or knowledge of the signs or
48 symptoms of psychosis, struggled the most to understand and/or make sense of the situations.
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53 Janine: I didn't know what this illness was. I thought it was just some kind of behaviours,
54 being angry or strange like teenagers could possibly experience sometime ... it was people
55 from the outside who used to tell me "No, this more than just ... you know teenager's
56 crisis." Not knowing [the] symptoms ... I just didn't know what was going on really.
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3 (Caribbean family members' focus group)
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8 Louise: My son was 17 when he had his psychotic break. I thought he was just being a
9 typical rebellious teenager ... he smoked pot. He didn't get violent. He was so scared and I
10 didn't know what else to do with him. I took him to [name of general hospital] ... after
11 about 15 hours convincing them that I was not taking him home, they admitted him.
12

13 (European family members' focus group)
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18 Often, family members attributed the changes in their relatives' behaviours to growing
19 up/going through adolescence, peer groups/wrong crowds, stress, and/or substance abuse in
20 young adults. Family members often thought that what their relatives were experiencing was
21 just a temporary phase in their relatives' lives without recognizing signs or symptoms of
22 psychosis. Help seeking often occurred after doubting the early signs of psychosis and, most
23 importantly, after feeling sadness and discomfort.
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33 Along with knowledge and awareness of signs or symptoms of psychosis, the role that
34 stigma played during the help-seeking process was also constantly present in the narratives.
35
36 Through the analysis conducted, it was possible to identify how individual and family
37 perceptions of mental illness influenced the internalization of stigma. For example, young
38 people involved in the study often distinguished between their rational understandings of the
39 mental health problems, symptoms, and causes, and, at the same time, their feelings of being
40 trapped in emotions such as shame.
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51 Karen: People are scared to look for help, and to ...
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53 Maria: And to admit to themselves even ... [Karen: Yeah!] that "I have schizophrenia"... I
54 never told anybody.
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56

57 June: I'm still ashamed of what I have.
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3 Samantha: Me too.

4
5 (European youth focus group)
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10 Participants described how, for fear of family members' and/or friends' reactions to their
11 conditions, they tried to ignore the signs and symptoms by, for example, using marijuana, and
12 attempted to hide their symptoms from others.
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15
16 Sandi: I was worried about what people around me might say ... once you're in the
17 hospital you can't really keep your secret anymore. There is a huge stigma about mental
18 illness; people tend to like to avoid it.
19

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21 (European youth focus group)
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26 Positive symptoms (e.g., hearing voices, bizarre behaviour, violence) were often
27 catalysts to treatment initiation. Family members often struggled to recognize when their
28 relative was no longer able to care for himself/herself or when he/she was asking for help as
29 the symptoms of psychosis took over his/her ability to make decisions. This created quite a
30 complex situation where family members felt threatened or worried about their safety and, at
31 the same time, guilty when they had to call the emergency department, ambulance, or,
32 unfortunately, the police. This was evident in family members' narratives.
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44 Natali: I have been there ... I couldn't stop crying for days ... when my daughter finally
45 broke down at school ... being scary violent with us. ... the first time she finally did get to
46 the hospital that day [name of the hospital] ... It was almost like a relief, she was safe and
47 she was away from us ... because we were scared. We were so afraid. [Sarah:
48 (overlapping) Yes. Yes. Yeah.]
49

50
51 (European family members' focus group)
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56 Stigma was also closely connected to how much the person who experienced psychosis was
57 considered responsible for his/her mental condition or was in control, or not, of his/her
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3 symptoms. Family members recognized that mental illness is not perceived the same as other
4 health problems. Physical disorders, such as cancer, generate compassion in extended family
5 members, whereas mental disorders bring reactions of distancing, blaming, and stigmatizing
6 from members of the extended family.
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11
12 Natali: Unfortunately, I still see ... my family members not so supportive. On the surface,
13 they are, but I see them shy away from my son. I see the stigma, it is still so much there. If
14 he was (clears throat) you know physically ill they would be right there.
15

16 (European family members' focus group)
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21 Overall, family members described how psychosis is hidden until it manifests through a
22 person's behaviours. It is difficult to understand what is happening to the person as well as to
23 assess if, when, and how to intervene.
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29 Differences in help seeking between the three groups: Internalized stigma as feeling shame
30 versus feeling guilty for their own condition
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34
35 Participants of European origin internalized mental health stigma as shame about their
36 symptoms (e.g., hearing voices, unpredictable or bizarre behaviours in front of family and
37 friends, or irrational actions). They felt distress caused by the awareness of their past bizarre
38 behaviours and a sense of humiliation for their conditions. In contrast, young people from
39 African- and, even more, Caribbean-origin groups stressed their responsibility for their
40 conditions, they felt that they had done something wrong (for having an mental illness), and
41 they felt a sense of failure for not being able to "snap out of it"—as a participant described
42 during a focus group. In this sense, they seemed to internalize mental health stigma as guilt—
43 there is shame and humiliation but also they felt that they had done something wrong.
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3 Paul: ... there was a lot of pressure to excel in school and succeed. I dabbled too much in,
4 dabbled too much in drugs, that was my problem ... that was really my fault. I have no
5 one else to blame but myself ... people expect you to just walk it off kind of thing. But you
6 really, you really can't, you can't really walk off a mental illness ... you can cope with it.
7
8

9 (African youth focus group)
10

11 Steve: Going through a mental illness totally flipped the way I view ... everything! It's also
12 made me become more aware of how family members react, and why are they reacting
13 that way. Eventually it is what got me onto the culture of it, my religion, and so forth. I
14 can't say exactly what it is about the Caribbean culture ... but, I can tell, those two things
15 definitely play a factor in it.
16
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18 (Caribbean youth focus group)
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21
22 In the African and Caribbean focus groups, participants discussed the role that religion
23 had in shaping their and their families' perceptions of mental illness and feelings of guilt for
24 their condition—this topic was not discussed in the European focus groups. In some cases,
25 people described how they grew up thinking that mental illness was a sin or God's punishment.
26 Although they did not think in this way now, they saw how this perception influenced their
27 understanding of early signs of psychosis, the focuses of their paranoid symptoms (in some
28 cases), and, most importantly, their asking for help.
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41 Suzanne: Well, it made me feel badly because I thought, "Wow. You know, she's so
42 nervous [mother] about me going to the hospital for help." It made me feel kind of
43 ashamed that I needed help. ... I guess it made me a little bit reluctant to seek care later
44 on. [Later on in the interview] ... in the beginning my mom was like, "Suzanne you need to
45 PRAY more. That's the problem." And, I'm like, "No mom, I need medication. I need some
46 help." ... Sometimes I just tell her that I prayed just so she can get off my case. My brother
47 often tell me that my life has gone in this direction because I stopped going to church. ... It
48 makes me feel bad. It's not helpful me to get better.
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51 (Caribbean youth interview)
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56 Greg: I can't say everybody but, A LOT of people in my family, and in the community ...
57 they become very superstitious. It's a mind job with Catholicism first of all—and no
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3 offense to anybody here who's Catholic, I am Catholic. Something simple as, as having a
4 mental condition, is not simple in this world anymore, it becomes then, "that person
5 needs to be exorcised, or that person's got bad demons—"
6
7

8 Steve: (overlapping) Oh, I've heard ... I've heard that, I've heard that, to get rid of my
9 voices I have to get an exorcism.
10

11 Greg: Yeah.
12

13 Steve: That's what I heard from a friend.
14

15 Greg: Like, my mom said that when she was uh, a kid, when she was like 5 or 6, she
16 actually witnessed someone getting exorcised, because of voices in his head and stuff like
17 that.
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20 (Caribbean youth focus group)
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25 As described, African- and, even more, Caribbean-origin young people reported that their
26 mental illnesses were taboos among members of their close or extended families. While young
27 people of African origin had their families around to support their struggles, young people of
28 Caribbean origin who attended the focus groups had no one or only a few close family
29 members. The support networks that could assist them in seeking help were not available.
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38 Simone: When people in the Caribbean get to know that your child has this issue [mental
39 illness] ... the whole family is labelled ... from the grandparent right the way down. The
40 family is labelled and you are sort of ostracized. That's why many of us don't want to
41 bring it up to the light ... we are in denial that this is not happening to this family. ... We,
42 as parents, don't have the freedom to talk about it ... because of the stigma that's still
43 attached ... we internalize it. When we internalize, we're stressed. We would love to know
44 that there is somewhere that we can go and sit down and talk. We need to unload but we
45 have no place to unload.
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49 (Caribbean family members' focus group)
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54 African- and Caribbean-origin participants described how when they experienced early
55 signs of psychosis, they tried to control them and they felt guilty if they were not able to. Their
56 sense of guilt was also connected with cultural interpretation of mental illness as sin, God's
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3 punishment, and a taboo illness heavily stigmatized—themes more present in the Caribbean-
4 origin focus group and interviews.
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7
8 *Understanding delay in entering first-episode psychosis programs (FEP)*
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10
11 Rachel: Now none of these people [university psychological service/psychiatrist] told me
12 about any other resources. ... All I knew was [name of mental health hospital], which was,
13 like, the last resort. ... I was in the dark. And then I went to my family doctor, and she was
14 the first person after like 3 months who told us that, “Oh, there’s actually an in-patient
15 program at [name of a general hospital], for if you’re in an emergency—go there.” ... So
16 then when I got really bad, I was in the in-patient at [name of a general hospital] and
17 there, it was when I actually found out about a bunch of other resources ...”
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21 (European youth focus group)
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25 Participants often recognized changes in behaviours and thinking but they did not always
26 attribute these to a mental illness; however they were active in seeking help, contacting
27 community services (e.g., school or university health services) or their family doctors, if they
28 had one. In reflecting on their pathways, they often felt upset, as early attempts to ask for help
29 were dismissed by providers and/or information was not provided to them.
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37 Negative experiences, stigma and care: First contact, therapeutic relationship, and disclosure of
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39 symptoms
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43 Once in the system, groups’ differences in the journeys to specialized treatment seemed
44 less present. Before entering into early intervention programs, young people saw between four
45 and six difference health providers/services (e.g., family doctor, emergency, police, detention
46 centre, in-patient unit). As young people described, the care they received (or did not receive)
47 and health care providers’ attitudes towards mental illness influenced what they shared about
48 their mental states (e.g., hearing voices, suicidal thoughts) and, overall, their trust in the
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3 system. From the first contact with a hospital, the majority of young people involved in the
4
5 focus groups reported that, if it was a negative experience, it affected their therapeutic
6
7 relationships, and, generally, their willingness to stay in the system and to return, if needed, a
8
9 second time.
10

14 Samantha: From my experience there's a lot of stigma and shame surrounding people
15 who have substance abuse problems. Whenever I've been in treatment, there has not
16 been an accepting atmosphere for me to discuss my issues or to make me feel like I'm
17 actually going to get help.
18

19
20 (European youth focus group)
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24 Steve: Well, I found, like, a number of them [mental health care providers] definitely
25 helped. I feel that the majority of [hospital name] staff definitely does have that, but
26 there are still the ones that can create that negative experience for you when you're
27 already going through a negative experience. ... It's funny ... you're going through stuff,
28 even though your mind's not in the right place, you still remember all the negativity. ...
29 [Andy: (overlapping) Yeah.] Yeah. Those are the things that I will always remember, about
30 [name of the hospital] and dealing with [the staff] at the first time. Like, although they
31 were there to help me, it didn't seem like half had actually studied mental health at all.
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35 (Caribbean youth focus group)
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40 During the focus groups and interviews, participants reported how their experiences of
41 poor quality of care was due to health providers' negative attitudes and behaviours towards
42 mental illness. Indeed, stigma does operate, albeit marginally, in mental health services, such as
43 primary care (e.g., family doctors), emergency departments, in-patient units, out-patient units,
44 and so on and, when present, it seems to be more hurtful than when experienced outside the
45 health care system.
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57 Eight young people who took part in the focus groups had police and detention centres
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3 as early contacts in their pathways to FEP treatment. Overall, police officers were perceived to
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5
6 be supportive, helpful, and understanding of the situations. Police officers have the duty to
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8
9 respond to an emergency call, accompany the person to the hospital emergency room, and stay
10
11 with them until the hospital staff takes over.
12

13
14 Linda: I did it twice. The first time, I went to the hospital was in an ambulance, and, the
15
16 second time was ... in a police car. I actually found the police were nice. Like, I was in
17
18 handcuffs [laughter], but I found them to be really nice ... they stayed with me until the
19
20 doctors started seeing me. They didn't judge me, and I asked the one cop if he was
21
22 married ... he was like showing me pictures of his kids. He was just nice.

23
24 (European youth focus group)
25
26

27 Three men of European origin had forensic services in their pathways. In these cases, the young
28
29 men had to stay in detention for several days before they were able to see a judge. During the
30
31 focus groups they described how they were exposed to verbal and physical violence as well as
32
33 the trauma of experiencing psychotic episodes while in detention.
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38 Rob: Well, for me the cops were ok. But, then at the detention centre, I said something
39
40 really dumb to the correctional officer and ... I'm walking ... he literally just POUNDS me,
41
42 he beat the shit out of me. Right there on the ground. I wasn't shaken by it at all because I
43
44 was psychotic, but like—I don't know, it was really weird. He literally took me from
45
46 behind and just pounded me. I guess his superior comes in and takes him off me. I guess
47
48 the cops are ok but the guys in the jail ...
49

50
51 Matt: Yeah, I had the same experience. One time, when I was psychotic, my mom called
52
53 the police on me ... She meant for me to go to the hospital but I got charged by the police
54
55 with a bunch of things. They sent me to JAIL, and I was completely psychotic ... they didn't
56
57 know what to do with me. They were physical with me, they injected me in the back of
58
59 my neck with I don't know what medication. They just locked me in a jail cell for probably
60
61 a month until I was transferred to a medical facility.

62
63 (European youth focus group)
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3 It was interesting to notice that men of European origin were able to share these experiences
4
5 during the focus group, whereas men of African and Caribbean origin just mentioned police
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7 involvement in their pathways without elaborating on it. We realized the sensitivity of this topic
8
9 which, combined with the sense of guilt, probably precluded any further disclosure.
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14 In total, 10 youth had family doctors as first contact in their pathways. Among all focus
15
16 groups, there was only one case in which referral was made to an FEP program directly by a
17
18 general practitioner. The majority of them reported to have been misdiagnosed or had their
19
20 symptoms dismissed by their family doctors.
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25 Benjamin: ... the family doctor doesn't, uh well, didn't work for me, he thought it was just
26
27 anxiety, like ... anxiety because of school ... 'cause I was going into university.

28
29 (African youth focus group)
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33 In other cases, a young man and woman described how their family doctors focused only on
34
35 their substance abuse problems and reprimanded them for their behaviours.
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39 Steve: I kind of did [went to see my family doctor at first], but, he turned me down flatly,
40
41 'cause I was smoking weed. I said, "I thinking, I'm suffering with depression." He asked me
42
43 if I did drugs, I said that I did smoke weed quite often, and he said stop smoking the weed
44
45 then "come back and I help you." I never heard about it after that. Next time, I saw him, I
46
47 had to tell him that, yeah, I was diagnosed with schizophrenia. So, my general
48
49 practitioner, unfortunately, wasn't able to do anything at the time.

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51 (Caribbean youth focus group)
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55 Jill: I recognized the symptoms but I didn't know the specifics of my diagnosis. I went to
56
57 the family doctor and explained that I felt that I was being followed and everything. And
58
59 then he told me, "Okay. You need to stop doing drugs," 'cause I was high on marijuana
60
61 when it first happened ... but [it happened] several time [before] and I just thought it was
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63 the pot.

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65 (African youth interview)
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6 It may be difficult for general practitioners to diagnose psychosis early; however, participants
7
8 felt that they had actively sought help but their requests were misunderstood or dismissed.
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11 When admitted to emergency units or in-patient services, participants described the
12
13 following negative experiences: being labelled, feeling like a number, feeling no longer a person
14
15 but an illness, being judged for behaviours/symptoms, and/or being treated like a child.
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20 Matt: I don't know, how it makes sense, but [hospital staff] were almost like TOO nice ... I
21 don't know the word, like, treating you like you're a child ... talking down to you. It was
22 NICE, but it didn't make me feel better ... other people were nice but, at the same time ...
23 made you feel like an equal. I felt like that was important.
24

25
26 Steve: I think maybe the word you were looking for was "pity." Like we were treated with
27 PITY [Matt: Yeah.] Yeah. I think that, people think that people with schizophrenia are
28 somehow STUPIDER or something ... I don't think people with schizophrenia are stupid at
29 all.
30

31 (European youth focus group)
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33
34 Robin: They treat you like a number [mumbles of agreement].
35

36 Samantha: When I went to the hospital last time ... I was going through a panic attack
37 when I FIRST found out I had schizophrenia, and they, the nurse was like, "Yeah, you're
38 just faking it, you're perfectly fine, nothing's wrong with you."
39

40 Robin: Yeah.
41

42 Samantha: It really, made me not like being in the hospital. I did not want to go back
43 there ever.
44

45
46 Natali: I agree. I think they treat you more like a number. And I think, being treated like
47 a PERSON instead of a number or a case because, if you're just a case, you're like "I'm
48 schizophrenic" ... you're not a person, anymore [mumbles of agreement].
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50 (European youth focus group)
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56 According to young people, all of these factors influenced the therapeutic relationship
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3 with services and providers and, in particular, affected young people's disclosures of
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5 symptoms—as described.
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8 9 **Discussion**

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12 Differences in pathways to care and the duration of untreated psychosis have been
13 reported in some studies of ethnic minority groups [13, 16]. The reasons for these differences
14 are unclear [25]. In this paper, the authors focused on participants' narrative accounts to
15 investigate the social and cultural contexts of help seeking. In doing so, we were able to further
16 investigate differences between the groups as well as how a number of factors, including
17 stigma, influenced both help seeking and access to specialized programs. We developed
18 preliminary hypotheses about the link between internalized stigma, cultural beliefs about
19 mental illness, and help seeking. At the same time, we discussed how interactions with health
20 care settings shape the experience of asking for help, influencing future engagement with
21 health providers and/or willingness to disclose symptoms.
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38 In our attempt to understand differences in the pathways to care and DUP between
39 African-, Caribbean-, and European-origin groups, we found similarities to other studies that
40 broadly explore help seeking among young people in FEP programs [26, 27] and their families
41 [28-33] without focusing on ethnicity. As with our findings, other qualitative works described
42 long and difficult periods from the realization of signs and symptoms of psychosis to the
43 initiation of help seeking [28-31]. As other studies reported, family members described how the
44 role of caregiver was emotionally draining [32] due to their inability to understand and cope
45 with the changes in their family members, feelings of guilt after calling the police, as well as
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3 frustration of their inability to navigate the health care system and/or lack of involvement in
4
5 the treatment program [33]. Family members' knowledge of mental illness and services
6
7 available to them was important in dealing with the situations. However, as other studies
8
9 described, they often mistook early signs of psychosis—especially in the prodromal phase of
10
11 the illness—for mood changes due to adolescence, social withdrawal, stress, or drugs [26-30].
12
13 At the same time, even if the young people who took part in our study recognized changes in
14
15 themselves, they did not attribute these changes to mental illness—as was also described in
16
17 other studies [26, 30]. Moreover, as we discussed, because of the associated stigma, young
18
19 people and family members engaged in denial, avoidance, and hiding of early symptoms of
20
21 psychosis which prevented them from seeking help [26-34].
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29 In *Stigma*, Goffman [22] defined and discussed stigma as *discredited* versus
30
31 *discreditable*; in the first case, a visible and physical mark defines stigma, where, in the second,
32
33 no visible or physical mark is present—as is the case with the stigma of mental illness. More
34
35 recently, further theories have been developed and used to understand the relationship
36
37 between stigma and mental illness (see Link & Phelan [23], and Corrigan [24]). In all of these
38
39 theories, stigma is based on signs that define who is different, stereotypes about the person or
40
41 group, marginalization, avoidance, discrimination, fear of what or who is different—where
42
43 normality and abnormality or similarity and difference are defined by socio-cultural norms and
44
45 beliefs. Furthermore, internalized stigma seems more distractive and harmful to the affected
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47 person's health and, broadly, to his/her sense of self [35].
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54 Several studies investigate stigma and mental illness [33, 35, 36]. Stigma about mental
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56 illness is prevalent in the general public but, unfortunately, occurs in health and mental health
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3 settings as well [36]. Work done in the Canadian context recognizes the role of stigma in
4
5 seeking help for mental illness in immigrant and refugee groups in Canada. The *Improving*
6
7 *mental health services for immigrant, refugee, ethno-cultural and racialized groups: Issues and*
8
9 *options for service development* report describes how immigrants, refugees, and racialized
10
11 groups are less likely to ask about mental health systems because of possible stigma and this
12
13 leads either to people not getting treatment or to a delay in getting treatment [15]. Other
14
15 studies describe the specific needs and issues that immigrant groups are facing in relation to
16
17 mental health services in urban settings in Canada [37, 38]. These studies, which were
18
19 conducted with West Indian immigrants in Montreal, focus on cultural beliefs in non-medical
20
21 interventions as the preferred form of treatment for mental illness (e.g., prayer or traditional
22
23 folk medicine) or on the perception of primary care (e.g., doctors often prescribing
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25 pharmaceutical medications, or lack of time from physicians in early encounters that deterred
26
27 the use of current health services) [37, 38].
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37 There are similarities but also differences with our findings compared to other studies.
38
39 This paper describes how stigma operated on young people and family members of African,
40
41 Caribbean, and European origin and how it influenced the help-seeking process. Although all
42
43 young participants internalized stigma as shame, fearing lifelong discrimination for their mental
44
45 health conditions, which often prevented them from disclosing their symptoms to others and
46
47 ask for professional help, those of African and Caribbean origin also internalized a sense of guilt
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49 for their conditions, holding them back from talking about their problems as well as pushing
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51 them to try to overcome their symptoms alone.
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4 As mentioned, Caribbean young people described the role of cultural beliefs about
5
6 mental illness and of religion in delay in getting treatment. African and Caribbean young people
7
8 were able to distinguish the difference between their own beliefs about mental illness and
9
10 those of their cultural groups. They were critical of traditional cultural beliefs, that see mental
11
12 illness as a sin for which praying to God is a solution. However, the stigma has been internalized
13
14 as guilt, which influenced their decisions to seek help. It could be that young people of
15
16 Caribbean origin waited longer to ask for help as a way to protect their families from being
17
18 labelled with a taboo illness; future studies are needed to verify this hypothesis. As family
19
20 members of Caribbean origin described, there is a desire and need to find a space and place to
21
22 bring to light these issues: “We need to unload but we have no place to unload.”
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29 Although the analysis presented in this paper helps in the understanding of some of the
30
31 differences in DUP between African-, Caribbean-, and European-origin immigrants, we
32
33 recognize that this work has some limitations First, the sample size in this study was relatively
34
35 small; only limited inferences can be drawn for other groups. Second, as described, the sample
36
37 size was defined from the quantitative part of the study. We were not able to involve any family
38
39 members of African origin as our original pool of participants was very small. Finally, there are
40
41 many different ways to group people from different ethnic groups and races. Our classification
42
43 was subjective, based on self-identification. At the same time, arbitrary choices were made for
44
45 the analysis of the quantitative part of the study—focus groups were based on these decisions.
46
47 We acknowledge that this did not necessarily reflect the fluidity of ethnic differences and
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49 diversity of identities represented by the participants.
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3 We were able to ask both young people and family members for possible strategies
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5 which could be used to support people in the help-seeking process and for ideas about how the
6
7 system of care could be improved (see Table 3). All participants described the importance of
8
9 anti-stigma initiatives in different settings (e.g., schools, universities, primary care
10
11 services/providers) and targeted to different groups. Anti-stigma initiatives could challenge
12
13 wrong beliefs and stereotypes around mental illness and, in particular, psychosis and raise
14
15 awareness about psychosis signs and symptoms to promote problem recognition. This could
16
17 empower young people as well as adults around them to promptly intervene if needed.
18
19 Furthermore, more knowledge about systems of care, early intervention programs, treatment
20
21 options, and positive prognosis promoted by early intervention can help young people and
22
23 family members to initiate help seeking and to better navigate the system. At the same time,
24
25 sensitivity training should be offered for general practitioners and emergency-room staff to
26
27 promote self-awareness on mental illness bias, the impact of stigma toward mental illness in
28
29 access to care and/or therapeutic relationships, and general information on early intervention
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31 programs, resources, and services. Based on our findings, anti-stigma initiatives should be
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33 developed through the lens of ethnocultural knowledge of and beliefs about mental health
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35 problems.
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46 **Conclusion**

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49 The findings of this study suggest that stigma, especially internalized stigma, operates in
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51 different ways in European-, African-, and Caribbean-origin individuals and that this could
52
53 explain the differences in the pathways to early intervention services for psychosis for these
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55 young people. These findings could inform the development of targeted anti-stigma campaigns
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3 as well as the implementation of more equitable services for people in early stages of
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6 psychosis. To do so, trust needs to be redefined and gained between ethnocultural groups and
7
8
9 mental health researchers/providers both in research and in clinical practice. Implementing a
10
11 community-based participatory framework could help to achieve this goal.
12
13

14 **Contributorship statement** KM contributed to the conception of the study. MF, NF, KA, and KM
15 developed the qualitative study protocol and materials. MF and NF implemented the focus
16 groups and MF implemented the individual interviews. MF performed data analysis, assisted by
17 NF; they presented findings to all the authors in different stages of the process. MF wrote the
18 manuscript and it was then revised by KM. All authors reviewed and approved the final
19 manuscript.
20
21

22 **Competing interests** The authors have no conflicts of interest with respect to the publication of
23 this manuscript.
24

25 **Funding** This study was funded by a Canadian Institutes of Health Research (CIHR) Operating
26 Grant (Grant #220976).
27

28 **Data sharing** No additional data available.
29

30 **ACE Project Team:**

31
32 Kelly K. Anderson,^a Suzanne Archie,^b Philippe-Edouard Boursiquot,^b Julie Buffett,^b Denise
33 Canso,^a Manuela Ferrari,^a Nina Flora,^a Lew Golding,^a Hayley Hamilton,^{a,c} Asante Haughton,^a
34 Sean Kidd,^{a,c} Laurence Kirmayer,^d Steve Lurie,^e Kwame McKenzie,^{a,c} Marianne Noh,^a Samuel
35 Noh,^{a,c} Karen O'Connor,^e Jennifer Parlee,^a Syb Pongracic,^a Delia Reuben,^a Rebecka T. Sheffield,^b
36 Laura Simich,^c Taryn Tang,^c Andrew Tuck^a
37
38

39 ^a Social and Epidemiological Research, Centre for Addiction and Mental Health (CAMH) Toronto,
40 Ontario, Canada
41

42 ^b Department of Psychiatry and Behavioural Neurosciences, McMaster University
43 Hamilton, Ontario, Canada
44

45 ^c Department of Psychiatry, University of Toronto
46 Toronto Ontario, Canada
47

48 ^d Division of Social and Transcultural Psychiatry, McGill University
49 Montreal Quebec, Canada
50

51 ^e Canadian Mental Health Association (CMHA), Toronto Branch
52 Toronto Ontario, Canada
53
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3 The team gratefully acknowledges the clinical staff from the participating early intervention
4 programs for their involvement in study recruitment. We also appreciate the contribution and
5 support of the Toronto Early Intervention in Psychosis Network.
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Table 1

Focus Group and Interview Questions: Young people	Focus Group and Interview Questions: Family members
<p>Opening question:</p> <p>Tell us your name and why you decided to participate in this focus group?</p> <p>Introductory:</p> <p>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?</p>	<p>Opening question:</p> <p>Tell us your name and why you decided to participate in this focus group?</p> <p>Introductory:</p> <p>2. If you feel like sharing it, how did [the person who referred you to the focus group, he/she can be your son/daughter, etc.] come into contact with mental health services the first time?</p>

<p>Key questions:</p> <p>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;</p> <p>Why do they think this happens?</p> <p>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.</p> <p>NOTE: For each provider we explore what was helpful and/or less helpful or frustrating.</p> <p>Specific question based on the analysis done (e.g., The Caribbean population have really long delays—why do they think this happens?)</p>	<p>Key questions:</p> <p>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;</p> <p>Why do they think this happens?</p> <p>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.</p> <p>NOTE: For each provider we explore what was helpful and/or less helpful or frustrating.</p>
<p>Ending questions:</p> <p>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?</p> <p>Is there anything that we missed?</p>	<p>Ending questions:</p> <p>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?</p> <p>Is there anything you want to say that we did not ask or you did not talk about today that you want to add?</p>

Table 2

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

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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)

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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;

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- 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.

For peer review only

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.

Manuela Ferrari,^a Nina Flora,^a Kelly K. Anderson,^b Andrew Tuck,^a Suzanne Archie,^c Sean Kidd,^{a,d} & Kwame McKenzie^{a,d} on behalf of the ACE Project Team

^a*Social and Epidemiological Research, Centre for Addiction and Mental Health (CAMH)*

Toronto, Ontario, Canada

^b*Department of Epidemiology & Biostatistics, Western University, London, Ontario, Canada*

^c*Department of Psychiatry and Behavioural Neurosciences, McMaster University*

Hamilton, Ontario, Canada

^d*Department of Psychiatry, University of Toronto*

Toronto, Ontario, Canada

Correspondence:

Manuela Ferrari, PhD

Social and Epidemiological Research

Centre for Addiction and Mental Health (CAMH)

455 Spadina Avenue, Suite 300

Toronto, ON M5S 2G8 CANADA

Phone: (416)535-8501 ext. 77614 Fax: (416) 979-0564

E-mail: manuela.ferrari@camh.ca

Word count : 6,433

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

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3 explain the differences in the pathways to early intervention services for psychosis for these
4 young people. These findings could inform the development of more equitable services for
5 people in early stages of psychosis.
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11 **Keywords:** First-episode Psychosis; Pathways to Care; Duration of Untreated Psychosis; Stigma;
12 Ethnicity.
13

14 **Key messages**

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

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35 1. Use qualitative methodology to explore similarity and differences in pathways to care
36 and DUP between African-, Caribbean-, and European-origin groups.
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41 2. Young people who experienced a first episode of psychosis and their family members
42 were invited to review ACE Study quantitative findings and elaborate on them.
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47 3. Young people and their family members were invited to comment on possible strategies
48 and ideas about how the system of care could be improved
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53 4. The sample size in this study was relatively small; only limited inferences can be drawn
54 for other groups.
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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

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3 months for the European group, nine months for the African group, and 16 months for the
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5 Caribbean group. Caribbean participants in the study had fewer health services/providers in
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7 their pathways to care, they more often accessed FEP programs from an in-patient admission,
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9 and they faced more obstacles in their access to specialized treatment for psychosis than the
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11 European group. African group members in the study more often had an emergency
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13 department as first contact in their pathways [17].
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19 Once disparities have been identified, understanding of the reasons why they may exist
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21 is necessary if we are to develop effective services. This paper reports a qualitative exploration
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23 of the reasons for differences in pathways to care and DUP in the ACE Study from the
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25 perspective of respondents to the study and their families. The aim was to understand
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27 differences in DUP between African-, Caribbean-, and European-origin groups. To do so, we
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29 explored young people's and their family members' journeys of seeking help for psychosis,
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31 investigating how people responded to early signs of psychosis as well as the roles that
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33 different people and services played in accessing specialized programs for psychosis.
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39 **Methods**

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42 This study used an inductive qualitative approach to examine differences in the routes
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44 to care between young people with lived experience of psychosis of African-, Caribbean-, and
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46 European-origin. In this exploratory and inductive qualitative study, the data analysis and
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48 interpretation developed from patterns originated in empirical data rather than a deductive
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50 process where an existing theory, or a hypothesis, guides the data analysis and interpretation
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52 process.
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3 Focus groups were used as a means of generating in-depth knowledge of pathways to
4 care, exploring the interaction between individual socio-cultural positions, young people's
5 experiences of seeking help, and group dynamics—as each participant's narrative is generated
6 out of the journeys of others. By using focus groups we were able to examine how participants
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8 (1) interacted with each other; (2) produced and reproduced knowledge; and (3) articulated
9 and/or defended their views [18].
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19 *Ethical considerations*

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

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3 those who agreed were approached for the qualitative study. They were asked if they would
4 take part in a two-hour focus group to discuss the results of the study. Participants' family
5 members were also contacted and asked if they were willing to take part in a separate focus
6 group. One hundred and nine quantitative interview participants were contacted to take part in
7 a focus group or an interview. Of these, 31 declined participation, 38 could not be reached, and
8 40 agreed to take part in the focus group or an individual interview and, due to scheduling
9 issues, only 25 of these individuals could attend a focus group or an interview.
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22 Four focus groups with young people were implemented: one male group for each of
23 the African-, Caribbean-, and European-origin groups as well as one female European-origin
24 groups (African = 3 male, Caribbean = 3 male, European= 7 male and women 8 male). Two focus
25 groups were organized for the family members, one for each of the Caribbean, and European
26 groups (European = 6, Caribbean = 3). Because of difficulty recruiting for the African and
27 Caribbean women's groups, we adjusted the study protocol and undertook individual in-depth
28 interviews, for total of two interviews with African women, and one interview with a Caribbean
29 woman with lived experience of psychosis. The protocol change allowed us to have a small, but
30 important, representation of women from these two groups. Furthermore, we were able to
31 conduct an interview with a young woman of European origin who, due to anxiety problems,
32 did not feel comfortable attending the focus group session.
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49 *Data collection*

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52 Focus groups were conducted by the first author, MF, who acted as focus group
53 moderator, and research assistants who were trained in focus groups, transcribing, and
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3 qualitative data analysis for the purpose of this study. Focus group questions were designed to
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5 be conversational, open, and clear. They unfolded according to Krueger and Casey's
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7 recommendations [18]: opening, introductory, key, ending (see Table 1). At the end of each
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9 focus group, the research team involved in the focus group completed 30–40 minutes of
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11 debriefing. During the focus groups, participants were presented with preliminary ACE Study
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13 quantitative data; we focused on the differences in DUP as well as pathways to care and asked
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15 participants to comment on them.
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21 Focus groups and in-depth interviews were digitally recorded. The digital audio files
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23 were transcribed by the research assistants and reviewed for data accuracy. One research
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25 assistant transcribed a focus group recording and the other reviewed the work done. Finally, all
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27 material was also reviewed by MF. Focus group transcripts were then prepared to facilitate
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29 thematic analysis. All participant names were changed to pseudonyms to ensure confidentiality.
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35 Traditional data saturation, that is, "collecting data until no new information is
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37 obtained," [19, p. 147] is often an object of controversy in qualitative research literature [19].
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39 As Morse described: "The *quantity* of the data in a category is not theoretically important to the
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41 process of saturation. Richness of the data is driven from detailed description, not the number
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43 of time something is stated. Frequency counts are out" [19, p. 148]. We used instead Morse's
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45 criterion of data saturation as "adequacy" of the data, which can be obtained through specific
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47 methodological choices. These methodological choices were (a) selecting and working with an
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49 ethnic- and gender-cohesive sample; (b) at the same time, working with three different
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51 ethnocultural groups so as to maximize and explore cultural contrasts in pathways to care—a
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3 gap in current literature; and (c) basing our sample on quantitative data analysis, which allowed
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5 focus-group-member checks on the quantitative findings, as well as the possibility for rich, full,
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7 and complete understanding.
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10 11 12 13 14 15 *Analysis*

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18 Thematic analysis was employed to identify, analyze, and report patterns or themes
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20 within data [20]. Our thematic analysis was data driven, rather than theoretically driven,
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22 making use of an inductive approach, as the themes identified were strongly linked to the data
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24 themselves. We followed Braun and Clark's steps of thematic analysis [21] by: (1) familiarizing
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26 ourselves with our data (transcribing data, reviewing transcriptions for accuracy, reading
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28 transcriptions over and over, and noting initial ideas); (2) generating initial codes and searching
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30 for themes (collating codes into potential themes); (3) reviewing and redefining themes
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32 (exploring how strong the identified themes are by assisting the relationship between first
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34 [code] and second [theme] level of analysis, generating a thematic map of the analysis); and (4)
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36 further unpacking the analysis through the writing process (identifying themes and initial
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38 stigma concepts was further explored through a review of existing models of mental health
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40 stigma).
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49 We compared each participant's journey to care (shared during the focus group), the
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51 pathway depicted during a semi-structured interview, and the participant's medical chart.
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53 Further, we performed an analysis within each ethnic group, comparing and contrasting young
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55 people's narratives with those of family members, and a cross-ethnic-group analysis. As a
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3 result, in the study findings we describe themes that were common across all the narratives as
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5 well as the ones that were different between the three ethnic groups. All young people's and
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7 family members' names used in this paper have been changed to ensure participants'
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9 confidentiality.

10 11 12 13 *Rigour*

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16 Lincoln and Guba [20] defined primary criteria to assess rigour and trustworthiness of
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18 the qualitative research process. Primary criteria—credibility, authenticity, criticality, and
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20 integrity—are necessary to all qualitative enquiry but they are insufficient in and of themselves.
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22 Trustworthiness was achieved within the study through the following criteria: *credibility* and
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24 *authenticity*, attained through multiple sources of data (e.g., pathways maps generated from
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26 semi-structured interviews, chart reviews, focus groups' data) as well as specific and different
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28 sample strategies being employed to generate rich and meaningful data; *criticality* and
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30 *integrity*, using team debriefing and analysis to ensure methodological effectiveness.
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36 37 38 **Results**

39 40 *Overview of the sample*

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42 A total of 34 people took part in the study; 25 young people with lived experiences of
43
44 psychosis (origins: European = 16, African = 5, Caribbean = 4) and nine family members (origins:
45
46 European = 6, African = 0, Caribbean = 3). Table 2 reports the socio-demographic information
47
48 for young people with lived experiences of psychosis only—no socio-demographic information
49
50 was collected for family members at the time of the focus group.
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56 Findings are presented in two main sections: (1) *Understanding help seeking*, in which
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3 we first present commonality across the three groups, and then we investigate differences in
4
5
6 DUP between African-, Caribbean-, and European-origin groups. In this section we unpack the
7
8 role of stigma and how it operates early on in pathways to care. In this paper, stigma refers to a
9
10 collection of negative attitudes, beliefs about, and behaviours directed at people with mental
11
12 disorders, which are manifested in rejection and avoidance of, and prejudice and discrimination
13
14 against people with mental illness conditions [22-24]. Stigma can be a barrier for people who
15
16 experience mental health problems by making them reluctant to ask for help due to fear of
17
18 prejudice, being labelled, and discrimination by others. Internalized stigma, or self-stigma,
19
20 occurs when a person takes on those negative stereotypes and assumptions and applies them
21
22 to themselves [23, 24]. Discrimination due to mental health stigma can take place in different
23
24 circumstances/settings: education, employment, housing, and treatment. (2) *Understanding*
25
26 *delay in entering first-episode psychosis (FEP) programs*, in which we explore the relationship
27
28 between negative experiences, stigma, health care delivery, and illness/symptoms disclosure.
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30 The themes presented in this section are also common across the three groups.
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Understanding help seeking

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

45 Consistent across all narratives, for both young people and family members, was that
46
47 knowledge or lack of knowledge about symptoms of psychosis, mental illness, and services
48
49 available to them was key to them recognizing the significance of changes in behaviour. Often
50
51 this knowledge was based on family members' or friends' past experiences of mental illness.
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3 Maria: The one person who really helped me to realize what I'm going through, and that I
4 need help, is my mother. She knows what I'm going through because she went through it
5 with my father. She helps me a lot. ...
6
7

8 (European youth focus group)
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11
12 Young people who did not have any knowledge of signs or symptoms of psychosis were
13 aware of personal changes but did not know that they were indicative of mental illness. In
14 these cases, family members played a key role in the help-seeking process by taking them to
15 the hospital.
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23 Benjamin: I was schizophrenic, and I didn't know what to do. I heard voices and stuff. I did
24 some stuff that I couldn't remember, so some people took me in ...
25

26 Paul: I kept hearing ... weird voices, but I didn't know what is. So, later on I came ... my
27 parents took me to the hospital ...
28

29 (African youth focus group)
30
31

32 Steve: I didn't know that I needed help. I had no one around me who knew what was
33 happening. ... I was staying with a friend, my mom was occasionally stopping by ... she saw
34 certain signs in me, and she immediately drove me to [name of the hospital].
35

36 (Caribbean youth focus group)
37
38

39 June: I wouldn't have stayed in the emergency room, I wouldn't have gone by myself ... I
40 didn't know what was going on. ... I didn't know *I was going crazy*, ... I thought everybody
41 was against me.
42

43 (European youth focus group)
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46

47 Young people and family members who did not have awareness or knowledge of the signs or
48 symptoms of psychosis, struggled the most to understand and/or make sense of the situations.
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53 Janine: I didn't know what this illness was. I thought it was just some kind of behaviours,
54 being angry or strange like teenagers could possibly experience sometime ... it was people
55 from the outside who used to tell me "No, this more than just ... you know teenager's
56 crisis." Not knowing [the] symptoms ... I just didn't know what was going on really.
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3 (Caribbean family members' focus group)
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8 Louise: My son was 17 when he had his psychotic break. I thought he was just being a
9 typical rebellious teenager ... he smoked pot. He didn't get violent. He was so scared and I
10 didn't know what else to do with him. I took him to [name of general hospital] ... after
11 about 15 hours convincing them that I was not taking him home, they admitted him.
12

13 (European family members' focus group)
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17

18 Often, family members attributed the changes in their relatives' behaviours to growing
19 up/going through adolescence, peer groups/wrong crowds, stress, and/or substance abuse in
20 young adults. Family members often thought that what their relatives were experiencing was
21 just a temporary phase in their relatives' lives without recognizing signs or symptoms of
22 psychosis. Help seeking often occurred after doubting the early signs of psychosis and, most
23 importantly, after feeling sadness and discomfort.
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33 Along with knowledge and awareness of signs or symptoms of psychosis, the role that
34 stigma played during the help-seeking process was also constantly present in the narratives.
35
36 Through the analysis conducted, it was possible to identify how individual and family
37 perceptions of mental illness influenced the internalization of stigma. For example, young
38 people involved in the study often distinguished between their rational understandings of the
39 mental health problems, symptoms, and causes, and, at the same time, their feelings of being
40 trapped in emotions such as shame.
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51 Karen: People are scared to look for help, and to ...
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53 Maria: And to admit to themselves even ... [Karen: Yeah!] that "I have schizophrenia"... I
54 never told anybody.
55
56

57 June: I'm still ashamed of what I have.
58
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1
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3 Samantha: Me too.

4
5
6 (European youth focus group)
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10 Participants described how, for fear of family members' and/or friends' reactions to their
11 conditions, they tried to ignore the signs and symptoms by, for example, using marijuana, and
12 attempted to hide their symptoms from others.
13
14

15
16 Sandi: I was worried about what people around me might say ... once you're in the
17 hospital you can't really keep your secret anymore. There is a huge stigma about mental
18 illness; people tend to like to avoid it.
19

20
21 (European youth focus group)
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26 Positive symptoms (e.g., hearing voices, bizarre behaviour, violence) were often
27 catalysts to treatment initiation. Family members often struggled to recognize when their
28 relative was no longer able to care for himself/herself or when he/she was asking for help as
29 the symptoms of psychosis took over his/her ability to make decisions. This created quite a
30 complex situation where family members felt threatened or worried about their safety and, at
31 the same time, guilty when they had to call the emergency department, ambulance, or,
32 unfortunately, the police. This was evident in family members' narratives.
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44 Natali: I have been there ... I couldn't stop crying for days ... when my daughter finally
45 broke down at school ... being scary violent with us. ... the first time she finally did get to
46 the hospital that day [name of the hospital] ... It was almost like a relief, she was safe and
47 she was away from us ... because we were scared. We were so afraid. [Sarah:
48 (overlapping) Yes. Yes. Yeah.]
49

50
51 (European family members' focus group)
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55
56 Stigma was also closely connected to how much the person who experienced psychosis was
57 considered responsible for his/her mental condition or was in control, or not, of his/her
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3 symptoms. Family members recognized that mental illness is not perceived the same as other
4 health problems. Physical disorders, such as cancer, generate compassion in extended family
5 members, whereas mental disorders bring reactions of distancing, blaming, and stigmatizing
6 from members of the extended family.
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11
12 Natali: Unfortunately, I still see ... my family members not so supportive. On the surface,
13 they are, but I see them shy away from my son. I see the stigma, it is still so much there. If
14 he was (clears throat) you know physically ill they would be right there.
15

16 (European family members' focus group)
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21 Overall, family members described how psychosis is hidden until it manifests through a
22 person's behaviours. It is difficult to understand what is happening to the person as well as to
23 assess if, when, and how to intervene.
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29 Differences in help seeking between the three groups: Internalized stigma as feeling shame
30 versus feeling guilty for their own condition
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34
35 Participants of European origin internalized mental health stigma as shame about their
36 symptoms (e.g., hearing voices, unpredictable or bizarre behaviours in front of family and
37 friends, or irrational actions). They felt distress caused by the awareness of their past bizarre
38 behaviours and a sense of humiliation for their conditions. In contrast, young people from
39 African- and, even more, Caribbean-origin groups stressed their responsibility for their
40 conditions, they felt that they had done something wrong (for having an mental illness), and
41 they felt a sense of failure for not being able to "snap out of it"—as a participant described
42 during a focus group. In this sense, they seemed to internalize mental health stigma as guilt—
43 there is shame and humiliation but also they felt that they had done something wrong.
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3 Paul: ... there was a lot of pressure to excel in school and succeed. I dabbled too much in,
4 dabbled too much in drugs, that was my problem ... that was really my fault. I have no
5 one else to blame but myself ... people expect you to just walk it off kind of thing. But you
6 really, you really can't, you can't really walk off a mental illness ... you can cope with it.
7
8

9 (African youth focus group)
10

11 Steve: Going through a mental illness totally flipped the way I view ... everything! It's also
12 made me become more aware of how family members react, and why are they reacting
13 that way. Eventually it is what got me onto the culture of it, my religion, and so forth. I
14 can't say exactly what it is about the Caribbean culture ... but, I can tell, those two things
15 definitely play a factor in it.
16
17

18 (Caribbean youth focus group)
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21
22 In the African and Caribbean focus groups, participants discussed the role that religion
23 had in shaping their and their families' perceptions of mental illness and feelings of guilt for
24 their condition—this topic was not discussed in the European focus groups. In some cases,
25 people described how they grew up thinking that mental illness was a sin or God's punishment.
26
27 Although they did not think in this way now, they saw how this perception influenced their
28 understanding of early signs of psychosis, the focuses of their paranoid symptoms (in some
29 cases), and, most importantly, their asking for help.
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41 Suzanne: Well, it made me feel badly because I thought, "Wow. You know, she's so
42 nervous [mother] about me going to the hospital for help." It made me feel kind of
43 ashamed that I needed help. ... I guess it made me a little bit reluctant to seek care later
44 on. [Later on in the interview] ... in the beginning my mom was like, "Suzanne you need to
45 PRAY more. That's the problem." And, I'm like, "No mom, I need medication. I need some
46 help." ... Sometimes I just tell her that I prayed just so she can get off my case. My brother
47 often tell me that my life has gone in this direction because I stopped going to church. ... It
48 makes me feel bad. It's not helpful me to get better.
49
50

51 (Caribbean youth interview)
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56 Greg: I can't say everybody but, A LOT of people in my family, and in the community ...
57 they become very superstitious. It's a mind job with Catholicism first of all—and no
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3 offense to anybody here who's Catholic, I am Catholic. Something simple as, as having a
4 mental condition, is not simple in this world anymore, it becomes then, "that person
5 needs to be exorcised, or that person's got bad demons—"
6
7

8 Steve: (overlapping) Oh, I've heard ... I've heard that, I've heard that, to get rid of my
9 voices I have to get an exorcism.
10

11 Greg: Yeah.
12

13 Steve: That's what I heard from a friend.
14

15 Greg: Like, my mom said that when she was uh, a kid, when she was like 5 or 6, she
16 actually witnessed someone getting exorcised, because of voices in his head and stuff like
17 that.
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19

20 (Caribbean youth focus group)
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25 As described, African- and, even more, Caribbean-origin young people reported that their
26 mental illnesses were taboos among members of their close or extended families. While young
27 people of African origin had their families around to support their struggles, young people of
28 Caribbean origin who attended the focus groups had no one or only a few close family
29 members. The support networks that could assist them in seeking help were not available.
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38 Simone: When people in the Caribbean get to know that your child has this issue [mental
39 illness] ... the whole family is labelled ... from the grandparent right the way down. The
40 family is labelled and you are sort of ostracized. That's why many of us don't want to
41 bring it up to the light ... we are in denial that this is not happening to this family. ... We,
42 as parents, don't have the freedom to talk about it ... because of the stigma that's still
43 attached ... we internalize it. When we internalize, we're stressed. We would love to know
44 that there is somewhere that we can go and sit down and talk. We need to unload but we
45 have no place to unload.
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48

49 (Caribbean family members' focus group)
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55 African- and Caribbean-origin participants described how when they experienced early
56 signs of psychosis, they tried to control them and they felt guilty if they were not able to. Their
57 sense of guilt was also connected with cultural interpretation of mental illness as sin, God's
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1
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3 punishment, and a taboo illness heavily stigmatized—themes more present in the Caribbean-
4 origin focus group and interviews.
5
6

7
8 *Understanding delay in entering first-episode psychosis programs (FEP)*
9

10
11 Rachel: Now none of these people [university psychological service/psychiatrist] told me
12 about any other resources. ... All I knew was [name of mental health hospital], which was,
13 like, the last resort. ... I was in the dark. And then I went to my family doctor, and she was
14 the first person after like 3 months who told us that, “Oh, there’s actually an in-patient
15 program at [name of a general hospital], for if you’re in an emergency—go there.” ... So
16 then when I got really bad, I was in the in-patient at [name of a general hospital] and
17 there, it was when I actually found out about a bunch of other resources ...”
18
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21 (European youth focus group)
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24
25 Participants often recognized changes in behaviours and thinking but they did not always
26 attribute these to a mental illness; however they were active in seeking help, contacting
27 community services (e.g., school or university health services) or their family doctors, if they
28 had one. In reflecting on their pathways, they often felt upset, as early attempts to ask for help
29 were dismissed by providers and/or information was not provided to them.
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37 Negative experiences, stigma and care: First contact, therapeutic relationship, and disclosure of
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39 symptoms
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43 Once in the system, groups’ differences in the journeys to specialized treatment seemed
44 less present. Before entering into early intervention programs, young people saw between four
45 and six difference health providers/services (e.g., family doctor, emergency, police, detention
46 centre, in-patient unit). As young people described, the care they received (or did not receive)
47 and health care providers’ attitudes towards mental illness influenced what they shared about
48 their mental states (e.g., hearing voices, suicidal thoughts) and, overall, their trust in the
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3 system. From the first contact with a hospital, the majority of young people involved in the
4
5 focus groups reported that, if it was a negative experience, it affected their therapeutic
6
7 relationships, and, generally, their willingness to stay in the system and to return, if needed, a
8
9 second time.
10

14 Samantha: From my experience there's a lot of stigma and shame surrounding people
15 who have substance abuse problems. Whenever I've been in treatment, there has not
16 been an accepting atmosphere for me to discuss my issues or to make me feel like I'm
17 actually going to get help.
18

20 (European youth focus group)
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23

24 Steve: Well, I found, like, a number of them [mental health care providers] definitely
25 helped. I feel that the majority of [hospital name] staff definitely does have that, but
26 there are still the ones that can create that negative experience for you when you're
27 already going through a negative experience. ... It's funny ... you're going through stuff,
28 even though your mind's not in the right place, you still remember all the negativity. ...
29 [Andy: (overlapping) Yeah.] Yeah. Those are the things that I will always remember, about
30 [name of the hospital] and dealing with [the staff] at the first time. Like, although they
31 were there to help me, it didn't seem like half had actually studied mental health at all.
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35 (Caribbean youth focus group)
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40 During the focus groups and interviews, participants reported how their experiences of
41 poor quality of care was due to health providers' negative attitudes and behaviours towards
42 mental illness. Indeed, stigma does operate, albeit marginally, in mental health services, such as
43 primary care (e.g., family doctors), emergency departments, in-patient units, out-patient units,
44 and so on and, when present, it seems to be more hurtful than when experienced outside the
45 health care system.
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57 Eight young people who took part in the focus groups had police and detention centres
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3 as early contacts in their pathways to FEP treatment. Overall, police officers were perceived to
4
5 be supportive, helpful, and understanding of the situations. Police officers have the duty to
6
7 respond to an emergency call, accompany the person to the hospital emergency room, and stay
8
9 with them until the hospital staff takes over.
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14 Linda: I did it twice. The first time, I went to the hospital was in an ambulance, and, the
15
16 second time was ... in a police car. I actually found the police were nice. Like, I was in
17
18 handcuffs [laughter], but I found them to be really nice ... they stayed with me until the
19
20 doctors started seeing me. They didn't judge me, and I asked the one cop if he was
21
22 married ... he was like showing me pictures of his kids. He was just nice.

23
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25
26
27 (European youth focus group)

28
29 Three men of European origin had forensic services in their pathways. In these cases, the young
30
31 men had to stay in detention for several days before they were able to see a judge. During the
32
33 focus groups they described how they were exposed to verbal and physical violence as well as
34
35 the trauma of experiencing psychotic episodes while in detention.
36
37

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39 Rob: Well, for me the cops were ok. But, then at the detention centre, I said something
40
41 really dumb to the correctional officer and ... I'm walking ... he literally just POUNDS me,
42
43 he beat the shit out of me. Right there on the ground. I wasn't shaken by it at all because I
44
45 was psychotic, but like—I don't know, it was really weird. He literally took me from
46
47 behind and just pounded me. I guess his superior comes in and takes him off me. I guess
48
49 the cops are ok but the guys in the jail ...

50
51 Matt: Yeah, I had the same experience. One time, when I was psychotic, my mom called
52
53 the police on me ... She meant for me to go to the hospital but I got charged by the police
54
55 with a bunch of things. They sent me to JAIL, and I was completely psychotic ... they didn't
56
57 know what to do with me. They were physical with me, they injected me in the back of
58
59 my neck with I don't know what medication. They just locked me in a jail cell for probably
60
61 a month until I was transferred to a medical facility.

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64
65
66 (European youth focus group)

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3 It was interesting to notice that men of European origin were able to share these experiences
4
5 during the focus group, whereas men of African and Caribbean origin just mentioned police
6
7 involvement in their pathways without elaborating on it. We realized the sensitivity of this topic
8
9 which, combined with the sense of guilt, probably precluded any further disclosure.
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14 In total, 10 youth had family doctors as first contact in their pathways. Among all focus
15
16 groups, there was only one case in which referral was made to an FEP program directly by a
17
18 general practitioner. The majority of them reported to have been misdiagnosed or had their
19
20 symptoms dismissed by their family doctors.
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25 Benjamin: ... the family doctor doesn't, uh well, didn't work for me, he thought it was just
26
27 anxiety, like ... anxiety because of school ... 'cause I was going into university.

28
29 (African youth focus group)
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33 In other cases, a young man and woman described how their family doctors focused only on
34
35 their substance abuse problems and reprimanded them for their behaviours.
36
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38

39 Steve: I kind of did [went to see my family doctor at first], but, he turned me down flatly,
40
41 'cause I was smoking weed. I said, "I thinking, I'm suffering with depression." He asked me
42
43 if I did drugs, I said that I did smoke weed quite often, and he said stop smoking the weed
44
45 then "come back and I help you." I never heard about it after that. Next time, I saw him, I
46
47 had to tell him that, yeah, I was diagnosed with schizophrenia. So, my general
48
49 practitioner, unfortunately, wasn't able to do anything at the time.

50
51 (Caribbean youth focus group)
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54

55 Jill: I recognized the symptoms but I didn't know the specifics of my diagnosis. I went to
56
57 the family doctor and explained that I felt that I was being followed and everything. And
58
59 then he told me, "Okay. You need to stop doing drugs," 'cause I was high on marijuana
60
61 when it first happened ... but [it happened] several time [before] and I just thought it was
62
63 the pot.

64
65 (African youth interview)
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5 It may be difficult for general practitioners to diagnose psychosis early; however, participants
6
7
8 felt that they had actively sought help but their requests were misunderstood or dismissed.
9

10
11 When admitted to emergency units or in-patient services, participants described the
12
13 following negative experiences: being labelled, feeling like a number, feeling no longer a person
14
15 but an illness, being judged for behaviours/symptoms, and/or being treated like a child.
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19
20 Matt: I don't know, how it makes sense, but [hospital staff] were almost like TOO nice ... I
21 don't know the word, like, treating you like you're a child ... talking down to you. It was
22 NICE, but it didn't make me feel better ... other people were nice but, at the same time ...
23 made you feel like an equal. I felt like that was important.
24

25
26 Steve: I think maybe the word you were looking for was "pity." Like we were treated with
27 PITY [Matt: Yeah.] Yeah. I think that, people think that people with schizophrenia are
28 somehow STUPIDER or something ... I don't think people with schizophrenia are stupid at
29 all.
30

31 (European youth focus group)
32

33
34 Robin: They treat you like a number [mumbles of agreement].
35

36 Samantha: When I went to the hospital last time ... I was going through a panic attack
37 when I FIRST found out I had schizophrenia, and they, the nurse was like, "Yeah, you're
38 just faking it, you're perfectly fine, nothing's wrong with you."
39

40 Robin: Yeah.
41

42 Samantha: It really, made me not like being in the hospital. I did not want to go back
43 there ever.
44

45
46 Natali: I agree. I think they treat you more like a number. And I think, being treated like
47 a PERSON instead of a number or a case because, if you're just a case, you're like "I'm
48 schizophrenic" ... you're not a person, anymore [mumbles of agreement].
49

50 (European youth focus group)
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56 According to young people, all of these factors influenced the therapeutic relationship
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3 with services and providers and, in particular, affected young people's disclosures of
4 symptoms—as described.
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8 9 **Discussion**

10
11
12 Differences in pathways to care and the duration of untreated psychosis have been
13 reported in some studies of ethnic minority groups [13, 16]. The reasons for these differences
14 are unclear [25]. In this paper, the authors focused on participants' narrative accounts to
15 investigate the social and cultural contexts of help seeking. In doing so, we were able to further
16 investigate differences between the groups as well as how a number of factors, including
17 stigma, influenced both help seeking and access to specialized programs. We developed
18 preliminary hypotheses about the link between internalized stigma, cultural beliefs about
19 mental illness, and help seeking. At the same time, we discussed how interactions with health
20 care settings shape the experience of asking for help, influencing future engagement with
21 health providers and/or willingness to disclose symptoms.
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38 In our attempt to understand differences in the pathways to care and DUP between
39 African-, Caribbean-, and European-origin groups, we found similarities to other studies that
40 broadly explore help seeking among young people in FEP programs [26, 27] and their families
41 [28-33] without focusing on ethnicity. As with our findings, other qualitative works described
42 long and difficult periods from the realization of signs and symptoms of psychosis to the
43 initiation of help seeking [28-31]. As other studies reported, family members described how the
44 role of caregiver was emotionally draining [32] due to their inability to understand and cope
45 with the changes in their family members, feelings of guilt after calling the police, as well as
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3 frustration of their inability to navigate the health care system and/or lack of involvement in
4
5 the treatment program [33]. Family members' knowledge of mental illness and services
6
7 available to them was important in dealing with the situations. However, as other studies
8
9 described, they often mistook early signs of psychosis—especially in the prodromal phase of
10
11 the illness—for mood changes due to adolescence, social withdrawal, stress, or drugs [26-30].
12
13 At the same time, even if the young people who took part in our study recognized changes in
14
15 themselves, they did not attribute these changes to mental illness—as was also described in
16
17 other studies [26, 30]. Moreover, as we discussed, because of the associated stigma, young
18
19 people and family members engaged in denial, avoidance, and hiding of early symptoms of
20
21 psychosis which prevented them from seeking help [26-34].
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29 In *Stigma*, Goffman [22] defined and discussed stigma as *discredited* versus
30
31 *discreditable*; in the first case, a visible and physical mark defines stigma, where, in the second,
32
33 no visible or physical mark is present—as is the case with the stigma of mental illness. More
34
35 recently, further theories have been developed and used to understand the relationship
36
37 between stigma and mental illness (see Link & Phelan [23], and Corrigan [24]). In all of these
38
39 theories, stigma is based on signs that define who is different, stereotypes about the person or
40
41 group, marginalization, avoidance, discrimination, fear of what or who is different—where
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43 normality and abnormality or similarity and difference are defined by socio-cultural norms and
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45 beliefs. Furthermore, internalized stigma seems more distractive and harmful to the affected
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47 person's health and, broadly, to his/her sense of self [35].
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54 Several studies investigate stigma and mental illness [33, 35, 36]. Stigma about mental
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56 illness is prevalent in the general public but, unfortunately, occurs in health and mental health
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3 settings as well [36]. Work done in the Canadian context recognizes the role of stigma in
4
5 seeking help for mental illness in immigrant and refugee groups in Canada. The *Improving*
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7 *mental health services for immigrant, refugee, ethno-cultural and racialized groups: Issues and*
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9 *options for service development* report describes how immigrants, refugees, and racialized
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11 groups are less likely to ask about mental health systems because of possible stigma and this
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13 leads either to people not getting treatment or to a delay in getting treatment [15]. Other
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15 studies describe the specific needs and issues that immigrant groups are facing in relation to
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17 mental health services in urban settings in Canada [37, 38]. These studies, which were
18
19 conducted with West Indian immigrants in Montreal, focus on cultural beliefs in non-medical
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21 interventions as the preferred form of treatment for mental illness (e.g., prayer or traditional
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23 folk medicine) or on the perception of primary care (e.g., doctors often prescribing
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25 pharmaceutical medications, or lack of time from physicians in early encounters that deterred
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27 the use of current health services) [37, 38].
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37 There are similarities but also differences with our findings compared to other studies.
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39 This paper describes how stigma operated on young people and family members of African,
40
41 Caribbean, and European origin and how it influenced the help-seeking process. Although all
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43 young participants internalized stigma as shame, fearing lifelong discrimination for their mental
44
45 health conditions, which often prevented them from disclosing their symptoms to others and
46
47 ask for professional help, those of African and Caribbean origin also internalized a sense of guilt
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49 for their conditions, holding them back from talking about their problems as well as pushing
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51 them to try to overcome their symptoms alone.
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3 As mentioned, Caribbean young people described the role of cultural beliefs about
4 mental illness and of religion in delay in getting treatment. African and Caribbean young people
5 were able to distinguish the difference between their own beliefs about mental illness and
6 those of their cultural groups. They were critical of traditional cultural beliefs, that see mental
7 illness as a sin for which praying to God is a solution. However, the stigma has been internalized
8 as guilt, which influenced their decisions to seek help. It could be that young people of
9 Caribbean origin waited longer to ask for help as a way to protect their families from being
10 labelled with a taboo illness; future studies are needed to verify this hypothesis. As family
11 members of Caribbean origin described, there is a desire and need to find a space and place to
12 bring to light these issues: “We need to unload but we have no place to unload.”
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29 Although the analysis presented in this paper helps in the understanding of some of the
30 differences in DUP between African-, Caribbean-, and European-origin immigrants, we
31 recognize that this work has some limitations. First, the sample size in this study was relatively
32 small; only limited inferences can be drawn for other groups. Second, as described, the sample
33 size was defined from the quantitative part of the study. We were not able to involve any family
34 members of African origin as our original pool of participants was very small. Finally, there are
35 many different ways to group people from different ethnic groups and races. Our classification
36 was subjective, based on self-identification. At the same time, arbitrary choices were made for
37 the analysis of the quantitative part of the study—focus groups were based on these decisions.
38 We acknowledge that this did not necessarily reflect the fluidity of ethnic differences and
39 diversity of identities represented by the participants.
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3 We were able to ask both young people and family members for possible strategies
4 which could be used to support people in the help-seeking process and for ideas about how the
5 system of care could be improved (see Table 3). All participants described the importance of
6 anti-stigma initiatives in different settings (e.g., schools, universities, primary care
7 services/providers) and targeted to different groups. Anti-stigma initiatives could challenge
8 wrong beliefs and stereotypes around mental illness and, in particular, psychosis and raise
9 awareness about psychosis signs and symptoms to promote problem recognition. This could
10 empower young people as well as adults around them to promptly intervene if needed.
11 Furthermore, more knowledge about systems of care, early intervention programs, treatment
12 options, and positive prognosis promoted by early intervention can help young people and
13 family members to initiate help seeking and to better navigate the system. At the same time,
14 sensitivity training should be offered for general practitioners and emergency-room staff to
15 promote self-awareness on mental illness bias, the impact of stigma toward mental illness in
16 access to care and/or therapeutic relationships, and general information on early intervention
17 programs, resources, and services. Based on our findings, anti-stigma initiatives should be
18 developed through the lens of ethnocultural knowledge of and beliefs about mental health
19 problems.

20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 **Conclusion**

48
49 The findings of this study suggest that stigma, especially internalized stigma, operates in
50 different ways in European-, African-, and Caribbean-origin individuals and that this could
51 explain the differences in the pathways to early intervention services for psychosis for these
52 young people. These findings could inform the development of targeted anti-stigma campaigns
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3 as well as the implementation of more equitable services for people in early stages of
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6 psychosis. To do so, trust needs to be redefined and gained between ethnocultural groups and
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8
9 mental health researchers/providers both in research and in clinical practice. Implementing a
10
11 community-based participatory framework could help to achieve this goal.
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14 **Contributorship statement** KM contributed to the conception of the study. MF, NF, KA, and KM
15 developed the qualitative study protocol and materials. MF and NF implemented the focus
16 groups and MF implemented the individual interviews. MF performed data analysis, assisted by
17 NF; they presented findings to all the authors in different stages of the process. MF wrote the
18 manuscript and it was then revised by KM. All authors reviewed and approved the final
19 manuscript.
20

21
22 **Competing interests** The authors have no conflicts of interest with respect to the publication of
23 this manuscript.
24

25 **Funding** This study was funded by a Canadian Institutes of Health Research (CIHR) Operating
26 Grant (Grant #220976).
27

28 **Data sharing** No additional data available.
29

30 **ACE Project Team:**
31

32 Kelly K. Anderson,^a Suzanne Archie,^b Philippe-Edouard Boursiquot,^b Julie Buffett,^b Denise
33 Canso,^a Manuela Ferrari,^a Nina Flora,^a Lew Golding,^a Hayley Hamilton,^{a,c} Asante Haughton,^a
34 Sean Kidd,^{a,c} Laurence Kirmayer,^d Steve Lurie,^e Kwame McKenzie,^{a,c} Marianne Noh,^a Samuel
35 Noh,^{a,c} Karen O'Connor,^e Jennifer Parlee,^a Syb Pongracic,^a Delia Reuben,^a Rebecka T. Sheffield,^b
36 Laura Simich,^c Taryn Tang,^c Andrew Tuck^a
37
38

39 ^a Social and Epidemiological Research, Centre for Addiction and Mental Health (CAMH) Toronto,
40 Ontario, Canada
41

42 ^b Department of Psychiatry and Behavioural Neurosciences, McMaster University
43 Hamilton, Ontario, Canada
44

45 ^c Department of Psychiatry, University of Toronto
46 Toronto Ontario, Canada
47

48 ^d Division of Social and Transcultural Psychiatry, McGill University
49 Montreal Quebec, Canada
50

51 ^e Canadian Mental Health Association (CMHA), Toronto Branch
52 Toronto Ontario, Canada
53
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3 The team gratefully acknowledges the clinical staff from the participating early intervention
4 programs for their involvement in study recruitment. We also appreciate the contribution and
5 support of the Toronto Early Intervention in Psychosis Network.
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Table 1

Focus Group and Interview Questions: Young people	Focus Group and Interview Questions: Family members
<p>Opening question:</p> <p>Tell us your name and why you decided to participate in this focus group?</p> <p>Introductory:</p> <p>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?</p>	<p>Opening question:</p> <p>Tell us your name and why you decided to participate in this focus group?</p> <p>Introductory:</p> <p>2. If you feel like sharing it, how did [the person who referred you to the focus group, he/she can be your son/daughter, etc.] come into contact with mental health services the first time?</p>

<p>Key questions:</p> <p>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;</p> <p>Why do they think this happens?</p> <p>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.</p> <p>NOTE: For each provider we explore what was helpful and/or less helpful or frustrating.</p> <p>Specific question based on the analysis done (e.g., The Caribbean population have really long delays—why do they think this happens?)</p>	<p>Key questions:</p> <p>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;</p> <p>Why do they think this happens?</p> <p>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.</p> <p>NOTE: For each provider we explore what was helpful and/or less helpful or frustrating.</p>
<p>Ending questions:</p> <p>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?</p> <p>Is there anything that we missed?</p>	<p>Ending questions:</p> <p>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?</p> <p>Is there anything you want to say that we did not ask or you did not talk about today that you want to add?</p>

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For peer review only

Table 2

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

1			
2			
3			
4	Born in Canada		
5			
6	Yes	17	(68)
7			
8	No	8	(32)
9			
10			
11	English Spoken at home		
12			
13	Yes	18	(72)
14			
15	No	5	(20)
16			
17	English and other	2	(8)
18			
19			
20	Sexual Orientation		
21			
22	Heterosexual	21	(84)
23			
24	Homosexual	1	(4)
25			
26	Bisexual	2	(8)
27			
28	Other	1	(4)
29			
30			
31			
32	Relationship Status		
33			
34	Single	23	(92)
35			
36	Married	0	(0)
37			
38	Cohabiting	1	(4)
39			
40	Separated/Divorced	1	(4)
41			
42			
43			
44	Parents Born in Canada		
45			
46	Both	5	(20)
47			
48	Father Only	4	(16)
49			
50	Mother Only	2	(8)
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52	Not born in Canada	14	(56)
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33 **Table 3**
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- 35 1. Universal and selected prevention interventions in school are needed:
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- 38 • Education in school settings,
 - 39
 - 40 • Early detection efforts should focus on identifying the full spectrum of psychotic
41 symptoms. As youth described, withdrawal and, broadly, negative symptoms,
42 often occur before the psychosis develops. However, these symptoms are often
43 questioned and neglected by family members and health providers;
44
45
- 46
- 47 2. Anti-stigma initiatives are needed and should be developed through the lens of
48 cultural knowledge of and beliefs about mental health problems;
49
- 50
- 51 3. Increased family involvement should be encouraged;
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- 53 4. Self-referral to early intervention services may be beneficial and the possibility for
54 a triage model should be explored;
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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.

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