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IMPROVING MENTAL HEALTHCARE FOR BLACK YOUTH: LESSONS FROM QUALITATIVE RESEARCH
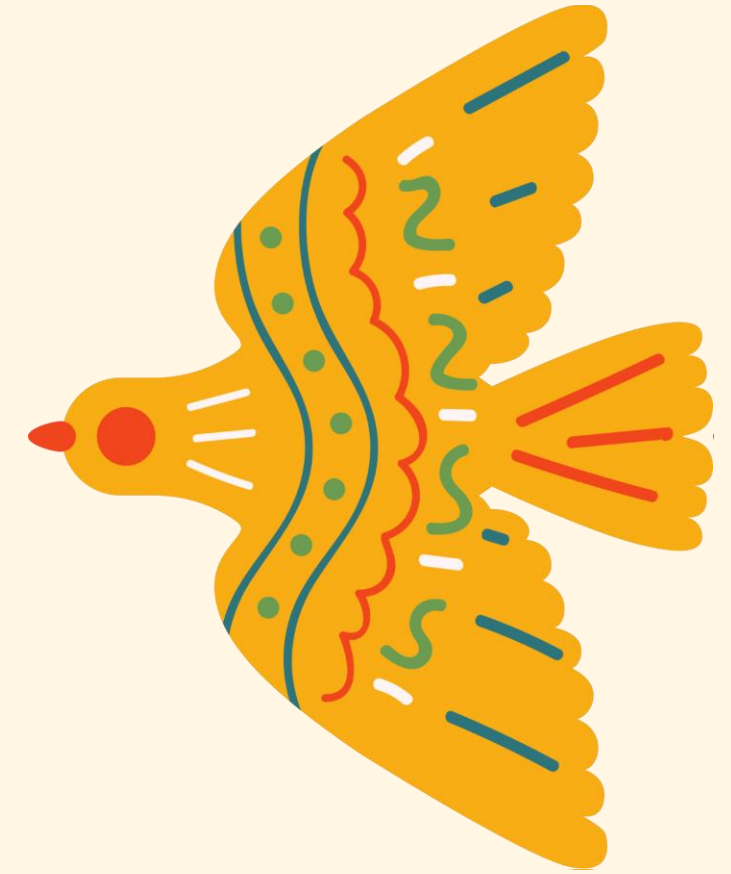
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Public Health Ontario Rounds
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FUNDING

Community partner: CAFCAN

LEARNING OBJECTIVES

01 LEARN ABOUT THE UNIQUE CHALLENGES AND OPPORTUNITIES IN EFFECTIVE SYSTEM DESIGN AND PROVISION OF CARE FOR BLACK YOUTH WITH MENTAL HEALTH DIFFICULTIES

02 REFLECT ON POTENTIAL STRATEGIES AND APPROACHES THAT INCREASE TRUST, DATA VALIDITY, AND PARTICIPATION IN CLINICAL RESEARCH FOR UNDERSERVED POPULATIONS

03 DISCUSS INNOVATIVE STRATEGIES FOR KNOWLEDGE TRANSLATION, WITH A FOCUS ON UNDERSERVED COMMUNITIES.

BACKGROUND

Black youth experience higher mental health needs but lower mental health access and wait longer to access services

Black youth are more likely to access care through emergency / forensic pathways and less likely to receive care in voluntary and outpatient settings

Black youth describe negative experiences with the mental health system in Canada when they do access care

Anderson, K. K., Cheng, J., Susser, E., McKenzie, K. J., & Kurdyak, P. (2015). Incidence of psychotic disorders among first-generation immigrants and refugees in Ontario. CMAJ, 187(9), 279–286.
Fante-Coleman, T., & Jackson-Best, F. (2020). Barriers and Facilitators to Accessing Mental Healthcare in Canada for Black Youth: A Scoping Review. Adolescent Research Review, 5(2), 115–136

BACKGROUND

Suicide rates and deaths secondary to opiate overdose are rising in Black youth

As mental health providers, we misdiagnose racialized people – more often diagnosing psychotic disorders, substance use problems, and behavioural disorders, than other diagnoses

Racialized people are more likely to be criminalized for substance use problems and mental health concerns than be offered treatment in the mental health system

Williams, D. R., González, H. M., Neighbors, H., Nesse, R., Abelson, J. M., Sweetman, J., et al. (2007). Prevalence and distribution of major depressive disorder in African Americans, Caribbean blacks, and non-Hispanic whites: Results from the National Survey of American Life. Archives of General Psychiatry,64(3), 305–315. https://doi.org/10.1001/archpsyc.64.3.305.

Social (In)justice and Mental Health. Ed Shim, R., and Vison, S.. APA Publishing, 2021

BACKGROUND

Reduced mental health access and adverse mental health outcomes are a result of systemic and structural racism, both within healthcare settings and elsewhere

Members of the Black community are aware of racism within medical settings, as well as the history of racism in medical education, clinical care, and research

They often understandably mistrust research and traditional clinical settings as a result

Williams, D. R., González, H. M., Neighbors, H., Nesse, R., Abelson, J. M., Sweetman, J., et al. (2007). Prevalence and distribution of major depressive disorder in African Americans, Caribbean blacks, and non-Hispanic whites: Results from the National Survey of American Life. Archives of General Psychiatry,64(3), 305–315. https://doi.org/10.1001/archpsyc.64.3.305.

Social (In)justice and Mental Health. Ed Shim, R., and Vison, S.. APA Publishing, 2021

CONCEPTUAL POSITION

Mental Health disparities and disparities in outcomes are a result of structural and systemic racism and structural determinants of health, not due to someone's racial / ethnic identity alone

Race, ethnicity, and culture vary – Race is conceptualized as a social construct that exists within a network of intersecting power dynamics

It is racism, not race, that leads to disparities in mental health outcomes

Communities have their own solutions, wisdom, strengths, and guidance to solving difficulties, including health disparities; knowledge is for sharing, not witholding

RESEARCH QUESTION

What are the barriers and facilitators for Black youth in accessing mental health care in hospitals and tertiary care settings?

METHODS

Qualitative study design

- Individual interviews with key stakeholders in multiple sectors (N=9)
- Focus groups with Black youth (N = 18)
- Focus groups with caregivers of Black youth with mental health difficulties (N=6)
- Individual interviews with stakeholder and caregiver who could speak to needs of Francophone Black youth (N=2)

METHODS

Youth
- 15-24
- Self-identified as having had difficulties with their mental health and as a member of the Black community

Caregiver
- Self-identified as caring for Black youth with mental health difficulties

Stakeholders
- Key informants across formal and informal sectors outside of hospital settings

METHODS

Partnership between CAMH and CAFCAN (Caribbean African Social Services) from study design through implementation and knowledge translation

Meaningful partnership, with input into all aspects of study

Study team was majority Black, many with front-line experience with Black youth, including youth engagement specialists

THEORETICAL FRAME

Critical Realism

Applies critical lens with awareness of how unobservable structures affect seen external reality

Critical Race Theory

Specific and explicit questions and analysis about the impacts of race and racism

Awareness and application of structural theory to determinants of health

Importance of counter narratives

The Team

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CAFCAN

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RESEARCH STAFF

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UNIVERSITY OF CALGARY

Araba Chintoh

*TRAINEE

RESULTS

Existing mental health systems issues are exacerbated for Black youth

- Lack of representation within mental health workers enhances mistrust, reduces care seeking, amplifies stigma, and was linked to more negative experiences of mental health care
- Implicit or explicit racism within the system and providers makes it more difficult to Black youth to access care through non-aversive pathways (ie: voluntary, outpatient, early intervention)
- General feeling of being dismissed interacts with systems wide challenges and continues to reduce trust and help-seeking

"my mom used to tell me, like, don't go to CAMH because they have a file on you and then if someone looks you up, they can find your file at CAMH. And it was just one of these things where it's like, why do I want to put that on - like, why would I want to leave a red ink on my file?"

RESULTS

Racism & Mental Health Care: "Black then Patient"

Black youth are seen as "Black then patient" and subject to biases and misperceptions by care providers that impact their access to and experiences of care

- Assumptions of criminality / bad intent
- Over-reliance on substance use as an explanation for distress or symptoms
- Using assumptions or relying on tropes rather than understanding the specific person and their own lived experience – dehumanization
- Not considering systemic issues and explanations and assuming adverse outcomes are linked to culture or Blackness

"people see you as Black before they see you as a patient. So, it's one of these things where it's like, people expect you to have all this trauma because you're Black, because most Black people are poor, we live off of - we don't have food stamps, so welfare? I don't know what the equivalent of food stamps is. But food stamps. And we have all these traumas and we come from these Black neighbourhoods, so people expect the Black experience to be rough. But they don't provide the help in these Black areas."

RESULTS

Minimize impact of adverse experiences

Providers and systems don't understand the degree to which these issues (staffing, poor coordination, racism) intersect to push Black youth through aversive pathways, nor the severity of the impact of this on the trajectory of a young person's life

"And what I'm saying is, you can't ignore the compounding effect of what these what these things do to people and do with kind of like their life trajectory. What's my point? Part of the impact is, you know, this very averse pathways, but I'm trying to, I'm trying to be clear that it's not just aversive pathway. It's there are there are certain experiences that people face, in through going through these aversive pathways that fundamentally changes their life, fundamentally changes their life"

RESULTS

& Black caregivers

- Rather than understanding the reality of how youth and caregivers try to access care but are often denied / turned away / dismissed, the mental health system codes this as Black caregivers not sufficiently caring for their loved ones and needing mental health literacy alone
- Sets up system as "savior / white savior" and caregivers/families / communities as in need of saving
- Paired with structural abandonment through underfunding, understaffing, and not adequately meeting the need at a systems level
- Justifies disempowerment / dismissal of Black caregivers and their advocacy for their loved one's care

And I think they're discouraging people to really ask for what they need, because when you are very clear about what you need, that doesn't mean you're gonna get it.

RESULTS

Burden on Black healthcare workers

- Families, youth, and caregivers come to rely on an "informal connect" to get access to care – working informal networks and personal connection because systemic routes fail
- This adds to the burnout, stress, and challenge for Black mental health workers who are in the system
  - Worsened by their own experience of racism in the system as well as vicarious trauma

and it must be because we have people again, who are so impacted by the system and the systems that surround them, that... it's... they cannot be responsible for doing the work....that re-traumatization for our Black leaders, and also our social workers and social service workers is extremely traumatizing to always be the person doing that work - and expected to do the work."

RESULTS

& intersectionality

- Specific services are needed to support Black 2SLGBTQIA+ youth in a way that is both culturally affirming and affirming of their gender and sexual identity
- Challenges both due to not always feeling comfortable in Black specific spaces and due to cumulative discrimination based on multiple marginalization

"And I think especially if they are trans or in any part of the LGBTQ community, if you have a nurse, in particular, because, you know, that's who they tend to deal with, or a social worker who is not, who is anti, and then you add a Black face onto it, it makes for a harder experience. Because you're judged. You're judged by your face and what they perceive you to be. And again, sometimes it's because that's how they've been socialized to think of who we are, unfortunately. "

RESULTS

& Psychosis

Specific need for culturally sensitive, affirming, and community led/engaged services for Black youth who experience psychosis that supports both youth and caregivers, reduces overrepresentation in forensic and criminal justice settings

"Yeah, it has been traumatic for me - it's been traumatic for me because sometimes, by the time we're at the point where we're looking for resources, whether it's like because an incident has recently occurred or has occurred, it's traumatic for me because I'm scared of things escalating out of control."

RESULTS

& stigma

- Stigma about mental health conditions is informed by caregivers own lived experience and treatment within the health system
- Youth and caregivers have different understandings and attitudes towards mental health, which can impact youth accessing care
- Youth shared a wish for their caregivers to know more about the system and mental health conditions in a way that is supportive, anti-racist, and culturally affirming

What do youth want from care?

- Youth friendly & culturally affirming care looks like:
  - Authenticity, humanity, true relating: 'talk to me on the level'
  - Better food! Understanding how food relates to culture
  - Spaces that are youth and Black friendly in their design and location – places that are beautiful, comfortable, and feel good to be in
  - Understand the whole person and their whole experience rather than relying on stereotypes or assumptions

What do youth want from care?

- Avoid where possible any connection to police / security / policing
- Look at someone when doing an assessment, writing notes can be seen / experienced as surveillance or that someone is in trouble
- Representation in care that is representative of the diversity of the Black community in the GTA
- Provide psychotherapy, and specifically trauma treatment / informed care
- Actively welcome youth into care – make them feel valued and wanted (needs to be more active to undo existing mistrust and fear)

What do caregivers want from care?

- To be involved / informed / updated where possible
- To address and understand the challenges and lived reality of being a caregiver who experiences marginalization while also supporting a loved one with mental health difficulties
- To better understand how to navigate the system and to know how to advocate and teach their loved ones to advocate for care effectively
- To know that their loved ones are being cared for as people and are safe when they are in mental health care settings
- To understand colloquialisms / common expressions that are cultural but don't actually signal potential harm / need for intervention

What do other professionals want from services?

- Integrate structural supports into mental health services – consider impact of poverty, housing instability, food insecurity, migration/immigration on lived experience of youth and caregivers and integrate this into care
- Collaborate with other organizations across the system to support and improve system navigation for youth
- Actively and` enthusiastically mentor and support Black mental health workers and be aware of the additional burdens and impact on them

"All this info for what?

Sharing Circle

LESSONS LEARNED

- Knowledge generation can be collaborative and support bridges between community and institutions, if there is a deep engagement and willingness to engage with anti-Black racism principles deeply rather then superficially
- "Nothing about us without us"
- We are privileged that youth, caregivers, and stakeholders want to share their stories with us, and we do what we can to treat them with the utmost respect
- Doing what we say by giving back knowledge to the community pushes against the feelings in community that research in underserved communities is extractive and for the interest of the researchers / institutions

Thank you!

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