Identifying Barriers to Mental Health Services Utilization for Black Young Adults in the United States: A Qualitative Study

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ABSTRACT

Mental health in Black communities and racial/ethnic disparities in mental health service utilization remain growing concerns. Evidence suggests that psychotic disorders may be more prevalent among Black individuals than white individuals and the Black community faces barriers to care that can negatively influence outcomes. To better understand these barriers, we interviewed mental healthcare providers ($n = 11$) and Black young adults with first-person experience of psychosis ($n = 13$) about the experiences of minority young adults with mental health treatment. We analyzed interview transcripts and, consistent with constructivist grounded theory methods, identified iterative patterns across individuals about barriers to care. From the 11 mental healthcare providers and 13 Black young adults in the present analyses, five overarching themes emerged: lack of knowledge about mental health help-seeking, material resource unavailability, stigma, lack of family support, and trauma. These themes represented factors that dissuaded individuals from seeking care and must be addressed to improve engagement and outcomes for minority young adults. Innovative approaches to improving mental health literacy and decreasing stigma, along with systemic, policy-based economic changes, may provide starting points for effectively addressing these barriers.

1. INTRODUCTION

The mental health of individuals in marginalized communities remains a growing concern among mental health researchers and racial/ethnic disparities in mental health service utilization have been identified as a major public health issue (U.S. Department of Health and Human Services, 2001). Serious mental illnesses, such as psychotic disorders, are especially important given the immense burden such illnesses can create (Insel, 2008; Viron & Stern, 2010), the disproportionate prevalence of psychosis symptoms in Black communities compared to White communities (Cohen & Marino, 2013), and the racialization and politicization of schizophrenia among persons from Black communities historically (Metzl, 2010).

Social factors are important determinants of mental health (Allen et al., 2014). It has been proposed that structural racism creates conditions (e.g., neighborhood-level disadvantage, individual-level social disadvantage, everyday discrimination, collective trauma) that lead to the disproportionate prevalence of psychosis in racial/ethnic minority communities (Anglin et al., 2021; see Figure 1). Black individuals in particular face increased prenatal and perinatal risk factors for psychosis, elevated levels of cumulative stress and trauma due to maltreatment and discrimination, and neighborhood-level concerns such as over-policing and exposure to violence, all of which have been shown to be social determinants of psychosis (Anglin

et al., 2021). In addition to contributing to increased prevalence of psychosis, these factors also contribute to delays in treatment initiation, limited use of mental health services, and potentially traumatic pathways to care (e.g., law enforcement; Oluwoye et al., 2021).
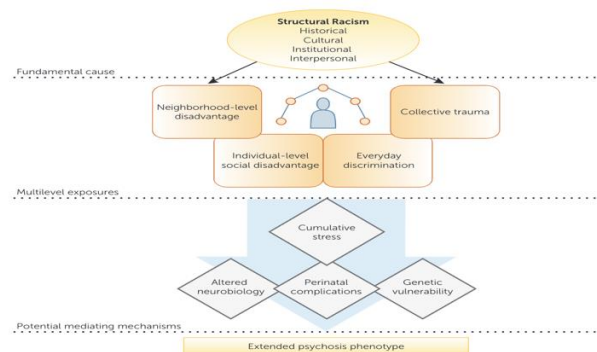

Figure 1: Model of systemic racism and psychosis in the United States (Anglin et al., 2021).

In addition to proposed structural barriers, substantial stigma regarding mental illness serves as a barrier to care in Black communities (Alvidrez et al., 2008). Stigma presents mental health concerns in a negative light and discourages people from seeking care (Corrigan, 2004).

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Although perceptions of mental illness have changed over time, many people still consider individuals with mental illnesses to be defective, unpredictable, and dangerous (Alvidrez et al., 2008; Silton et al., 2011; Gangi, 2021). Early intervention efforts are useful in helping support persons with serious mental illness, such as psychotic disorders, but stigma hinders help seeking (Gronholm et al., 2017). Stigma in Black communities may be fueled in part by a lack of "mental health literacy" (i.e., one's knowledge of current understandings of mental health and illness) and high levels of medical mistrust (i.e., a lack of trust in biomedical power structures and biomedical practitioners; Muvuka et al., 2020; Lillie-Blanton et al., 2000; Hammond, 2010; Haynes et al., 2017). It is important to underscore that low mental health literacy is not a personal failing or the fault of individuals, but rather part of the larger medical and structural disadvantages experienced by persons from Black communities historically and today. These factors, which include inequitable policies and practices related to economic opportunity and mental healthcare (e.g., cost of care, lack of insurance), may also explain decreased service access and utilization (Fiscella et al., 1998; LaVeist et al., 2007; Anglin et al., 2021).

Given the complex barriers that persons from Black communities face in the United States related to mental health services access, utilization, and outcomes, we set out to better understand the perspectives of mental health care providers who work with persons from marginalized communities and self-identifying Black young adults with first-person experience of psychosis. Five salient barriers emerged from provider interviews that were reflected by Black young adult participants.

2. METHODS

This study is a secondary analysis of data collected from two studies between 2014 and 2017. The first study used semi-structured, open-ended interviews to elicit ideas about facilitators and barriers to treatment from mental health providers. Additional interview data from an ethnographic study with Black young adults experiencing early psychosis was also reviewed to provide a further understanding of the relevance of the providers' claims to Black young adults. These two studies were not connected.

A. Mental Healthcare Providers Study

Mental healthcare providers were recruited between 2015 and 2017 from throughout the Dallas–Fort Worth Metroplex. Providers ranged in age from late twenties to early seventies and most identified as people of color. They had varying education levels, ranging from some college to obtaining a doctoral-level degree, occupations (e.g., social worker, psychiatrist, counselor), and occupational settings (e.g., private practice, hospital). Providers participated in one- to two-hour, semi-structured interviews regarding their views and perspectives on the mental health barriers faced by minority young adults, the resources available to them, and the perspectives of minority communities. These interviews were audio-recorded and transcribed professionally. Interview transcripts were then coded using grounded theory methods (Charmaz, 2006) with the cloud-based, mixed methods software package, Dedoose.

B. Black Young Adults Study

Young adult participants were recruited between 2014 and 2016 from a psychiatric emergency hospital serving patients in North Texas. The hospital served 23,000 patients per year and an estimated two young adults with early psychosis per week in 2014. Participants were recruited using purposive, snowball sampling. Purposive sampling is a widely used method in qualitative research whereby researchers recruit individuals knowledgeable about a subject or with experience related to the topic of interest (Palinkas et al., 2015). Snowball sampling refers to the process by which one participant is asked if they know any additional individuals that may wish to participate. In this study, participants were asked to identify other potential participants and the research team solicited referrals online from mental health professionals and members of local organizations supporting people of color. Eligibility criteria for young adults included being age 18 to 30 with no history of a psychiatric hospitalization for a psychotic disorder earlier than the 3 prior months, no history of antipsychotic medication usage for more than three months, and a diagnosis of a nonaffective psychotic disorder. Both uninsured and insured patients were included in this study (see Myers et al. [2019] for a full description of the methods used).

Potential participants were identified by treatment staff and after their conditions stabilized, they were informed of the study. The research team then obtained key demographic and contact information (e.g., names and phone numbers) and administered an initial audio-recorded interview while the participants were in the hospital. Upon release, the research team engaged participants in at least three follow-up visits. In teams of two, the researchers observed participants' everyday routines, activities, and conversations, which were then recorded in field notes. The research team also engaged participants in 45- to 75-minute, open-ended, person-centered interviews (Levy & Hollan, 1998). Participant information is presented in aggregate or deidentified in this manuscript as a common qualitative research convention.

Interview transcripts were coded using Dedoose. Once coded, text was extracted, aligned, and compared across transcripts, visits, and participants (Gladwin, 1989). Consistent with grounded theory methods (Charmaz, 2006), the team reviewed the coding analysis, field notes, and lab meeting research memos to look for iterative patterns across the data and generate themes about key barriers faced by Black young adults. Employing grounded theory methods enables researchers to incorporate various types of data and analyze both action and process to gain a more holistic account of an individual's experiences (Charmaz, 2006).

3. RESULTS

A total of 11 mental healthcare providers and 13 Black young adults were included in the present analyses. The top five mental health barriers for minority young adults as identified by mental healthcare providers included lack of mental health literacy, material resource unavailability, stigma, lack of family support, and trauma (see Table 1).

Rank	Barrier
1	Lack of Mental Health Literacy (10 providers)
2	Material Resource Unavailability (9 providers)
3	Stigma (9 providers)
4	Lack of Family Support (9 providers)
5	Trauma (6 providers)

Table 1: Top 5 Barriers Identified by Mental Healthcare Providers.

A. Lack of Knowledge about Mental Health Help-Seeking

Providers thought that many young adults from marginalized communities lacked knowledge about mental health topics and proposed culturally sensitive, community-based mental health education as one possible solution to low service utilization and stigma in those communities. As one provider said, "I think education is the first step. I don't think it's the only step. I think that what's really difficult when it comes to mental health is changing the culture. And so, in order to change the culture, you have to speak up about it. Two, you have to educate people on it. And three, you have to be willing to stand up and have these really tough conversations. And I think that's just the first few steps on trying to change the culture" (PP11). Other providers emphasized the importance of engaging families: "I think you have to do a lot more family education than you do with other people who are more exposed to it. 'Cause again a lot of the families that we have, people of color, this is new to them" (PP2).

Black young adults were less direct about their endorsement of knowledge about mental health as a barrier but expressed a desire for more information and guidance on how to navigate mental healthcare. For example, one young adult participant said: "I don't know how to seek out help, really…I need guidance and I don't really have a lot of guidance at home (YP3)."

Many Black young adults in this sample also cited religious or spiritual activities as a primary form of treatment. For example, one young adult participant shared that prayer is a key to healing: "That's supposed to be part of daily activity, to help you believe in God. He can help you through anything. That one story, Jesus walking on the water, Peter met him but as soon as he dropped his faith, he started to fall. Jesus picked him up... That's just my belief" (YP4).

B. Material Resource Unavailability

Another concern was the lack of material resource availability (e.g., transportation, insurance, money) experienced by many individuals in marginalized communities. Providers recognized mental health treatment as expensive, and that financial barriers may inhibit many individuals from seeking and utilizing care. For example, one provider shared that socioeconomic issues, such as insurance coverage, can be burdensome: "I think that creates health barriers for many. For example, with insurance, even if someone has insurance, it often does not cover mental health. It's also an exhausting process to try to get that funding" (PP6). Resource availability can also be an issue

for healthcare providers and treatment programs in low-income, predominantly minority areas: "So if the funding is there, I think that can change a little bit. When our hospital itself is starting campaigns where it's looking at specifically being more engaged with patients" (PP3).

Young adult participants also identified financial issues as a key barrier to help seeking and service utilization. "Money, money, money," said one young adult participant (YP1). Having a steady job, transportation, and housing were concerns for most of the young adults. Oftentimes, young adults struggling with serious mental illness find it difficult to maintain employment and become disconnected from financial support networks: "It got to the point where it's a financial problem, which I feel like it should have never been a financial problem for me because I used to do so much, and I know how to do so much... I feel [outcast]" (YP2).

C. Stigma

Stigma emerged as another barrier to service utilization. Providers commented that topics related to mental health are still largely not tolerated in the United States: "Mental health is... a taboo or something. People who have mental health problems, they are ostracized from the society, they are considered evil, or witches and wizards, and it's not very good... They're not embraced. People who have mental [illness], they are just left to wander around and deteriorate mostly" (PP9). Some providers pointed out the common responses that young adults may receive when they voice concern about a mental health issue: "'Stop being dramatic,' or 'You're just making it up,' or 'You'll be fine, just get over it'" (PP11).

Black young adults echoed these sentiments. One shared the common refrain, "I don't want people to think that I'm crazy" (YP7). Increasing awareness of the importance of mental health and improving mental health literacy in minority communities may help with stigma. Mental illness is often associated with negative connotations and, therefore, people become discouraged to seek help: "A condition – like, all right, let's say, you see a beautiful girl walking down the street, all right. She's beautiful. She has pretty eyes, long hair, yellow skin. She's good. Everything you see about her, you like her, but she's walking funny. '"Oh, shit, she's got some condition, something you've got to live with'" (YP1).

D. Lack of Family Support

Providers discussed the importance of social support, especially from family members. They highlighted the lack of support that many Black young adults receive and the importance of feeling comfortable talking with those around them about mental health topics: "You got to talk about depression, how do you feel, days when you are just down – where's your support system? Who do you talk to? So one of the critical points is that we need to focus on community clinics that can work with families from a total perspective. Family counseling needs to be there" (PP7).

Young adult participants also discussed family support, usually in the context of negative family dynamics or negative experiences discussing mental health or their illness with parents. For example, one young adult participant recalled a time when their dad called the police on them: "And my father, he didn't understand, you know

what I'm saying. So he was like, 'You need to go somewhere.' And then I- when he dropped me off at the store, I thought he was leaving. Next thing I know I saw police officers" (YP9).

E. Trauma

The final theme that emerged was trauma as a barrier. Providers believed that an individual's social factors (e.g., exposure to violence, police involvement, carceral pathways to care) greatly impacted their mental health and that trauma must be addressed and reduced to improve service engagement and positive outcomes. One provider shared that when they worked in a public hospital, "one of the rooms they had a poster that said 'In this country, we institutionalize the mentally ill.' And yeah, we institutionalize them in prison" (PP6).

Black young adults identified police involvement and incarceration as a main source of trauma. For example, one young adult participant recounted her pathway to care and the regimented and defeating structure of a psychiatric hospital: ""Yeah. I was in the part of the jail for mentally unstable people... I stayed in there for fifty-three days. I got out, ended up in some more trouble. I ended up here.... Everyday, you have a counselor come in, speak to you, ask you how you're doing. You have your medicine everyday. Your meals everyday. Only thing is you're locked in one room the whole time" (YP1).

4. DISCUSSION

Mental healthcare providers in the United States are concerned about the mental health of young adults from marginalized communities. The top five concerns of providers in this sample for Black young adults were lack knowledge about mental health help-seeking, material resource unavailability, stigma, lack of family support, and trauma. These concerns were shared by Black young adults with first-person experience of psychosis and align well with the extant literature related to mental health for Black individuals in the United States. Against the backdrop of structural and historical discrimination, trauma and economic disadvantage have disproportionately affected Black communities. About one-third of Black Americans report experiencing discrimination in healthcare settings (Bleich et al., 2019). A lack of access to mental health information may contribute to stigma, and a lack of family support likely stems from any or all these factors.

To improve the situation for Black communities and to alleviate these barriers, the United States needs to address fundamental causes and consequences of mental health inequities (Burns, 2015; Knapp & Wong, 2020). Intergenerational trauma and economic disadvantage must be addressed by sweeping policy and practice changes, as well as by better understanding and enforcing existing policies (Snowden, 2012). In addition to national policy solutions, mental health services can help to mitigate economic inequities by providing material support, such as appointments during non-business hours, free transportation, or telehealth options (e.g., Chaudhry et al., 2021; Kohrt et al., 2018). Properly funding treatment programs is an important step toward equitably improving outcomes.

The providers in this study highlighted concerns regarding a lack of knowledge about mental health topics and help-seeking among Black young adults. We suggest that this data supports the conclusion that a lack of mental health literacy can contribute to stigma and resistance to engage with services in communities of color. The term mental health literacy was first introduced in 1997 and was defined as "knowledge and beliefs about mental disorders which aid their recognition, management or prevention" (Jorm et al., 1997). Thus, it is a broad term inclusive of knowledge and beliefs about many important concepts, including risk factors, etiologies, and treatments, that impact ability to identify and describe mental disorders and attitudes toward and use of available services (Sampaio, et al., 2022). Despite efforts to address inequities in health literacy, Black communities in the United States are disproportionately affected by low health literacy (Kutner et al., 2006). Systemic factors (e.g., limited educational opportunities, racism, health system mistrust) have been identified in the literature as major barriers to mental health literacy experienced by Black young adults in the United States (Muvuka, et al., 2020). In clinical settings, proper identification of one's degree of mental health literacy may provide helpful information to improve communication between patient and provider, increasing mutual understanding and treatment adherence.

Evidence suggests that novel interventions for improving mental health literacy in Black communities and in the general population show promise (Robinson et al., 2017; Jorm, 2012; Mumbauer-Pisano & Barden, 2020); however, research is limited. As providers suggested, focusing on schools as a primary point of contact may be effective for improving mental health literacy in young adults (Kelly et al., 2007; Whitley et al., 2013). In addition, pilot studies have shown positive impacts of novel interventions on stigma and help-seeking among Black young adults and their parents (e.g., Chakawa, 2022); however, research is limited.

Black communities rely heavily on religion and religious institutions as a source of knowledge and support for a variety of issues, including mental health, which was clear in this sample. Given the salience of religious activity within Black communities, a focus on faith-based interventions may also help to improve mental health literacy and decrease stigma (Hays & Aranda, 2016; Stansbury & Schumacher, 2008). Religious institutions are essential sources of social support and various resources in Black communities (Nguyen, 2020). Due in part to the systemic barriers described above, Black Americans often turn to religious institutions for information. It is a common practice for Black individuals to consult clergy for mental health related questions and for some, religious institutions are a primary source of mental health information. Places of worship offer community programs, health services, and other beneficial resources (Nguyen, 2020). Interventions focused on increasing mental health literacy for religious leaders could provide a useful and effective method to raise awareness on this topic (Allotey, 2022). In addition, with more education on services available related to mental wellbeing, utilization of these resources could increase as well (Allotey, 2022). Tailoring mental health services to emphasize spirituality in the Black community may also increase the effectiveness of treatments (Nguyen, 2020).

Lastly, trauma-informed care may be effective for increasing accessibility and improving outcomes among Black Americans. Developmental trauma is associated with increased risk of psychosis and poorer mental health prognosis (Bloomfield et al., 2020). Individuals in marginalized communities remain at an increased risk for experiencing trauma and thus, a greater likelihood of developing psychosis (Rosen et al., 2017). Implementing trauma-informed care may allow for better treatment of trauma survivors (Nation et al., 2022). Trauma-informed care also targets systematic change by focusing on the psychosocial and environmental context of distress (Nation et al., 2022). In addition, trauma-informed care in mental health settings and training for police to avoid the perpetuation of trauma may help to alleviate the effects of stress in minority communities (Black et al., 2012); however, research in the United States is limited.

This work demonstrates the need to increase knowledge about mental health, reduce stigma, and address the barriers persons from marginalized groups face when attempting to access mental health services. Employing culturally relevant strategies (i.e., providing training for religious leaders) can help address this issue. This study is limited by a small sample size and a non-matched sample (i.e., service providers and young adults interviewed were not connected as providers and patients). Further research is needed to delineate the mental health needs of marginalized young adults in the U.S. and to better understand barriers to care to promote positive outcomes for all.

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