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The unfulfilled promise of equitable first episode care for Black-Americans: A way forward

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The current paradigm of reporting on differences between racial and ethnic groups and not investigating solutions to address racial disparities, must shift if we are to provide equitable care for Black consumers with a psychosis spectrum disorder, moving forward. Over a decade ago, Merritt-Davis and Keshavan (2006) critiqued care disparities in early psychosis for Black-Americans and it is not clear how much we have progressed in reducing such disparities since then. They noted several factors influencing outcome disparities in Black populations such as stigma, lack of information about psychosis, and greater risk for aversive pathways to care (e.g., civil commitment and police involvement). Qualitative studies with Black families continue to echo these concerns highlighting how family decisions to seek care for loved ones experiencing early psychosis are still hampered by concerns about stigmatizing labels associated with psychosis and waiting too long for symptom acuity to increase before seeking help (Bergner et al., 2008; Franz et al., 2010). Importantly, these aforementioned studies amplifying the experiences of Black families are too far and few between, revealing a lack of diversity in the majority of research samples within the area of early psychosis. There remains a strong scientific and moral imperative to overcome historic barriers, steeped in a historical legacy of racism, that have contributed to the disenfranchisement of Black-Americans from the medical establishment. The onus remains on researchers and providers to build trust and investigate novel methods that are centered on Black-Americans, particularly those experiencing psychosis.

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Lead author BJD, conceptualized, wrote, and reviewed the literature for this commentary. Senior author, MSK, oversaw and provided comments on the manuscript. OO and DA helped with the conceptualization, editing the manuscript and inclusion of relevant literature.

Coordinated specialty care (CSC) programs have boomed over the past seven years and show promise in reducing the duration of untreated psychosis and improving psychiatric and functional outcomes (Kane et al., 2015). Yet, despite showing similar duration of untreated psychosis as others, Black-Americans still often enter treatment later in the course of illness (Nagendra et al., 2018), a fact that has profound consequences on initial engagement and subsequent outcomes (Oluwoye et al., 2021). In present times these known differences have been compounded by the COVID pandemic, where disparities in equitable care for racially minoritized individuals with serious mental illnesses has been further amplified (Ferrarelli & Keshavan 2020). Several studies call for the training of primary care physicians to recognize, monitor, and refer individuals with psychosis to CSC programs; however, no studies to date have incorporated factors particularly relevant for engaging Black-Americans such as those connected to discrimination, racial identity, and neighborhood factors such as increased police surveillance, neighborhood violence, and lack of access to resources (Richman et al., 2007; Wilson et al., 2016).

This disparity, specifically lower rates of engagement among Black-Americans diagnosed with psychosis spectrum disorders relative to other racial groups has been well documented for the past 50 years (Oluwoye et al., 2018; van der Ven et al., 2020). Strikingly, this difference persists after controlling for socioeconomic status, discrediting the myth that these differences are largely driven by poverty. Adding to this, a study of Black consumers recently discharged from the hospital found that 54.5% of these individuals had three or less outpatient mental health visits in the following year (Myers et al., 2017). The consequences of decreased engagement have been explored longitudinally, where Black-Americans with early psychosis have been documented to have smaller improvements than White Americans in functioning in virtually all symptom domains, as well as less medication adherence across one year of treatment (Li et al., 2011). The combination of these studies suggests that initial and sustained engagement in CSC remains elusive for many Black consumers.

Recent awareness of social inequities has led to a push towards understanding personal and systemic biases, however, these biases shape virtually all aspects of the Black-American experience and therefore shape treatment engagement. Within the context of early intervention, many of the barriers to engagement start before the first treatment encounter; and include past and current experiences of institutional racism, lack of access to medical and social support resources, and cultural mistrust (Anglin et al., 2021; Whaley, 2001). Moreover, the medical structures which they engage with often perpetuate experiences of racism. Notably, calls for novel intervention strategies for Black consumers are not limited to the United States—the work of Nazroo et al. (2020) in the United Kingdom and Knight et al. (2022) in Canada show that Black clients across the Global West remain at higher risk for worse outcomes. At this point, it is crucial that more work is done to develop novel engagement strategies for Black individuals and their families.

Some have begun to do this work already by investigating culturally-informed interventions for families engaged in CSC (Oluwoye et al., 2020a, 2020b) including telephone-based strategies to circumvent structural barriers such as difficulty getting to CSC clinics. Additional work has been done using cultural formulation tools to address cultural factors, but larger scale interventions must be done for us to fulfill the promise of recovery-oriented care for all consumers and their families. The work of Oluwoye et al. (2020a, 2020b) shows tremendous promise for increasing family engagement for Black consumers, a factor known to be associated with better outcomes. Despite this, more work needs to be done to engage individuals and to understand the mechanisms leading to treatment disengagement (Alang, 2019).

So, what are we to do to address barriers to engaging Black consumers in CSC? This commentary underscores the need for a large-scale shift in research funding priorities, workforce diversification, and policy changes (see Table 1 for a focused list of problem areas and solutions). Most importantly, the current state of the literature does little to include the voices of Black consumers and their families about factors leading to disengagement from care. The methodologies and mixed methods designs which synthesize qualitative and quantitative factors such as Critical Interpretive Synthesis may bridge the gap between consumers and researchers (Flemming, 2010). There is an overarching need for participatory research focused on understanding the perspectives of multiple stakeholders in order to develop adaptations, novel interventions, or equitable implementation strategies that address the needs of Black consumers and families.

Additionally, structural and societal factors must also be explored such as the equitable distribution of CSC (i.e., placement and access to care), racial equity within CSC programs themselves (i.e., policies related to risk) as well as clinician perspectives of Black consumers (i.e., perception of dangerousness or symptom severity for consumers of color vs. white consumers). Moreover, additional research investigating ways to address the “digital divide” wherein, Black consumers report having less access to necessary tools to access telemedicine services such as high-speed internet, smartphones with a wireless data plan, or desktops/laptops must be done to minimize the impact of the pandemic on access to care (Roberts & Mehrota, 2020). Addressing these factors and building trust will minimize the reasonable cultural mistrust Black consumers and families experience and begin to address the wounds inflicted by aversive pathways to care. Finally, the lack of diversity within the clinician workforce is a key issue that remains understudied. The pipeline for clinicians beginning with the recruitment of trainees enrolled in masters- and doctoral-level programs, staff recruited to work in CSC, as well as the retention of racially and ethnically diverse staff must be addressed systematically. These initial steps will catalyze addressing the issue of racial equity in early psychosis care and hopefully lead to better engagement and outcomes for Black consumers enrolled in CSC.

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Table 1

List of barriers to equitable care and proposed solutions.

Level of intervention	Barriers		
	Aversive pathways to care	**Cultural racism in mental healthcare**	**Lower engagement in CSC**
Individual	• Adaptation of trauma-informed approach to care.	• Examination of individual biases leading to attribution of affective symptoms to psychosis • Clinician training to minimize diagnostic bias	Use of novel strategies to promote engagement such as: • Increased telephone appointments • Scheduling flexibility • Meeting in the community
Organizational	• Change in policies to lead to increased voluntary hospitalizations • Promotion of patient agency in treatment decision at all time points • Examination of policies leading to increased hospital stay length for Black patients • Increased diversity of staff • Navigator models	• Organizationwide trainings on racial equity, anti-racism, and the presentation of affective symptoms for Black clients	• Targeted recruitment and subsequent retention of racially and ethnically diverse clinicians • Adaptation of anti-racist and racially equitable practices
Systems-Level	• Increased training for police and first responders on psychosis • Increased presence of social workers on mental health crisis response teams • Examination of the juvenile justice pipeline for youth experiencing early psychosis or at CHR		• Novel, participatory research seeking to incorporate the perspectives of Black consumers and their families on care.

Note. CSC=coordinated specialty care.