

Dismantling Racial Inequities in Early Psychosis Family Psychoeducation

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Families and caregivers play a critical role in the recovery of their loved ones with schizophrenia. Early intervention services, including family psychoeducation, can improve clinical outcomes and reduce stress for caregivers. Despite the benefits of family psychoeducation, Black caregivers engage in treatment at lower rates than do White caregivers. To eliminate disparities in early intervention care, mental health clinicians must understand the system of

racism that shapes the Black caregiver experience. This column examines racial disparities in family psychoeducation engagement by contextualizing the Black caregiver experience and encourages culturally appropriate early intervention services to improve psychosis care.

Psychiatric Services 2022; 73:1065–1068; doi: 10.1176/appi.ps.202100459

Schizophrenia is a functionally and emotionally debilitating illness with significant health, economic, and social consequences. Early intervention in the course of psychotic illness is associated with better functional outcomes, fewer negative symptoms, fewer suicide attempts, and better treatment response (1). Black individuals are at increased risk for developing psychosis, in part because of exposure to chronic stress and trauma from vicarious, individual, systemic, and structural racism. Furthermore, after a diagnosis of psychosis, Black individuals continue to experience not only the trauma associated with psychosis but also the repeated trauma of racism. Additionally, Black individuals experience a longer duration of untreated psychosis, leading to worse longitudinal disease outcomes (1). Family psychoeducation is a crucial treatment component associated with reduced rates of psychotic relapse and hospitalization, improved quality of life, and increased likelihood of employment (2, 3). Other benefits of family psychoeducation include improved understanding of diagnosis, improved stress management skills, decreased family burden of navigating the mental health care system, and decreased anxiety and depression (2, 3). Families play a critical role in improving their affected family member's disease course (3). However, despite significant benefits to family psychoeducation, Black individuals with psychosis are less likely than White individuals with psychosis to receive family psychoeducation. Here, we describe both the current and historical contexts of the Black caregiver experience and address methods for increasing Black family engagement in care for early psychosis. Throughout our analysis, we use the term *Black* to encompass the various groups within the African diaspora.

EARLY INTERVENTION PROGRAMS

Early intervention psychosis programs include critical services such as medication management, psychotherapy, family psychoeducation, case management, and supported employment and education. The RAISE-ETP (Recovery After an Initial Schizophrenia Episode, Early Treatment Program) study, a cluster-randomized trial of coordinated specialty care (CSC) for first-episode psychosis, found that Black individuals with psychosis who received usual community care had lower rates of engagement in individual therapy and family psychoeducation, despite displaying more severe positive symptoms, disorganized thoughts, and hostility than did White individuals with psychosis (1). Although CSC treatment reduced racial and ethnic differences in psychiatric symptoms, Black individuals who received CSC treatment remained less likely than White individuals to participate in family psychoeducation. Furthermore, a descriptive analysis examining family engagement across a

HIGHLIGHTS

- Systemic racism increases Black individuals' risk for developing psychosis through exposure to chronic stress and trauma.
- Black individuals with psychosis and their caregivers have a unique experience navigating treatment; this experience should be incorporated into family psychoeducation and evidence-based models for early-episode psychosis care.

network of CSC programs in Washington State controlled for duration of untreated psychosis, insurance type, and baseline Positive and Negative Symptom Scale score; this analysis demonstrated that, despite having more phone contact with clinicians than did White families, Black families were scheduled for fewer psychoeducation sessions compared with White families (3).

The racial disparities in family psychosis psychoeducation treatment perpetuate inequities in longitudinal disease outcomes. More broadly, Black—specifically African American—family members report higher levels of negative caregiver experience, less knowledge of mental illness, and more difficulty using mental health care services but higher levels of problem-solving coping (i.e., taking steps after identifying a problem) and emotion-focused coping (i.e., seeking social supports) (4). Lack of perceived benefit of treatment, often resulting from medical mistrust or anticipated discrimination, may be a barrier for Black families seeking early intervention care. Institutional bias and a health care system built on centering the White experience may make the psychoeducation framework less appealing or seemingly less applicable to Black caregivers. We begin by exploring effects of racism on Black caregivers in the United States.

SYSTEMIC RACISM IN MEDICAL SETTINGS

Systemic racism has long existed in medical institutions, resulting in decreased access to medical care for Black individuals in the United States. Examples of racist practices include the use of enslaved Black people as anatomical material, the sterilization of Black women amid desegregation, and the racial disparities in treatment of cardiovascular disease (5, 6). In a sample of >1,000 Black adults, 75% believed that racial discrimination interferes with the ability of members in their racial or ethnic community to receive good health care, and 22% reported that racial discrimination has interfered with their own ability to get good health care (5). Even positive perceptions of mental health care do not translate to seeking treatment within the Black community; Black individuals may believe that they can improve mental health conditions on their own (7).

A timely example of the long-lasting effects of racism in medical care is the perception of COVID-19 vaccination in communities of color. Black individuals have been disproportionately affected by the COVID-19 pandemic and, as a result, are more likely to experience hospitalization and death than White individuals (5). Despite the disparities in COVID-19 outcomes, a U.S. survey revealed that only 14% of Black Americans trusted the safety of a COVID-19 vaccine (5). Notably, at our home institution, Boston Medical Center, in January of 2021 employees of color declined to schedule a first dose of COVID-19 vaccinations at a much higher rate compared with White employees (personal communication with David Henderson, M.D., at Boston Medical Center Psychiatry Department Meeting, Department of Psychiatry,

Boston Medical Center, Boston, Jan 21, 2021). The presence of racism present in the health care system today, even subtly in the form of microaggressions, has endangered Black lives. In addition to medical racism, modern-day examples of racism such as the 2015 Emanuel African Methodist Episcopal Church massacre, state-sanctioned violence, and televised racist ideology reinforce racism's ubiquitous nature. Living under a constant threat of harm or persecution, Black individuals may be hypervigilant and rightfully weary of the ways in which institutions, including the medical institution, are inherently racist systems and potentially dangerous. Because of the enduring effects of medical racism, Black caregivers may rely on community involvement and religion for support rather than medical institutions (4, 7). Community organizations and trusted establishments such as barber shops, salons, and churches offer nurturing spaces that the medical establishment has failed to provide for Black individuals. As Black caregivers turn to interpersonal relationships developed in community settings as sources of support, they may turn away from formal mental health supports such as family psychoeducation. The systematic exclusion from and inequitable access to medical care have informed Black caregiver cultural practices, including the limited involvement in early intervention psychoeducation.

Black caregivers also may question the validity of the diagnosis of psychosis, given clinician bias in the diagnosis of psychosis between Black and White individuals. Even when presented with similar symptomatology, psychiatrists diagnosed schizophrenia more often among Black individuals than among White individuals (8). Pathologizing Black individuals' concerns of unequal or discriminative treatment has been a long-standing practice in the United States, and the diagnosis of psychosis specifically has been weaponized against the Black community. In the 1960s, at the height of the civil rights movement, schizophrenia became associated with Black individuals who explicitly named racism, expressed their discontent with their subjugated status, or protested their social conditions (9). Physicians often described these Black individuals as suspicious, irritable, or combative, quickly applying a psychosis diagnosis to explain away the Black individuals' observations (9). The psychosis misdiagnosis is driven by racist practices, creating an environment that threatens the emotional and general medical health of Black individuals. Furthermore, in the clinical setting, when Black individuals share their experiences with racism and being wrongly targeted, clinicians who are not cognizant of such racism-based occurrences may unintentionally invalidate or pathologize the experiences. Systemic oppression and repeated experiences of discrimination may lead Black individuals to develop a "healthy paranoia" that may be misinterpreted or misdiagnosed as psychosis-associated paranoid delusions (8). Black caregivers may thus be mistrustful of the psychosis diagnosis, as well as of the medical institution that has historically denied them high-quality care. If clinicians mistake consequences of

racism with psychopathology, Black caregivers may question the validity of psychoeducation.

Moreover, given the extensive history of medical experimentation on Black individuals and the role of medication in unethical practices such as the Tuskegee experiment, Black caregivers may be weary of family psychoeducation that overemphasizes the importance of medication. Adverse general medical effects of antipsychotic medication such as akathisia, weight gain, and extrapyramidal symptoms may elicit particular apprehension in Black caregivers. By the time Black caregivers are introduced to early intervention psychosis services, they are likely to have already observed negative experiences associated with treatment. For example, Black individuals with psychosis are more likely than White individuals with psychosis to be introduced to psychiatric care through emergency care settings and crisis situations with police involvement (10). Black individuals may receive an initial diagnosis of schizophrenia in stressful, acute settings such as the emergency department and be prescribed antipsychotic medication involuntarily with minimal explanation and education (10). Although early intervention psychosis treatment seeks to provide comprehensive care, initial treatment experiences may engender mistrust of future services and, in particular, of any benefits of medication treatment.

IMPROVING EARLY INTERVENTION PSYCHOEDUCATION FOR BLACK FAMILIES

Family psychoeducation for Black caregivers must consider the experience of the Black family and the racism that shapes the Black experience in the United States. We must also be mindful of avoiding an overgeneralization of Black families and recognize that Blackness is not a monolith. We need to acknowledge that not all Black individuals are aware of historic examples of medical mistreatment. However, cultural memory, passed on by family members, is frequently preserved. Racism has dictated methods of survival and self-preservation in Black communities in the United States and, thus, the ways in which Black individuals may seek health care. Experiences of discrimination and difficulty navigating the medical system may explain why Black caregivers report more independent, problem-focused coping and involvement in community advocacy, rather than seeking help from health care professionals (4). Therefore, we propose future directions for optimizing early intervention psychoeducation for Black families in the United States.

First, Black family psychoeducation could occur, at least in part, outside of the clinical setting and in the community. Building trust in psychiatric care relies on developing confidence in the providers and institutions delivering the care (5). To address medical distrust in the Black community, existing relationships with community leaders, business owners, and church leaders can be used to build rapport and establish trust between clinicians and Black caregivers. Clinicians' awareness and active reflection of the ways in

which systemic racism has shaped the Black caregiver experience may help Black caregivers feel validated and understood. We encourage clinicians to explore methods of incorporating religious and spiritual conceptualizations of psychosis into family psychoeducation and extending psychoeducation into places of worship. We also implore clinicians to develop community engagement strategies that could include identifying leaders in the Black community and developing partnerships with established Black organizations. Clinicians may ask permission to join Black spaces, such as community meetings or forums, to learn from Black community members. Clinicians may even consider collaborating with individuals within organizations, churches, and establishments to deliver psychoeducation to ensure that the information comes from a trusted source. Attending community events regularly may help strengthen an understanding of community and caregiver needs, build trust, and create a relationship conducive to providing clinical care.

Second, Black individuals' long-standing mistrust of the field of medicine and the stigma around mental health conditions must be acknowledged in treatment. Family psychoeducation that provides strategies to decrease the stigma around mental health conditions within the Black community may also improve the effectiveness of the intervention. Although the effects of the stigma around mental disorders affect families and patients of all races, Black families in particular may not acknowledge the challenges of caring for an individual with a psychiatric illness compared with White families (4). Black family members may deny a family member's psychotic illness to avoid disclosing the illness to others in the community and to avoid interaction with the medical system (4). In a culture that has exemplified resilience despite the atrocities of slavery and discrimination, many Black individuals may view mental illness as a weakness and highly stigmatizing (7). Clinicians could reinforce coping mechanisms that have already been established by Black families; such practices may counteract negative, emotion-based coping efforts such as denial (4).

Third, promoting greater diversity among the mental health care workforce may increase Black individuals' trust of clinicians, treatment plans, and medical care by bridging gaps in cultural and lived experiences. Currently, only 10.4% of practicing psychiatrists in the United States come from minoritized backgrounds, a significant underrepresentation of the demographic characteristics of the U.S. population (11). Clinicians who seek to understand the cultural nuances of Black family values, parenting, and interpersonal dynamics may help increase family participation and engagement in care. Greater workforce diversity may also improve Black caregivers' longitudinal treatment adherence. Clinicians providing early intervention can contribute to a more diverse psychosis care team by supporting Black trainees and advocating for the recruitment of physicians and mental health care providers of color. Black clinicians may explore shared cultural conceptions of psychosis with Black caregivers and underscore unique cultural experiences to create

a safe space for Black families. In a study of three Latino focus groups comprising family members of individuals with psychosis, four categories were identified as topics to emphasize in family psychoeducation: the importance of family ties, stigma about mental illness, respect and trust in interpersonal relationships, and facilitators and barriers to implementing family psychoeducation (2). Some of these aforementioned findings may also be applicable to Black families, because Latino patients and families similarly describe negative experiences with the mental health care system and the importance of family in care (7). Specifically, Latino families emphasized the importance of trust and respect in interpersonal interactions with providers when seeking care (2). Psychosis psychoeducation for Black caregivers should focus on preexisting patient strengths, family structure, religious supports, varying conceptualizations on the origins of mental illness, the stigma of mental illness, and family dynamics such as conflict, trust, and respect of elders.

CONCLUSIONS

Family psychoeducation in psychosis care improves disease outcomes but remains inaccessible for many Black caregivers. We must acknowledge the racism that shapes the Black caregiver experience and must take an antiracist approach when adapting family psychoeducation treatment. Although Black caregivers support family members with psychosis, early intervention psychosis clinical teams must commit to equitable psychosis care that amplifies Black voices and addresses unmet needs.

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The authors report no financial relationships with commercial interests.

Received August 2, 2021; revision received November 23, 2021; accepted December 30, 2021; published online March 16, 2022.

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