African Americans with Obsessive-Compulsive Disorder: An Update

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Abstract: Although considerable strides have been made in understanding, diagnosing, and treating obsessive-compulsive disorder (OCD), not all groups have benefited from these advances. OCD in ethnic and racial minority groups has been – and continues to be – a neglected area of study. The last 15 years of research has shed new light on OCD in African Americans, with some fascinating findings and new questions to answer. This review describes barriers to treatment, such as low income, reduced access to care, racism, and mental health stigma. Also addressed are cultural differences in symptomology, test and measurement issues, and family factors in the development and maintenance of the disorder. Implications of findings to date are discussed, as well as unstudied areas of concern, such as treatment efficacy and African American youth with OCD.

Keywords: African Americans, obsessive-compulsive disorder, ethnic differences, assessment.

1. INTRODUCTION

Over the last two decades, there has been increasing attention focused on the issue of mental health disparities [1]. Given the growing diversity of the United States population, it is vitally important to ensure that the population as a whole is as healthy as possible. The Institute of Medicine and the National Institutes of Health (NIH) thought it important to designate disparities in mental health as a research priority, with The President's New Freedom Commission on Mental Health, including eliminating disparities as an essential goal for improving the mental health care system [1].

Mental health disparities may be observed in relation to the amount of attention given to mental health problems between different populations, and the inequity between populations with respect to quality, accessibility, and outcomes of mental health care. Considerable progress has been made in understanding, diagnosing, and treating obsessive-compulsive disorder (OCD), but not all groups have been helped by these advances, resulting in a notable mental health disparity. OCD in ethnic minority groups has been – and continues to be – a neglected area of scientific inquiry [2, 3].

In 1993, the NIH issued a mandate necessitating that funded research include adequate representation of racial and ethnic minority groups [4]. Researchers were newly required to include methods through which they would achieve diverse samples in their proposal strategies.

Nonetheless, our own comprehensive review of the literature found widespread and ongoing exclusion of various racial and ethnic minority groups [2, 3]. Among almost all major OCD clinical trials conducted in North America, ethnic minorities were either underrepresented or their participation was not reported. African Americans comprised less than 2% of all subjects in randomized trials. Researchers failed to adhere to NIH guidelines regarding inclusion of minority populations, yet inclusion of these groups is essential to fully understanding OCD in non-White populations.

Minority inclusion in specialized treatment for OCD is likewise inadequate. The DSM-IV field trial – one of the largest studies of Americans with OCD – was devised to draw from patients in specialty OCD clinics at several urban sites, including Atlanta, Boston, New Haven, New York, Philadelphia, Providence, and Toronto. However, out of 454 participants, only 2.8% were African American. We recently examined the demographics of OCD patients over a 13-year span at Rogers Memorial Hospital – which is one of the largest residential treatment centers for OCD and found that only 6.7% were ethnic or racial minorities, and only 0.9% were African American [6].

1.1. African Americans and OCD

Earlier studies of non-clinical African American samples noted differences in contamination anxiety and concerns about animals [7]. These findings were interesting, but it was unclear if this would be an important feature of OCD symptomology in African Americans with the disorder. Very few studies included African Americans diagnosed with OCD, therefore only tentative conclusions could be drawn from these student and community samples. Aside from a
few case studies [8, 9], and one naturalistic study [10], prior to 2008 there were no other published studies focused on the phenomenology, assessment, or treatment of African Americans with an actual OCD diagnosis.

It was hypothesized that low research participation among African Americans was due to a lack of interest in treatment, less impairment from OCD symptoms, or lower prevalence rates [11]. One critical turning point in our knowledge was the completion of the National Survey of American Life (NSAL) epidemiological study, where it was demonstrated that African Americans were suffering from OCD in the exact same numbers as the larger US population, and likewise experienced functional impairments, but were less likely to receive treatment [12]. Even among those who were able to access medical care, few received mental health care, and only 20% were receiving an SRI medication [12], which is the pharmacological first-line approach for OCD.

These findings were important, but created even more questions. If there was no difference in prevalence, what obstacles were keeping African Americans from receiving treatment? Were African Americans experiencing different types of symptoms, potentially leading to an incorrect or missed diagnoses? Was there something about African American culture that discouraged seeking treatment for conditions like OCD? Were there barriers within the mental health care system that made engaging in treatment difficult? Such questions could only be answered through an in-depth study of African Americans clinically diagnosed with OCD [11].

1.2. Recruitment of African Americans

Careful study design was crucial for identification of a population that by all accounts did not exist. Cultural factors were an early consideration, as many African Americans are uncomfortable participating in research due to ongoing experiences of discrimination in medical contexts [13, 14]. There are cultural memories of abuse, such as the US Public Health Service Syphilis Study at Tuskegee, which continues to influence medical decision-making to this day [15]. In addition many are aware of more current research abuses, such as the Baltimore Lead Paint Study, which disproportionately affected low-income African American families [16].

In 2009, investigators at the University of Pennsylvania (Penn) launched a study to better understand OCD in African Americans, with cultural considerations in mind. To reduce cultural fears associated with medical research, outreach materials in the study minimized use of terms like "research," in favor of "study" or "project." African American therapists practicing in the community were hired and trained to conduct the evaluations, with a subset of participants reevaluated by expert Penn psychologists to ensure fidelity. A combination of recruitment methods were used, including the posting of advertisements in African American newspapers, on the radio, on public transit, in flyers, and on the Internet. Advertising materials consisted of psycho-educational material outlining the symptoms of washing or hoarding behaviors and unwanted thoughts, as some potential participants may not have had previous knowledge that these behaviors were typical of OCD [17]. The research team made sure to include various African American institutions in the recruitment of the participants including a mental health program sponsored by an African American church, a local chapter of a national mental health advocacy program, a historically Black College/University (HBCU), and a local professional organization of Black psychologists [17].

The research team successfully identified and assessed 75 African American adults with OCD, which was the largest such sample to date, and a substantial improvement over the NSAL sample, where participants were evaluated by trained lay people using computerized measures that only queried for a subset of typical OCD symptoms [12].

1.3. Barriers to Treatment

Data from the Penn study confirmed that recruitment into research studies is only a part of the problem, and in fact many barriers to treatment among African Americans with OCD were identified. These included the cost of treatment, stigma/shame, fears of therapy, belief that a clinician would not be able to help, not perceiving a need for treatment, and treatment logistical issues [18].

Among lower income participants, problems in the community mental health system were an obstacle, including a low priority for treatment anxiety disorders, and a lack of community mental health providers adequately trained to provide OCD treatment. There were also issues concerning the recognition of OCD symptoms among African Americans, and failing to report symptoms to health care providers. Cultural issues noted among the sample included prohibitions against mental health care and a tendency toward viewing distressing thoughts as a spiritual problem to be resolved through religious practices. However, the most common issue reported by participants was that the person did not realize s/he had a disorder or that there were effective treatments for OCD [18].

One participant in the Penn study said, "I was just embarrassed. Getting this type of help has, and continues to be, like a sore thumb in the African American community. Unfortunately, I don't have insurance, so my fear was that if I sought help, it would not be good because I couldn't afford it." For several participants, the study assessment process and subsequent discussion of treatment with a clinician resulted in a change of thinking. Another confessed, "I was unaware, deluded, or in denial about the level of impact my condition had on life. Too much tolerance for deficiencies" [18, 19].

Concerns expressed by the African American sample were compared to non-Hispanic Whites in a previous study about barriers to treatment [19]. There were no racial group differences in worries about the cost of treatment, or feelings of shame and stigma; however, African Americans were significantly less likely to know where to go the receive help and almost a quarter endorsed fears about racism and discrimination from treatment providers. These issues are therefore uniquely important to long-term goals concerning outreach and treatment for African Americans [11].
Although the Penn study was not a clinical treatment study, treatment was discussed with each participant. The vast majority expressed a desire for treatment, and many attempted to obtain or even started treatment during the follow-up period. Unfortunately, many others who were interested were unable to obtain care.

1.4. Symptom Dimensions and Cognitions

It is important for clinicians to accurately understand symptom differences in African Americans because patients who do not meet the most common OCD presentations (i.e., contamination fears and overt repetitive checking) may not be quickly identified for intervention. African Americans are routinely over diagnosed with psychotic disorders and more likely to be hospitalized, even after controlling for symptom severity and socioeconomic status [20]. Given the bias toward a psychotic diagnosis for this group, it is quite possible that African Americans with the most severe OCD may be misdiagnosed with psychosis – especially those with unusual obsessions or compulsions [21, 22]. Effective treatments for OCD are typically quite different than those for psychotic disorders [23, 24]. Thus, clinicians must have a good understanding of OCD symptomology when assessing and treating patients in this ethnic/racial group.

To explicate these differences, the specific OCD symptoms reported by participants in the Penn study was compared to these symptoms reported by African Americans in the NSAL study [25]. Although the NSAL dataset provides fewer specific details about OCD symptoms, researchers were able to make some relevant comparisons to aid in understanding the disorder in African Americans nationally.

Six symptom dimensions were identified, which were similar to those of previous studies in primarily European and European American samples. These dimensions included contamination/washing, symmetry/perfectionism, doubts about harm/checking, sexual obsessions/reassurance, aggression/mental compulsions, and hoarding [23]. African Americans with OCD reported increased contamination symptoms relative to their White counterparts and were twice as likely to report excessive concerns about animals, which was consistent with studies conducted with non-clinical samples.

African Americans with OCD were more likely to include not being understood clearly as a primary concern when compared to White samples. This finding, along with more commonly endorsed concerns related to contamination, potentially indicate that specific cultural experiences and values may influence the presentation of obsessive compulsive symptoms in African Americans. For example, experiences with disenfranchisement as a result of ethnic and racial discrimination may further perpetuate anxiety about not being heard or understood; while prejudiced assumptions about the cleanliness of African Americans may further perpetuate contamination concerns [23].

In terms of cognitions, a study of a student sample indicated a weaker relationship between OCD-related beliefs and OCD symptoms in African Americans compared to European Americans [26]. The investigators also found that African American OCD symptoms were more strongly related to the use of avoidant control strategies in response to intrusive thoughts than were European Americans' symptoms – although the difference did not reach statistical significance. In particular, African Americans' control strategies were more strongly related to checking symptoms. No studies have been published on the topic of OCD cognitions in African Americans diagnosed with OCD, but one preliminary study of the Penn sample indicated that African Americans scored significantly higher on all three scales of the Obsessive-Compulsive Questionnaire-Short Form [27] OBQ-44 (responsibility and threat estimation, perfectionism and intolerance for uncertainty, and importance and control of thoughts) than the primarily White validation sample [28]. However, it is not clear if the OBQ-44 functions in the same matter across ethnoracial groups, so more work is needed to determine the cause of these differences.

1.5. Comorbidity

Comorbidity is common in OCD, with the vast majority of sufferers meeting criteria for another disorder in addition to OCD [12]. A preliminary study of the Penn sample revealed a number of important findings. For lifetime disorders, 87.9% of the Penn sample had at least one other comorbid condition. Comorbid conditions can complicate treatment and increase disease burden. The most prevalent comorbidities were mood disorders (67.1%), anxiety disorders (51.4%), and substance abuse disorders (38.0%). There was low comorbidity with eating disorders, as only 4.1% had binge eating disorder and none met criteria for anorexia or bulimia nervosa. In terms of gender differences, females were more likely to have posttraumatic stress disorder, and males were more likely to have a comorbid alcohol use disorder [29].

Hoarding is no longer considered a subtype of OCD, having since been designated as its own disorder in the DSM-5 [30] under the category of OCD and Related Disorders. To date there are no published studies of hoarding symptoms in African Americans, with or without an OCD diagnosis. However, over half of participants had hoarding compulsions (56.0%) as indicated by the Yale-Brown Obsessive-Compulsive Scale. [31]. African Americans with hoarding behaviors tended to earn less money, have lower levels of educational attainment and be more likely to rely on a spouse or partner for financial support than those with OCD but without hoarding symptoms. Hoarders were also more likely to have comorbid mood and substance abuse disorders, while non-hoarders were more likely to endorse anxiety-related psychopathological symptoms. Hoarders were also more likely to experience slowness, indecisiveness, and pathological doubting when compared to non-hoarders. These differences illustrate that hoarding in African Americans may involve increased disability compared to OCD without hoarding [31].

1.6. Diagnosing OCD

The lack of diversity in the initial development of most OCD assessment measures has made screening and diagnosis
of African Americans more difficult [32]. Research has shown that many self-report measures, such as the Maudsley Obsessive Compulsive Inventory (MOCI) and Padua Inventories, lack validity in non-clinical samples of African Americans [7, 33-35]. For example, on the MOCI, African American students scored higher on contamination and checking scales than European American students [33]. On the Padua Inventories, African Americans endorsed greater contamination anxiety and higher total scores [7, 34-36]. On the Obsessive Compulsive Inventory, Revised (OCI-R), African Americans scored higher on the washing scale [7, 35]. The OCD subscale of the National Anxiety Disorders Screening Day instrument – utilized among five ethnic groups – demonstrated a problematic factor loading for African Americans [37].

In a study exploring symptom dimensions in several ethnoracial groups using the Dimensional Scale for Obsessive Compulsive Scale (DOCS) [38], African American participants reported more contamination-related symptoms compared to European Americans, but no differences were found in other areas (i.e., responsibility for harm, unacceptable thoughts, and symmetry). However, it is difficult to draw meaningful conclusions from these type of findings, as several of these measures had yet to be validated in a sample that includes African Americans with OCD.

The Penn study enabled an investigation of the psychometric properties of three different clinical measures in African Americans diagnosed with OCD: the Obsessive Compulsive Inventory-Revised (OCI-R) [39], the Yale-Brown Obsessive Compulsive Scale (Y-BOCS) [40], and the Structured Clinical Interview for the DSM-IV Axis I (SCID) [41].

It was found that the SCID was not a reliable method to determine the presence of OCD in African Americans (33.8% missed diagnosis rate for African American with verified OCD) [42], but the Y-BOCS Severity Scale [43], and the Obsessive Compulsive Inventory-Revised [44] showed good validity when compared to related measures in African Americans with OCD. On the OCI-R, African American college students in a control group reported more contamination concerns when compared with non-Hispanic White students, and this cultural difference led to higher optimal cut-off scores for African Americans in order to meet diagnostic criteria (36 versus 21).

1.7. Family Factors

Another important research goal is gaining a better understanding of environmental factors in the development of OCD symptoms. Many disorders have shown relationships between childhood family functioning and the occurrence of symptoms in adults. In a study conducted by Sawyer et al.,[45] data about childhood family functioning in African Americans with OCD was compared to a community sample using a retrospective version of the Family Assessment Device [46]. The results revealed that communicative and emotional problems in childhood predicted anxiety and depression in adulthood, but were not correlated with OCD. This led researchers to speculate that biological factors may be more important in the development of OCD in African Americans than familial environment, but this has yet to be studied, as there are currently no biological or developmental studies of OCD that include adequate numbers of African Americans to make a determination [45].

CONCLUSION

The last decade has marked tremendous growth in our understanding of OCD in African Americans, including the publication of research methodology to enable greater African American inclusion in future studies [12, 23]. It is clear that raising awareness within the African American community about OCD, improving knowledge of effective treatments, and educating more clinicians so that treatments are available and accessible in underserved communities are all crucial to addressing the problems discussed [11]. Critical future avenues of research include genetic studies, psychopharmacology studies, and psychotherapy treatment outcome studies for African Americans.

One other vastly neglected area in need of immediate attention is the development of an understanding of OCD in African American children. Youth with OCD are at an increased risk of depression, academic problems, familial problems, and isolation [47, 48]. Minority children with OCD are underrepresented or absent from treatment centers and research studies, although evidence suggests that OCD may be particularly persistent in these groups [12]. Thus, there is still much work that needs to be done to provide us with a comprehensive understanding of OCD in the African American population.

CONFLICT OF INTEREST

The authors confirm that this article content has no conflict of interest.

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REFERENCES


