



Minority participation in a major residential and intensive outpatient program for obsessive-compulsive disorder



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ABSTRACT

Obsessive-Compulsive Disorder (OCD) is prevalent among children and adults across racial and ethnic groups, causing significant and pervasive impairment in home life, work, and relationships. This article includes a review of the literature surrounding utilization of mental health care and barriers to treatment for OCD in four specific ethnoracial minority groups, followed by an examination of minority participation in a large intensive/residential OCD treatment facility. Participants included 924 children or adults diagnosed with OCD at Rogers Memorial Hospital between 1999 and 2012. The overwhelming majority of participants were non-Hispanic White (93.3%), indicating a significant mental health disparity. Patients were: 2.4% Hispanic/Latino American, 1.2% Asian American, 0.9% African American, 0.8% biracial/multiracial, 0.7% Indian American, 0.6% other, 0.1% Native American, and 0.1% Pacific Islander. Minority patients required significantly longer stays, despite no differences in mean OCD severity pre- or post treatment. The percentage of minority patients significantly increased over a 13-year span. Implications of findings and recommendations for increasing minority participation are discussed.

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1. Introduction

1.1. Background

Obsessive-compulsive disorder (OCD) is a highly disabling and distressing disorder, which has made it a major cause of disability worldwide (Ayuso-Mateos, 2006; Zohar, Fostick, Black, & Lopez-Ibor, 2007), afflicting an estimated 2.3% of the American population (Ruscio, Stein, Chiu, & Kessler, 2010). Obsessions are intrusive, unwanted thoughts, images, or urges that increase anxiety, whereas compulsions are repetitive behaviors or mental acts used to decrease anxiety. The disorder causes significant and pervasive impairment in multiple domains, including home life, work, and relationships (Karno, Golding, Sorenson, & Burnam, 1988; Kessler et al. 2005; Ruscio et al., 2010; Zhang, Snowden, & Sue, 1998). OCD-related costs have previously been estimated at \$8 billion annually in the US (DuPont, Rice, Shiraki, & Rowland, 1995) and this figure would likely be higher today.

An estimated 7.3 million people in the United States will suffer from OCD during their lives. Although OCD prevalence rates are generally consistent cross-culturally (Himle et al. 2008; Karno et al., 1988; Kessler et al., 2005; Zhang et al., 1998; Williams, Chapman, Simms, & Tellawi, in press), previous literature reveals a lack of ethnic minority participation in mental health care for OCD. Williams Powers, Yun, and Foa (2010) assessed 21 clinical research trials that provided data on race and ethnicity ($N=2221$) among subjects with OCD from 1989 to 2009. Fully 91.5% of participants reported their race/ethnicity as European American, and the remainder included small numbers of African Americans (1.3%), Hispanic Americans (1.0%), Asian Americans (1.6%), and others (1.5%). These numbers fall far below expectations based on US Census data, with 12.3% of the US population being African American, 12.5% Hispanic or Latino American, and 3.6% Asian American (US Census, 2000). A potential cause for this disparity is that ethnic minority individuals may be less likely to receive specialized OCD treatment, which may limit research participation as subjects are often recruited from OCD specialty clinics (Williams et al., 2010).

Although the development and maintenance of OCD has been well described in the literature, little is known about OCD in ethnic minority populations because OCD studies generally include low percentages of ethnic minorities (i.e., Williams et al., 2010); thereby making it difficult to understand OCD within these groups. In addition, research has

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shown that ethnic minorities may underutilize mental health services (Kearney, Draper, & Barón, 2005; Snowden & Cheung, 1990), suggesting that there may be culture-specific barriers to receiving evidenced-based treatments.

1.2. OCD in African Americans

Although 40% of African Americans with OCD report their obsessional concerns to a doctor, very few receive treatment (Simmons et al., 2012; Williams, Domanico, Marques, Leblanc, & Turkheimer, 2012). African Americans appear to be underrepresented in OCD treatment clinics and research studies (Foa et al., 1995). Among all Americans, for those with severe OCD, 93% receive some type of treatment (Ruscio et al., 2010); however, this is true for only 60% for African Americans with severe OCD (Himle et al., 2008), indicating a substantial mental health disparity. Even among those who are able to access mental health care, few African Americans with OCD receive empirically-supported treatments for the disorder, and only 20% use a serotonin reuptake inhibitor medication (Himle et al., 2008).

In a study by Williams et al. (2012) the authors investigated barriers to obtaining OCD treatment in both African Americans and non-Hispanic Whites. Results indicated that both groups reported concerns about the cost of treatment, shame, stigma, and wanting to handle the problem on their own. However, certain barriers disproportionately affected African Americans, including stigma and judgment, denying a need for treatment, lack of disorder/treatment awareness, fears of discrimination, and concerns about the treatment process. Participants in this study endorsed negative attitudes about individuals who seek mental health care and difficulty in identifying as someone with mental illness (Williams, Beckmann-Mendez, & Turkheimer, 2013). Additionally, subjects reported significant concerns about the therapist or treatment process (i.e., treatment failure, satisfaction, too difficult, etc.) as a serious barrier to treatment.

1.3. OCD in Latinos/Hispanic Americans

Latinos are insufficiently represented in clinical studies for OCD, making it unclear whether evidence-based treatments demonstrate the same efficacy and effectiveness for Latinos as has been demonstrated for non-Hispanic Whites (Wetterneck et al., 2012). This calls into question the cross-cultural applications of evidence-based treatments for OCD based on diagnostic constructs developed for Westernized presentations of OCD symptoms, leading to potential barriers in treatment efficacy for these populations.

There have not been many studies investigating attitudes about OCD in Latino and Hispanic individuals, however it is likely that cultural attitudes significantly impact treatment seeking. Additionally, lack of clinician knowledge of these socioeconomic, cultural and linguistic barriers, and how they can influence OCD symptomology, can create treatment barriers in therapy (Wetterneck et al., 2012).

1.4. OCD in Asian and Indian Americans

Unfortunately, little research has been conducted to examine barriers to mental health treatment, or specifically OCD, in Asian Americans. Asian American, including East Indian American (AA/IA), individuals' utilization of mental health services is heavily influenced by their cultural beliefs as well as accessibility, and understanding how these factors influence mental health treatment seeking for OCD is essential. While AA/IA's are composed of very heterogeneous subgroups, including Chinese, Japanese, Cambodian, Vietnamese, Indian, and others, many researchers have studied these populations together because of similar cultural views in comparison to their Western counterparts. However, there remain distinct cultural and

socioeconomic influences of the various subgroups that have a differential impact on mental health care attitudes and treatment seeking that need to be considered as well.

Studies have shown that compared to other ethnic groups, AA/IA's are the least likely to seek professional services for mental illness and endorse low rates of psychopathology; however, newer research suggests these low rates are due to a number of reasons, including low treatment seeking and high therapy drop-out (Leong, Kim, & Gupta, 2011). AA/IAs are more likely to use informal sources of support, such as family and friends, or try to work out problems on their own until the problem becomes too severe to manage (Durvasula & Sue, 1996; Kearney et al., 2005; Narikiyo & Kameoka, 1992; Zhang et al., 1998). Furthermore, AA/IA culture tends to value self-control and intellectualization over emotional expression, and as a result, AA/IAs tend to be more likely to internalize mental distress and tolerate their suffering as opposed to engaging in emotional self-disclosure (Mysorekar, 2006; Ramisetty-Mikler, 1993).

1.5. OCD in Native Americans

Although there is an absence of research on OCD in Native Americans (American Indian and Alaska Natives), treatment barriers in these populations have been established with other mental health issues that could extend to OCD treatment. Cultural differences in communication and reporting systems continue to be an issue regarding under diagnosis, misdiagnosis and delays in seeking treatment. Thompson, Walker and Silk-Walker (1993) found that different tribes have different meanings when it comes to mental illness, including beliefs that mental and physical illness are the same, that mental health symptoms are representative of disharmony within their soul, or supernatural possession. Considering these meanings, many tribes prefer to seek treatment through their traditional, spiritual practices rather than Westernized practices that may not apply to how they are expressing symptoms, creating underutilization of these mental health services or high therapy dropout.

1.6. Purpose of the current study

Evidenced by previous epidemiological studies or lack thereof, little is known about OCD treatment program utilization by ethnic minorities. There have been no published studies examining minority participation for OCD treatment in any setting, and as such, the current study fills an important gap in the literature. Having knowledge as to which ethnic and racial groups are underrepresented would be important to inform outreach efforts to promote equity in access and treatment for OCD. Additionally, it is not known if treatments for OCD are equally effective for ethnic minority patients as few studies have contained enough minorities to make such comparisons. This information would help to inform clinicians and researchers as to the importance of cultural differences when implementing treatment. Thus, we investigate minority participation in a large OCD treatment program over a thirteen-year span. Given that the US is becoming increasingly diverse, with ethnoracial minorities at 37.4% in the US population and 50.4% of all births (US Census, 2012b, 2014), such investigations are important for our understanding of treatment use and accessibility.

Based on low rates of inclusion found in research studies, we hypothesize that minorities are underrepresented as OCD patients, although we would also predict a shift over the course of the years in favor of greater inclusion. We hypothesize that treatment would be less effective for minorities (shorter stays and subsequently smaller reduction in symptoms) for many of the same reasons that impede the initiation of treatment in minorities (i.e., cultural mistrust, mental health stigma).

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