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Minority participation in randomized controlled trials for obsessive–compulsive disorder

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ABSTRACT

This paper reviews published randomized trials in North America to determine whether minority groups are underrepresented in clinical trials of OCD. A search of the literature produced 40 randomized trials of both adults and children with OCD, conducted in the U.S. and Canada from 1989 to 2009 ($N = 3777$). The groups included in this review were Caucasians/European Americans, Black/African-Americans, Hispanic/Latino-Americans, Asian-Americans, Others, and Unknown. Of these, 22 of 40 trials reported ethnic/racial information or data was available by request. We focused on the 21 trials from 1995 to 2008 providing ethnic/racial information, and among those ($N = 2221$), 91.5% of participants were Caucasian, 1.3% were African-American, 1.0% were Hispanic, 1.6% were Asian, 1.5% were Other, and 3.1% were Unknown. We conclude that minorities are underrepresented in North American OCD trials. Therefore, it is not known if empirically validated treatments are effective for these groups. Recommendations for improving recruitment of minorities for future studies are discussed.

1. Introduction

It is estimated that between 2 and 3 million people are suffering from obsessive–compulsive disorder in the United States. The National Comorbidity Survey Replication (NCS-R) showed that approximately 1.6% of the United States population met criteria for OCD at some point in their lives (Kessler, Berglund, et al., 2005), with 1% of the sample meeting criteria within the last year (Kessler, Chiu, Demler, Merikangas, & Walters, 2005). Prevalence of OCD appears to be roughly consistent across ethnic and national groups. For example, a recent epidemiological study of 3417 African-Americans showed an OCD lifetime prevalence of 1.6% (Himle et al., 2008).

Although prevalence rates may be similar, the clinical presentation of African-Americans with OCD may be substantially different from that of European-Americans (Guarnaccia, 1997; Hollander & Cohen, 1994). For example, Himle et al. (2008) found that black Americans were more likely to have a later age of onset, with mean of 31.8 years, as opposed to a mean of 19.5 years for the general population, as reported in the NCS-R study (Ruscio, Stein, Chiu, & Kessler, 2008). Later age of onset is associated with greater severity, poorer insight, and greater comorbidity (Ruscio et al., 2008). Himle et al. (2008) also found that once black patients met criteria for OCD, they were very unlikely to experience remission, leading the authors to conclude, "high levels of overall mental illness comorbidity and severity, limited access to state-of-the-art treatments, or reduced responses to currently available OCD treatments, which have not been well tested in the African-American population, may all contribute to the high OCD persistence" (p. 999).

Effective psychological and pharmacological treatments for OCD are available. Meta-analyses of controlled trials consistently show very large effect sizes for exposure with ritual/response prevention (EXRP) and pharmacotherapy (Kobak, Greist, Jefferson, Katzelnick, & Henk, 1998; Rosa-Alcázar, Sánchez-Meca, Gómez-Conesa, & Marín-Martínez, 2008). However, the efficacy of available treatment with minorities with OCD is unclear because sub-analyses that will provide an answer to this question have not been published. There is some evidence that ethnic minorities show differential response to psychological and pharmacological treatments for other anxiety disorders (Chambless & Williams, 1995; Roy-Byrne, Perera, Pitts, & Christi, 2005; Roy-Byrne, Russo, Cowley, & Katon, 2003). For example, Chambless and Williams (1995) showed that in vivo exposure was less effective among African-Americans with agoraphobia compared to white patients. Roy-Byrne et al. (2003) found that minority status predicted poor response to paroxetine for panic disorder. Finally, a review of 104 studies by Roy-Byrne et al. (2005) showed that the odds of response to paroxetine in anxiety and mood disorder participants was lower in Hispanic and Asian participants than white and black participants. Based on the possibility of such differences, the National Institutes of Health have emphasized minority inclusion in clinical research.

In July 1989, an *NIH Memorandum on Inclusion* encouraged research solicitations to include adequate numbers of women and minorities and provide a rationale if they were excluded. To ensure that these policies were implemented, Congress legally mandated inclusion through the *NIH Revitalization Act of 1993*. By 1994, the NIH had revised its policy to require that women and minorities be included, and by 1995 the NIH refused to fund any project that did not adhere to these policies (USDHHS, 2002). The *Outreach Notebook for the NIH Guidelines on Inclusion of Women and Minorities as Subjects in Clinical Research* states that "it is imperative to determine whether the intervention or therapy being studied affects ... members of minority groups and their subpopulations

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differently" (USDHHS, 2002, p. 103). Unless it is clear that no important public health questions can be resolved by inclusion of minorities, the study design must include "sufficient and appropriate representation of minority groups to permit valid analyses of differential intervention effect" (USDHHS, 2002, p. 25). This typically means oversampling; that is, including more minorities than would constitute a nationally representative sample to achieve enough statistical power to determine if group differences exist in important outcome variables.

NIH annual research reports show some progress in minority inclusion, with about a quarter of all clinical research participants as part of ethnic or racial minority groups. However, it is unknown to what extent NIH guidelines for minority inclusion have also resulted in more representative samples in OCD randomized controlled trials. This is an important question because inadequate representation of minorities in clinical trials would potentially call in to question the generalizability of research findings. Furthermore, lack of inclusion means that minorities would fail to share in both the burden and benefits of the research conducted, making these groups less than equal partners in the process. The aim of this paper is to review the literature relevant to minority inclusion in OCD randomized controlled trials (RCT) completed from the first NIH memorandum in 1989 to the present to determine if minorities are adequately represented. We also review recruitment techniques to determine what means have been effective in the successful recruitment of minorities.

2. Method

2.1. Study selection

We selected randomized controlled trials for OCD using a comprehensive strategy and conducted a search on the following databases: PsycINFO (1989 to March 2009), Scopus (1989 to March 2009), and reference lists from published material concerning OCD. The search included the following terms: "obsessive–compulsive disorder," "obsessive–compulsive," "random," "randomly," "randomise," "randomize," "randomised," "randomized," "controlled," and "controlled trial." These words were searched as keywords, title, abstract, and medical subject headings. Also, we examined citation maps and used the "cited by" search tools. These findings were cross-referenced with references from review articles. As in the previous OCD reviews, only published research was considered for inclusion. These initial search strategies identified 58 potential articles. Next we limited the findings to studies conducted in U.S. and Canada because ethnic breakdowns of the populations in other countries may not directly correspond with U.S. categories. Examination of the abstracts and method sections from each publication identified 40 relevant articles.

In our analysis, we reviewed available data for ethnic/racial breakdowns of the samples, and included trials of both adults and children with OCD. The groups that we included in this study were Caucasians/European Americans, Black/African-Americans, Hispanic/Latino Americans, Asian Americans, Others, and Unknown.

Studies meeting the following inclusion criteria were selected for analysis: (a) random assignment, and (b) either an active or inactive control group.

2.2. Missing data

Authors of selected studies were contacted directly through e-mail or phone when there were no demographic data about ethnic/racial information provided in their articles to include in the analysis. The first contact attempt included an e-mail/phone call to the first or corresponding author. In the event of no response, this step was repeated. If still no response, we attempted to contact the second author and so on. Some of the authors failed to provide data because the data requested were no longer available or not collected when the study was conducted. Some authors were not available for contact.

2.3. Data range

Based on the 1989 *NIH Memorandum on Inclusion* (USDHHS, 2002), we only focused on articles published from 1989 to 2009. Specifically, the studies reporting demographic data in our current analysis were published between 1992 and 2008.

3. Results

Of the 40 randomized controlled trials for OCD conducted in North America between 1989 and 2008, 22 trials either provided ethnic/racial information (13 trials) or this information was available by request (9 trials). Of 18 trials not reporting demographic data, nine studies were excluded because the data was no longer available or not collected when the study was conducted (Bergeron et al., 2002; Hollander, Kaplan, & Stahl, 2003; Fallon et al., 1998; Foa, Kozak, Steketee, & McCarthy, 1992; Jenike, Baer, Minichiello, Rauch, & Buttolph, 1997; Jenike, Baer, et al., 1990; Jenike, Hyman, et al., 1990; Mallya, White, Waternaux, & Quay, 1992; Wilhelm et al., 2008). The remaining nine studies were excluded because the authors did not respond to our request to provide the relevant data (Benkelfat et al., 1989; Fals-Stewart, Marks, & Schafer, 1993; Goodman, Kozak, Liebowitz, & White, 1996; Goodman et al., 1989; Hiss, Foa, & Kozak, 1994; Katz, DeVeaugh-Geiss, & Landau, 1990; Leonard et al., 1991; March et al., 1998; Stein, Hollander, Mullen, DeCaria, & Liebowitz, 1992).

We grouped the studies into two periods, 1989–1994 (when inclusion of minorities was strongly encouraged) and 1995–2008 (when inclusion was both legally required by congress and enforced by the NIH). From the first period (1989–1994), only one study reported minority inclusion (Beasley et al., 1992) out of 12 studies. "Non-white" participants made up 9.3% of the sample; however the racial breakdown of this minority subsample was not described. The total number of studies found in U.S. and Canada for the periods: 1989–1994, 1995–2008 and 1989–2008, are presented in Table 1.

From the second period (1995–2008), 21 studies reported minority inclusion (53.8%) out of 28 studies. Specific study-by-study ethnic/racial breakdowns are presented in Table 2.

Of the 21 trials providing ethnic/racial information ($N = 2221$), 91.5% of participants were Caucasian, 1.3% were African-American, 1.0% were Hispanic, 1.6% were Asian 1.5% were other, and 3.1% were unknown.

To better understand causes for the low number of minority participants, we examined factors related to recruitment which may impact minority enrollment, such as the age groups of the participants, location where the studies were conducted, how patients were recruited, and if compensation was offered. This information is summarized in Table 3. When provided by the authors we listed the study locations. For studies without specified locations or with more than 6 sites we listed only the number of sites in the study.

Table 1
Total number of studies used in U.S. and Canada.

	Study period		
	1989–1994	1995–2008	1989–2008
With ethnic data	1	21	22
Without ethnic data	11	7	18
Total *N* of studies	12	28	40

Table 2
Minority inclusion from 1995 to 2008.

Study	*N*	Ethnicity					
		White (%)	Black (%)	Hispanic (%)	Asian (%)	Other (%)	Unknown (%)
Greist, Chouinard, et al. (1995); Greist, Jefferson, et al. (1995)	325	317 (97.5%)	2 (0.6%)	0 (0.0%)	0 (0%)	6 (1.8%)	0 (0.0%)
Koran, Mcelroy, Davidson, Hollander, and Jenike (1996)	79	76 (96.2%)	2 (2.5%)	0 (0.0)%	1 (1.3%)	0 (0.0%)	0 (0.0%)
Freeston et al. (1997)	29	29 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Koran, Sallee, and Pallanti (1997)	15	14 (93.3%)	0 (0.0%)	1 (6.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Kronig et al. (1999)	167	160 (95.8%)	0 (0.0%)	2 (1.2%)	0 (0.0%)	5 (3.0%)	0 (0.0%)
Shannahoff-Khalsa et al. (1999)	21	19 (90.5%)	0 (0.0%)	1 (4.8%)	0 (0.0%)	1 (4.8%)	0 (0.0%)
Hoehn-Saric et al. (2000)	164	154 (93.9%)	3 (1.8%)	0 (0.0%)	1 (0.6%)	6 (3.7%)	0 (0.0%)
Geller et al. (2001)	103	89 (86.4%)	2 (1.9%)	7 (6.8%)	1 (1.0%)	4 (3.9%)	0 (0.0%)
McLean et al. (2001)	63	50 (79.4%)	0 (0.0%)	0 (0.0%)	11 (17.5%)	2 (3.2%)	0 (0.0%)
Romano, Goodman, Tamura, and Conzales (2001)	71	66 (93.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	5 (7.0%)
Greist et al. (2002)	218	203 (93.1%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	15 (6.9%)
Koran, Hackett, Rubin, Wolkow, and Robinson (2002)	224	211 (94.2%)	5 (2.2%)	0 (0.0%)	5 (2.2%)	3 (1.3%)	0 (0.0%)
Liebowitz et al. (2002)	43	35 (81.4%)	3 (7.0%)	2 (4.7%)	1 (2.3%)	2 (4.7%)	0 (0.0%)
Geller et al. (2004)	207	183 (88.4%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	24 (11.6%)
POTS Team (2004)	112	103 (92.0%)	5 (4.5%)	3 (2.7%)	1 (0.9%)	0 (0.0%)	0 (0.0%)
Foa et al. (2005)	122	103 (84.4%)	4 (3.3%)	5 (4.1%)	5 (4.1%)	0 (0.0%)	5 (4.1%)
Whittal, Thordarson, and McLean (2005)	59	50 (84.7%)	0 (0.0%)	0 (0.0%)	7 (11.9%)	2 (3.4%)	0 (0.0%)
Kushner et al. (2007)	25	21 (84.0%)	1 (4.0%)	0 (0.0%)	1 (4.0%)	2 (8.0%)	0 (0.0%)
Storch et al. (2007)	24	22 (91.7%)	1 (4.2%)	0 (0.0%)	1 (4.2%)	0 (0.0%)	0 (0.0%)
Freeman et al. (2008)	42	34 (81.0%)	0 (0.0%)	1 (2.4%)	1 (2.4%)	1 (2.4%)	5 (11.9%)
Simpson et al. (2008)	108	94 (87.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	14 (13.0%)
Total	2221	2033 (91.5%)	28 (1.3%)	22 (1.0%)	36 (1.6%)	34 (1.5%)	68 (3.1%)

A number/percentage of participants included in the ethnic breakdown of the sample provided by each study.

Table 3
Participant age groups locations, and recruitment techniques from 1995 to 2008.

Study	Age group	Setting	Location(s)	Country	Recruitment technique
Greist, Chouinard, et al. (1995); Greist, Jefferson, et al. (1995)	Adults	Not described	11 sites	USA	Not described
Koran et al. (1996)	Adults	Urban	6 sites	USA	Not described
Freeston et al. (1997)	Adults	Suburban	Quebec	Canada	Not described
Koran et al. (1997)	Adults	Urban/Suburban	Stanford, CA, Charleston, SC	USA	Not described
Kronig et al. (1999)	Adults	Urban/Suburban	10 sites	USA	Not described
Shannahoff-Khalsa et al. (1999)	Adults	Urban	San Diego	USA	TV news, newspaper ads, physician referral
Hoehn-Saric et al. (2000)	Adults	Urban	16 sites	USA	OCD treatment center
Geller et al. (2001)	Children	Urban/Suburban	21 sites	USA	Not described
McLean et al. (2001)	Adults	Urban	Vancouver, BC	Canada	Physician referral, newspaper ads, other media features
Romano et al. (2001)	Adults	Urban	11 sites	USA	Not described
Greist et al. (2002)	Adults	Urban/Suburban	7 US sites, Canada site	USA/Canada	Radio, newspaper ads ad articles, clinician's current case loads, and referrals
Koran et al. (2002)	Adults	Not described	21 sites	USA	Newspaper, radio ads, the clinical practices of the investigators
Liebowitz et al. (2002)	Children	Urban	New York, Charleston, SC	USA	Not described
Geller et al. (2004)	Children	Urban/Suburban	34 centers	USA/Canada	Not described
POTS Team (2004)	Children	Urban	Providence, RI, Philadelphia, PA Durham, NC	USA	Clinical referral, advertising in print and radio media
Foa et al. (2005)	Adults	Urban	Philadelphia, PA, NYC, Winnipeg, Manitoba	USA/Canada	Self/professional referrals, media ads
Whittal et al. (2005)	Adults	Urban	Vancouver, BC	Canada	Self-referred/referred by health professionals
Kushner et al. (2007)	Adults	Urban	Minneapolis, MN/ Philadelphia, PA	USA	Newspaper ads
Storch et al. (2007)	Adults	Urban	Gainesville, FL	USA	UFL OCD program
Freeman et al. (2008)	Children	Urban	New England	USA	Not described
Simpson et al. (2008)	Adults	Urban	Philadelphia, NYC	USA	Ads, word of mouth, clinical referrals

Of the studies reporting ethnic data since 1995, 71.4% were conducted in the US, 14.3% in Canada, and 14.3% were multisite studies conducted in both the US and Canada, 61.9% were conducted in urban areas, 23.8% were child studies and 76.2%were adult studies. None reported offering compensation for participation or assessment. Ten of the 21 studies did not describe their recruitment techniques.

4. Discussion

4.1. Minority participation rates low

Results of our review indicate a paucity of ethnic minority inclusion in OCD research studies. Despite NIH requirements that all studies include and report on minority participation, a

substantial number of studies did not report on minority participation. Only one study between 1989 and 1994 reported minority participation (Beasley et al., 1992) despite the NIH's strong encouragement. Only 75% (21 out of 28) of studies from 1995 to 2008 were able to provide information about minority participation, despite mandated requirements to report and include minority participants. No studies included a representative sample of minorities consistent with the US population demographics, and none oversampled minority groups.

A few studies are worth noting for their relative success in the inclusion of minority participants. McLean et al. (2001) conducted a CBT study of participants in British Columbia and was successful in recruiting Asian Americans, however, no separate analyses were reported for this group. The authors described the use of physician referral, newspaper advertisements, and other media features for recruitment.

In 2007, the last available NIH report, minorities constituted 26.5% of enrollment across all NIH U.S. domestic clinical studies. For domestic Phase III trials, there was an average of 22.6% minority subjects enrolled in protocols from 2002 to 2007 (USDHHS, 2008). Among the minorities, 9.6% were African-American, 1.9% Asian American, 1.0% Native American, 9.8% Hispanic ethnicity, and 1.8% of more than one race (Table 9, USDHHS, 2008). These numbers are in sharp contrast to our findings for North American OCD trials where minority inclusion was much lower (5.4%), particularly among African-Americans (1.0%) and Hispanic participants (1.6%).

4.2. Causes for low minority participation

Mistrust of the larger medical system is typically believed to constitute the major cause of low minority participation (Suite, La Bril, Primm, & Harrison-Ross, 2007). According to the US Surgeon General, research shows that "many members of minority groups fear, or feel ill at ease with, the mental health system" (USDHHS, 1999). However, reasons minority groups underutilize mental health care may not be the same as those which prevent participation in clinical trials. Financial barriers, language barriers, proximity to specialty clinics, and cultural beliefs about the best approaches to mental illness may all be factors that contribute to underuse of mental health care that are unrelated to institutional mistrust.

There is, however, a cultural memory of government sanctioned research abuses, such as the Tuskegee Syphilis study of African-Americans (Freimuth et al., 2001). It has been hypothesized that the Tuskegee Study is why African-Americans are extremely reluctant to participate in medical research (Gamble, 1993). The Tuskegee Legacy Project surveyed 1133 adult blacks, Hispanics, and non-Hispanic whites in four U.S. cities. The findings revealed no difference in self-reported willingness to participate in biomedical research, between groups. However, black participants were significantly more likely than whites to have a higher fear of participation in biomedical research, based on the Guinea Pig Fear Factor (GPFF) Scale (OR 1.8). Hispanic participants also reported higher GPFF scores (OR 1.3), but the study was underpowered to detect a significant difference (Katz et al., 2006). Despite history of documented research abuses of minorities, there are few studies that validate mistrust as a causal factor in their exclusion from current research trials. Judging by the success of other types of NIH studies in the recruitment of minorities (USDHHS, 2008), medical mistrust is unlikely to be the main factor.

Many researchers reported recruiting existing OCD clinic patients as the source of participants for their studies; however, there is evidence that minorities are poorly represented in anxiety specialty clinics. The DSM-IV field trial, one of the largest studies of Americans with OCD, was devised to better understand the phenomenology of OCD (Foa & Kozak, 1995). The study drew from patients in top OCD specialty clinics at five urban sites. Out of 454 participants, only 5.4% were minorities, whereas 94.6% were European-Americans. It is not known why minorities are underrepresented in these settings. The low number of OCD patients in specialty clinics underscores why simply using existing clinic patients for recruitment is unlikely to yield sufficient numbers of minority participants in OCD studies.

Williams, Chambless, and Steketee (1998), also reported difficulty in recruiting African-Americans for an OCD outcome trial. The study was conducted in Washington DC, an area with a large African American population. During the five years the study was underway, only two African-Americans participated. The authors believe that black participants felt uncomfortable venturing into an affluent, white section of the city, and also theorize that black participants may feel a heightened sense of fear and shame about their symptoms.

None of the OCD trials included in this review described financial compensation for study participants, often drawing from participants who were already seeking specialty treatment. Lack of compensation may be one reason for low minority inclusion, as financial concerns can be a practical barrier to research participation because ethnic minority communities are disproportionately economically disadvantaged (Fisher et al., 2002). Indeed, studies suggest that offering compensation for visits facilitates participation by African-Americans (Clay, Ellis, Amodeo, Fassler, & Griffin, 2003; Hatchett, Holmes, Duran, & Davis, 2000). Gallagher-Thompson, Solano, Coon, and Arean (2003) noted that for Hispanic participants, adequate compensation helps to offset practical barriers, such as wages lost from missing work, the cost of extra child care, and the cost of transportation.

OCD is a highly heterogeneous disorder, and it is important to understand whether OCD symptoms in minorities are different from those of Caucasians. This is because patients who do not present the most common symptoms (i.e., excessive washing and overt repetitive checking) may not be diagnosed correctly by medical professionals. There may be cross-cultural differences in obsessive, compulsive, and anxiety symptoms (Guarnaccia, 1997; Hatch, Friedman, & Paradis, 1996), and it is possible that minorities with the most severe form of the disorder, especially those with unusual obsessions or compulsions, may be misdiagnosed as psychotic (Hollander & Cohen, 1994). Cross-cultural research has documented differences in obsessional content and compulsions in studies done internationally (i.e., Karadag, Oguzhanoglu, Ozdel, Atesci, & Amuk, 2006), but few such studies have been done with ethnic minorities in the US (Hatch et al., 1996). Thus, misdiagnosis may be a factor in the lack of identified minority OCD patients (Friedman et al., 2003).

Minority participants may answer questions about symptoms differently in the presence of European-American therapist. For example, in an OCD assessment study, African-American participants expressed significantly more concerns about washing in the presence of a black experimenter than a white experimenter (Williams & Turkheimer, 2008). Malgady and Costantino (1998) found that ethnic and language matching of patient and clinician promoted improved clinical judgments of psychopathology severity for Hispanic patients, even among those who were bilingual. Therefore, an ethnic mismatch of patients and evaluators may decrease identification of OCD.

4.3. Implications of low minority participation

The consistently low participation rates of US ethnic minority groups in OCD research studies is a concern to researchers, clinicians, and patients as this brings into question the generalizablity of the work that has been done to date.

While there is wide agreement that OCD studies should include more minority participants, there are few reports in the literature

to inform researchers about effective outreach strategies for recruitment (Meinert, Blehar, Peindi, Neal-Barnett, & Wisner, 2003). Nonetheless, many mental health researchers studying other disorders have been successful despite the obstacles described previously.

4.4. Recommendations for increasing minority participation

Although minority groups are underrepresented in OCD research trials, there is no conclusive data on the reasons for this. The RCTs examined in this paper provided few details concerning the recruitment process, and even fewer reported success in minority recruitment. Thus, in order to make recommendations we must draw on the literature as it pertains to minority recruitment for other types of studies and disorders. The following measures are recommended to enhance minority inclusion.

Forming connections with community organizations, churches, and local leadership: Study personnel should devote substantial time and effort into developing and maintaining personal relationships with leaders and key organizations in the minority communities of interest (Gallagher-Thompson et al., 2003; Meinert et al., 2003; Sweeney, Robins, Ruberu, & Jones, 2005). Endorsements and referrals from pastors, doctors, and others esteemed people in the community facilitate trust and interest among potential participants.

Broad advertising strategies: Information about the study should be disseminated widely, beyond existing patient pools or affiliated clinics. Ads should be placed in newspapers with high minority readership, public transportation, and Internet venues. Fliers about the study should be placed which are frequented by minorities. Print advertisements should feature photos of minorities to facilitate a positive impression about the study among these groups (Avery, Hernandez, & Hebl, 2004). Ads should clearly state the purpose of the study, participant involvement, incentives, and sponsoring organization (Clay et al., 2003; Hatchett, Holmes, & Ryan, 2002). Interviews on local TV news and talk shows, on radio shows, and in community newspapers have also been effective in promoting awareness of studies among minorities (Jackson et al., 2004).

Minority staff, faculty, and consultants: Several studies reported that having adequate staff members of diverse groups is key to successful efforts at minority recruitment (i.e., Gallagher-Thompson et al., 2003). Multicultural project teams increases cultural awareness among the study personnel. Furthermore, minority research participants may feel more at ease discussing psychological problems with someone of the same ethnic background (Jackson et al., 2004; Malgady & Costantino, 1998; Williams & Turkheimer, 2008).

Participant compensation: Offering no-cost treatment to an existing patient pool is often an adequate incentive for someone already considering specialized OCD treatment, but may not be effective for groups that are not seeking specialized treatment. Adequate compensation communicates to the participant that study personnel appreciate their time and effort, and also generates additional interest in a program that might not have been considered otherwise (Clay et al., 2003; Hatchett et al., 2000). Compensation helps to offset practical barriers, such as wages lost from missing work, the cost of extra child care, and the cost of transportation (Gallagher-Thompson et al., 2003).

4.5. Future directions

Randomized treatment outcome studies with adequate numbers of minorities are desperately needed to determine how effective evidence-based treatments are among these groups. Implementing the recruitment strategies described herein should help to increase the participation of ethnic minorities in North American OCD trials. However, research examining the effectiveness of different strategies on recruitment and retention of minorities into OCD trials is essential in order to overcome the barriers of including these groups in future studies.

It is also worth noting that there are many published OCD studies that are not randomized, and these have not been included in this review. Additional examination of the problem with a wider range of studies and for other anxiety disorders is needed to ensure that all groups are equal partners on in the scientific process of treatment outcome research.

Most randomized trials of OCD patients have been conducted in North America and Europe (Williams, Powers, & Foa, in press), with scattered reports from a handful of other areas, most notably Japan (Nakatani et al., 2005), India (Mehta, 1990), and Brazil (Cordioli et al., 2003). When treatments are conducted with non-Western patients, cultural adaptations may be necessary. For example, Mehta (1990) found that outcomes for East Indian patients were improved when CBT was administered according to a family-based model, taking into consideration the centrality of the patients' family in this particular cultural group. More work in this area would be a valuable contribution to the understanding of OCD treatment in the US and globally.

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References

Avery, D. R., Hernandez, M., & Hebl, M. R. (2004). Who's watching the race? Racial salience in recruitment advertising. *Journal of Applied Social Psychology, 34*, 146–161.

Beasley, C. M., Jr., Potvin, J. H., Masica, D. N., Wheadon, D. E., Dornseif, B. E., & Genduso, L. A. (1992). Fluoxetine: no association with suicidality in obsessive–compulsive disorder. *Journal of Affective Disorders, 24*, 1–10.

Benkelfat, C., Murphy, D. L., Zohar, J., Hill, J. L., Grover, G., & Insel, T. R. (1989). Clomipramine in obsessive–compulsive disorder. *Archives of General Psychiatry, 46*, 23–28.

Bergeron, R., Ravindran, A. V., Chaput, Y., Goldner, E., Swinson, R., Van Ameringen, M. A., et al. (2002). Sertraline and fluoxetine treatment of obsessive–compulsive disorder: results of a double-blind, six month treatment study. *Journal of Clinical Psychopharmacology, 22*, 148–154.

Chambless, D. L., & Williams, K. E. (1995). A preliminary study of African-Americans with agoraphobia: symptom severity and outcome of treatment with in vivo exposure. *Behavior Therapy, 26*(3), 501–515.

Clay, C., Ellis, M. A., Amodeo, M., Fassler, J., & Griffin, M. L. (2003). Recruiting a community sample of African-American subjects: the nuts and bolts of a successful effort. *Families in Society, 84*, 396–404.

Cordioli, A. V., Heldt, E., Bochi, D. B., Margis, R., De Sousa, M. B., Tonello, J. F., et al. (2003). Cognitive-behavioral group therapy in obsessive–compulsive disorder: a randomized controlled trial. *Psychotherapy and Psychosomatics, 72*, 211–216.

Fallon, B. A., Liebowitz, M. R., Campeas, R., Schneier, F. R., Marshall, R., Davies, S., et al. (1998). Intravenous clomipramine for obsessive–compulsive disorder refractory to oral clomipramine. *Archives of General Psychiatry, 55*, 918–924.

Fals-Stewart, W., Marks, A., & Schafer, J. (1993). A comparison of behavioral group therapy and individual behavior therapy in treating obsessive–compulsive disorder. *Journal of Nervous and Mental Disease, 181*, 189–193.

Foa, E. B., Kozak, M. J., Steketee, G. S., & McCarthy, P. R. (1992). Treatment of depressive and obsessive–compulsive symptoms in OCD by imipramine and behaviour therapy. *British Journal of Clinical Psychology, 31*, 279–292.

Foa, E. B., & Kozak, M. J. (1995). DSM-IV field trial: obsessive–compulsive disorder. *American Journal of Psychiatry, 152*, 90–96.

Foa, E. B., Liebowitz, M. R., Kozak, M. J., Davies, S., Campeas, R., Franklin, M. E., et al. (2005). Randomized, placebo-controlled trial of exposure and ritual prevention, clomipramine, and their combination in the treatment of obsessive–compulsive disorder. *American Journal of Psychiatry, 162*, 151–161.

Fisher, C. B., Hoagwood, K., Boyce, C., Duster, T., Frank, D. A., Grisso, T., et al. (2002). Research ethics for mental health science involving ethnic minority children and youth. *American Psychologist, 57*, 1024–1039.

Freeman, J. B., Garcia, A. M., Coyne, L., Ale, C., Przeworski, A., Himle, M., et al. (2008). Early childhood OCD: preliminary findings from a family-based cognitive-behavioral approach. *Journal of the American Academy of Child, 47*, 593–602.

Freeston, M. H., Ladouceur, R., Gagnon, F., Thibodeau, N., Rheaume, J., Letarte, H., et al. (1997). Cognitive-behavioral treatment of obsessive thoughts: a controlled study. *Journal of Consulting and Clinical Psychology, 65*, 405–413.

Freimuth, V. S., Quinn, S. C., Thomas, S. B., Cole, G., Zook, E., & Duncan, T. (2001). African Americans' views on research and the Tuskegee syphilis study. *Social Science and Medicine, 52*, 797–808.

Friedman, S., Smith, L. C., Halpern, B., Levine, C., Paradis, C., Viswanathan, R., et al. (2003). Obsessive–compulsive disorder in a multi-ethnic urban outpatient clinic: initial presentation and treatment outcome with exposure and ritual prevention. *Behavior Therapy, 34*, 397–410.

Gallagher-Thompson, D., Solano, N., Coon, D., & Arean, P. (2003). Changes in indices of distress among Latino and Anglo female caregivers of elderly relatives with dementia: site-specific results from the REACH national collaborative study. *Gerontologist, 43*, 45–51.

Gamble, V. N. (1993). A legacy of distrust: African-Americans and medical research. *American Journal of Preventive Medicine, 9*, 35–38.

Geller, D. A., Hoog, S. L., Heiligenstein, J. H., Ricardi, R. K., Tamura, R., Kluzynski, S., et al. (2001). Fluoxetine treatment for obsessive–compulsive disorder in children and adolescents: a placebo-controlled clinical trial. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*, 773–779.

Geller, D. A., Wagner, K. D., Emslie, G., Murphy, T., Carpenter, D. J., Wetherhold, E., et al. (2004). Paroxetine treatment in children and adolescent with obsessive–compulsive disorder: a randomized, multicenter, double-blind, placebo-controlled trial. *Journal of the American Academy of Children and Adolescent Psychiatry, 43*, 1387–1396.

Goodman, W. K., Kozak, M. J., Liebowitz, M., & White, K. L. (1996). Treatment of obsessive–compulsive disorder with fluvoxamine: multicenter, double-blind, placebo-controlled trial. *International Clinical Psychopharmacology, 11*, 21–29.

Goodman, W. K., Price, L. H., Rasmussen, S. A., Delgado, P. L., Heninger, G. R., & Charney, D. S. (1989). Efficacy of fluvoxamine in obsessive–compulsive disorder. *Archives of General Psychiatry, 46*, 36–44.

Greist, J., Chouinard, G., Duboff, E., Halaris, A., Kim, S. W., Koran, L., et al. (1995). Double-blind parallel comparsion of three dosages of sertraline and placebo in outpatients with obsessive–compulsive disorder. *Archives of General Psychiatry, 52*, 289–295.

Greist, J., Jefferson, J. W., Kobak, K. A., Chouinard, G., DuBoff, E., Halans, A., et al. (1995). A one year double-blind placebo-controlled fixed dose study of sertraline in the treatment of obsessive–compulsive disorder. *International Clinical Psychopharmacology, 10*, 57–65.

Greist, J., Marks, I. M., Baer, L., Kobak, K. A., Wenzel, K. W., Hirsch, M. J., et al. (2002). Behavior therapy for obsessive–compulsive disorder guided by a computer or by a clinician compared with relaxation as a control. *Journal of Clinical Psychiatry, 63*(2), 138–145.

Guarnaccia, P. J. (1997). A cross-cultural perspective on anxiety disorders. In: S. Friedman (Ed.), *Cultural issues in the treatment of anxiety* (pp. 3–20). New York: The Guilford Press.

Hatch, M. L., Friedman, S., & Paradis, C. M. (1996). Behavioral treatment of obsessive–compulsive disorder in African-Americans. *Cognitive and Behavioral Practice, 3*, 303–315.

Hatchett, B. F., Holmes, K., Duran, D. A., & Davis, C. (2000). African-Americans and research participation: the recruitment process. *Journal of Black Studies, 30*, 664–675.

Hatchett, B. F., Holmes, K., & Ryan, E. I. (2002). Attitudes of a predominantly hispanic college sample towards older adults. *Journal of Gerontological Social Work, 37*, 45–59.

Himle, J. A., Muroff, J. R., Taylor, R. J., Baser, R. E., Abelson, J. M., Hanna, G. L., et al. (2008). Obsessive–compulsive disorder among African-Americans and blacks of Caribbean descent: results from the national survey of American life. *Depression and Anxiety, 25*(12), 993–1005.

Hiss, H., Foa, E. B., & Kozak, M. J. (1994). Relapse prevention program for treatment of obsessive–compulsive disorder. *Journal of Consulting & Clinical Psychology, 62*, 801–808.

Hoehn-Saric, R., Ninan, P., Black, D. W., Stahl, S., Greist, J., Lydinard, B., et al. (2000). Multicenter double-blind comparison of sertraline and desipramine for concurrent obsessive–compulsive and major depressive disorders. *Archives of General Psychiatry, 57*, 76–82.

Hollander, E., & Cohen, L. J. (1994). Obsessive–compulsive disorder. In: S. Friedman (Ed.), *Anxiety disorders in African-Americans* (pp. 185–202). New York: Springer Publishing Co.

Hollander, E., Kaplan, A., & Stahl, M. S. (2003). A double-blind, placebo controlled trial of clonazepam in obsessive–compulsive disorder. *World Journal of Biological Psychiatry, 4*, 30–34.

Jackson, J. S., Torres, M., Caldwell, C. H., Neighbors, H. W., Nesse, R. M., Taylor, R. J., et al. (2004). The national survey of American life: a study of racial, ethnic, and cultural influences on mental disorders and mental health. *International Journal of Methods in Psychiatric Research, 13*, 196–207.

Jenike, M. A., Baer, L., Minichiello, W. E., Rauch, S. L., & Buttolph, L. (1997). Placebo-controlled trial of fluoxetine and phenelzine for obsessive–compulsive disorder. *American Journal of Psychiatry, 154*, 1261–1264.

Jenike, M. A., Baer, L., Summergrad, P., Minichiello, W. E., Holland, A., & Seymour, R. (1990). Sertraline in obsessive–compulsive disorder: a double-blind comparison with placebo. *American Journal of Psychiatry, 147*, 923–928.

Jenike, M. A., Hyman, S., Baer, L., Holland, A., Minichiello, W. E., Buttolph, L., et al. (1990). A controlled trial of fluvoxamine in obsessive–compulsive disorder: implications for a serotonergic theory. *American Journal of Psychiatry, 147*, 1209–1215.

Karadag, F., Oguzhanoglu, N. K., Ozdel, O., Atesci, F. C., & Amuk, T. (2006). OCD symptoms in a sample of Turkish patients: a phenomenological picture. *Depress Anxiety, 23*, 145–152.

Katz, R. J., DeVeaugh-Geiss, J., & Landau, P. (1990). Clomipramine in obsessive–compulsive disorder. *Biological Psychiatry, 28*, 401–414.

Katz, R. V., Kegeles, S. S., Kressin, N. R., Green, B. L., Min, Q. W., James, S. A., et al. (2006). The tuskegee legacy project: willingness of minorities to participate in biomedical research. *Journal of Health Care for the Poor and Underserved, 17*, 698–715.

Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the national comorbidity survey replication. *Archives of General Psychiatry, 62*(6), 593–602.

Kessler, R. C., Chiu, W. T., Demler, O., Merikangas, K. R., & Walters, E. E. (2005). Prevalence, severity, and comorbidity of 12-month DSM-IV disorders in the national comorbidity survey replication. *Archives of General Psychiatry, 62*(6), 617–627.

Kobak, K. A., Greist, J. H., Jefferson, J. W., Katzelnick, D. J., & Henk, H. J. (1998). Behavioral versus pharmacological treatments of obsessive–compulsive disorder: a meta-analysis. *Psychopharmacology, 136*(3), 205.

Koran, L. M., Hackett, E., Rubin, A., Wolkow, R., & Robinson, D. (2002). Efficacy of sertraline in the long-term treatment of obsessive–compulsive disorder. *American Journal of Psychiatry, 159*, 88–95.

Koran, L. M., Mcelroy, S. L., Davidson, J. R. T., Hollander, E., & Jenike, M. A. (1996). Fluvoxamine versus clomipramine for obsessive–compulsive disorder: a double-blind comparison. *Journal of Clinical Psychopharmacology, 16*, 121–129.

Koran, L. M., Sallee, F. R., & Pallanti, S. (1997). Rapid benefit of intravenous pulse loading of clomipramine in obsessive–compulsive disorder. *American Journal of Psychiatry, 154*, 396–401.

Kronig, M. H., Apter, J., Asnis, G., Bystritsky, A., Curtis, G., Gerguson, J., et al. (1999). Placebo-controlled, multicenter, study of sertraline treatment for obsessive–compulsive disorder. *Journal of Clinical Psychopharmacology, 19*, 172–176.

Kushner, M. G., Kim, S. W., Donahue, C., Thuras, P., Adson, D., Kotlyar, M., et al. (2007). D-Cycloserine augmented exposure therapy for obsessive–compulsive disorder. *Biological Psychiatry, 62*, 835–838.

Leonard, H. L., Swedo, S. E., Lenane, M. C., Rettew, D. C., Cheslow, D. L., Hamburger, S. D., et al. (1991). A double-blind desipramine substitution during long-term clomipramine treatment in children and adolescents with obsessive–compulsive disorder. *Archives of General Psychiatry, 48*, 922–927.

Liebowitz, M. R., Turner, S. M., Piacentini, J., Beidel, D. C., Clarvit, S. R., Davies, S. O., et al. (2002). Fluoxetine in children and adolescents with OCD: a placebo-controlled trial. *Journal of the American Academy of Children and Adolescent Psychiatry, 41*, 1431–1438.

McLean, P., Whittal, M., Thordarson, D., Taylor, S., Soechting, I., Koch, W., et al. (2001). Cognitive versus behavior therapy in the group treatment of obsessive–compulsive disorder. *Journal of Consulting and Clinical Psychology, 69*, 205–214.

Malgady, R. G., & Costantino, G. (1998). Symptom severity in bilingual Hispanics as a function of clinician ethnicity and language of interview. *Psychological Assessment, 10*, 120–127.

Mallya, G. K., White, K., Waternaux, C., & Quay, S. (1992). Short - and long-term treatment of obsessive–compulsive disorder with fluvoxamine. *Annals of Clinical Psychiatry, 4*, 77–80.

March, J. S., Biederman, J., Wolkow, R., Saffermanm, A., Mardekian, J., Cook, E. H., et al. (1998). Sertraline in children and adolescents with obsessive–compulsive disorder. *JAMA, 280*, 1752–1756.

Mehta, M. (1990). A comparative study of family-based and patient-based behavioral management in obsessive–compulsive disorder. *British Journal of Psychiatry, 157*, 133–135.

Meinert, J. A., Blehar, M. C., Peindi, K. S., Neal-Barnett, A., & Wisner, K. L. (2003). Bridging the gap: recruitment of African-American women into mental health research studies. *Academic Psychiatry, 27*, 21–28.

Nakatani, E., Nakagawam, A., Nakao, T., Yoshizato, C., Nabeyama, M., Kudo, A., et al. (2005). A randomized controlled trial of Japanese patients with obsessive–compulsive disorder—effectiveness of behavior therapy and fluvoxamine. *Psychotherapy and Psychosomatics, 74*, 269–276.

Romano, S., Goodman, W., Tamura, R., & Conzales, J. (2001). Long-term treatment of obsessive–compulsive disorder after an acute response: a comparison of fluoxetine versus placebo. *Journal of Clinical Psychopharmacology, 21*, 46–52.

Rosa-Alcázar, A. I., Sánchez-Meca, J., Gómez-Conesa, A., & Marín-Martínez, F. (2008). Psychological treatment of obsessive–compulsive disorder: a meta-analysis. *Clinical Psychology Review, 28*(8), 1310–1325.

Roy-Byrne, P. P., Perera, P., Pitts, C. D., & Christi, J. A. (2005). Paroxetine response and tolerability among ethnic minority patients with mood or anxiety disorders: a pooled analysis. *Journal of Clinical Psychiatry, 66*(10), 1228–1233.

Roy-Byrne, P. P., Russo, J., Cowley, D. S., & Katon, W. J. (2003). Unemployment and emergency room visits predict poor treatment outcome in primary care panic disorder. *Journal of Clinical Psychiatry, 64*(4), 383–389.

Ruscio, A. M., Stein, D. J., Chiu, W. T., & Kessler, R. C. (2008). The epidemiology of obsessive–compulsive disorder in the national comorbidity survey replication. *Molecular Psychiatry [advance online publication].*

Shannahoff-Khalsa, D. S., Ray, L. E., Levine, S., Gallen, C. C., Schwartz, B. J., & Sidorowich, J. J. (1999). Randomized controlled trial of yogic meditation techniques for patients with obsessive–compulsive disorder. *CNS Spectrums, 4*, 34–47.

Simpson, H. B., Foa, E. B., Liebowitz, M. R., Ledley, D. R., Huppert, J. D., Cahill, S., et al. (2008). A randomized, controlled trial of cognitive-behavioral therapy for augmenting pharmacotherapy in obsessive–compulsive disorder. *American Journal of Psychiatry, 165*, 621–630.

Stein, D. J., Hollander, E., Mullen, L. S., DeCaria, C. M., & Liebowitz, M. R. (1992). Comparison of clomipramine, alprazolam and placebo in the treatment of obsessive–compulsive disorder. *Human Psychopharmacology, 7*, 389–395.

Storch, E. A., Merlo, L. J., Bengtson, M., Murphy, T. K., Lewis, M. H., Yang, M. C., et al. (2007). D-Cycloserine does not enhance exposure-response prevention therapy in obsessive–compulsive disorder. *International Clinical Psychopharmacology, 22*, 230–237.

Suite, D. H., La Bril, R., Primm, A., & Harrison-Ross, P. (2007). Beyond misdiagnosis, misunderstanding and mistrust: relevance of the historical perspective in the medical and mental health treatment of people of color. *Journal of the National Medical Association, 99*(8), 879–885.

Sweeney, M., Robins, M., Ruberu, M., & Jones, J. (2005). African-American and Latino families in TADS: recruitment and treatment considerations. *Cognitive and Behavior Practice, 12*, 221–229.

The Pediatric OCD Treatment Study (POTS). (2004). Cognitive-behavior therapy, sertraline, and their comnination for children and adolescents with obsessive–compulsive disorder. *American Medical Association, 292*, 1969–1976.

U.S. Department of Health and Human Services. (1999). The fundamentals of mental health and mental illness, chapter 2. *Mental health: a report of the surgeon general.* Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.

U.S. Department of Health and Human Services, Public Health Service. (2002). *National Institutes of Health: outreach notebook for the NIH guidelines on inclusion of women and minorities as subjects in clinical research*. Bethesda, MD, National Institutes of Health (NIH Pub. No. 03-7036).

U.S. Department of Health and Human Services. (2008). National Institutes of Health: monitoring adherence to the NIH policy on the inclusion of women and minorities as subjects in clinical research. *Comprehensive report: tracking of human subjects research as reported in fiscal year 2006 and fiscal year 2007*.

Whittal, M. L., Thordarson, D. S., & McLean, P. D. (2005). Treatment of obsesive–compulsive disorder: cognitive-behavior therapy vs. exposure and response prevention. *Behaviour Research and Therapy, 43*, 1559–1576.

Wilhelm, S., Buhlmann, U., Tolin, D. F., Meunier, S. A., Pearlson, G. D., Reese, H. E., et al. (2008). Augmentation of behavior therapy with D-cycloserine for obsessive–compulsive disorder. *American Journal of Psychiatry, 165*, 335–341.

Williams, K. E., Chambless, D. L., & Steketee, G. (1998). Behavioral treatment of obsessive–compulsive disorder in African-Americans: clinical issues. *Journal of Behavior Therapy and Experimental Psychiatry, 29*, 163–170.

Williams, M., & Turkheimer, E. (2008). The effects of interviewer race on anxiety in African-Americans. In: L. V. Sebeki (Ed.), *Leading-edge health education issues*. Nova Publishers.

Williams, M., Powers, M. B., Foa, E. B. (in press). Psychological treatment for obsessive–compulsive disorder, chapter 16. In P Sturmey, & M Hersen (Eds.). *Handbook of evidence-based practice in clinical psychology: Vol. 2*.

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