



Published in final edited form as:

J Natl Med Assoc. 2013 ; 105(1): 33–41.

Cultural Barriers to African American Participation in Anxiety Disorders Research

Dr Monnica T. Williams, PhD,

Department of Psychological and Brain Sciences, University of Louisville, Kentucky

Dr Diana A. Beckmann-Mendez, PhD, RN, and

School of Nursing, University of Texas Health Science Center, San Antonio

Dr Eric Turkheimer, PhD

Department of Psychology, University of Virginia, Charlottesville

Abstract

Anxiety disorders are understudied, underdiagnosed, and undertreated in African Americans. Research focused on the phenomenology, etiology, and treatment of anxiety in African Americans has been hampered by lack of inclusion of this population in clinical research studies. The reason for exclusion is not well understood, although cultural mistrust has been hypothesized as a major barrier to research participation. This article reviews the relevant literature to date and examines the experience of 6 African American adults who participated in a larger clinical assessment study about anxiety. Drawing upon in-depth semistructured interviews about their subjective experiences, we examined participant perspectives about the assessment process, opinions about African American perception of anxiety studies, and participant-generated ideas about how to improve African American participation. Based on a qualitative analysis of responses, feelings of mistrust emerged as a dominant theme. Concerns fell under 6 categories, including not wanting to speak for others, confidentiality, self and group presentation concerns, repercussions of disclosure, potential covert purposes of the study, and the desire to confide only in close others. Suggestions for increasing African American participation are discussed, including assurances of confidentiality, adequate compensation, and a comfortable study environment.

Keywords

African Americans; recruitment; barriers; anxiety; race/ethnicity; health disparities

Introduction

Anxiety disorders cause distress and disability and include generalized anxiety disorder, specific phobia, obsessive-compulsive disorder (OCD), social phobia, panic disorder, and posttraumatic stress disorder (PTSD). Anxiety disorders are a serious problem, with a lifetime prevalence in the general population¹ of 28.8%, but there have been conflicting

reports in prevalence rates for US ethnic/racial minorities.² In examining racial and ethnic differences in the National Comorbidity Study Replication (NCS-R), Breslau et al³ report that African Americans experience significantly lower rates of most anxiety disorders (and the majority of other psychological disorders as well)—with disadvantaged individuals experiencing even lower rates of psychopathology than those of higher socioeconomic status. The authors make the unlikely speculation that disadvantaged minority status may be protective factor but also concede that other factors may be producing these counterintuitive results, including differential response bias, instrument bias, and ethnic differences in the experience of psychopathology.

Patients who do not meet symptom criteria for disorders as defined in the *Diagnostic and Statistical Manual of Mental Disorders* (Fourth Edition, Text Revision; *DSM-IV-TR*) may not be properly identified.⁴ For example the culture-bound anxiety disorder *ataque de nervios*, which is seen Caribbean and other Latino populations, appears in the *DSM-IV-TR* only as an appendix.⁴ Perhaps what is occurring in studies such as the NCS-R is that cultural variations of common disorders are not being identified, leading to the false impression that African Americans experience lower rates of psychopathology. In his review of anxiety in minority populations, Guarnaccia⁵ noted that more research is needed to identify the range of symptoms associated with anxiety disorders in different cultural groups. A comprehensive understanding of anxiety may be particularly important for African Americans, as the experience of anxiety may be confounded by cultural factors, including different cultural practices, memory of historical abuses, the stress of underrepresented minority status, and anxiety surrounding the awareness of racism.^{6,7}

Misperceptions about the likelihood of anxiety as a primary disorder in African Americans can lead to a failure to identify these disorders in African American patients. A large study (N = 32 752) found that African Americans were significantly less likely to receive treatment for anxiety disorders than European Americans even after controlling for predisposing factors and severity (odds ratio [OR], 1.77).⁸ In this same study, no evidence of lower service utilization emerged for alcohol or other substance use problems among black respondents, despite adequate statistical power to detect a difference. A similar pattern was found among dual-diagnosis patients and those with a comorbid Axis II disorder. The authors attribute the cause of these differences to several factors, including social programs and policies that may disproportionately affect African American neighborhoods.⁸ It is possible that stereotypes about the mental health needs of African Americans have influenced the type of services available in those communities.

To best serve all Americans, it is of vital importance that scientific inquiry into medical and psychological issues include all segments of our society. However, treatment studies of anxiety disorders frequently lack adequate minority participation. For example, one of the largest studies on the treatment of panic disorder (N = 312) had a total minority enrollment of only 9%, despite being conducted at several urban sites (eg, Pittsburgh, Pennsylvania; Boston, Massachusetts; Long Island, New York), presumably with access to a large minority population.⁹ No information was provided as to how many of the minority participants were African American. A large randomized trial to improve the treatment of panic and generalized anxiety disorders in a primary care setting recruited patients from 4 centers in

Pittsburgh (N = 191), but minority participation was scant¹⁰; the authors noted that “our findings may apply only to Caucasians who comprised 95% of the study patients.”

One of the largest cognitive behavior therapy treatment studies for OCD (N = 218) was conducted at multiple urban sites in North America and compared behavioral treatment from a therapist to computer therapy or relaxation;¹¹ this study had only 7% minority inclusion with no data as to how many of these were African American. A comprehensive review of OCD randomized clinical trials in North America found that across 40 studies (N = 2221), only 1.3% of participants were identifiable as African Americans.¹² Such small numbers of minorities make it difficult to draw meaningful conclusions about the efficacy of treatment for these groups. One large study of the effectiveness of the selective serotonin reuptake inhibitor paroxetine for anxiety disorders was able to examine ethnic differences only by pooling data from 104 studies for 4.6% African American inclusion; the authors of that study urged clinical researchers to advocate for increased “clinical trial involvement among minority populations.”¹³

There have been some anxiety studies that are noteworthy due to their relative success at minority recruitment. The Child/Adolescent Anxiety Multimodal Study, a study of 488 children with separation anxiety disorder, generalized anxiety disorder, or social phobia, was 9.0% African American.¹⁴ This study recruited from 6 different sites nationwide. Recruitment techniques were not described, although the authors noted having engaged in “intense outreach,” which, though successful, did not include the most socioeconomically disadvantaged children. Furthermore, African American participation was still lower than the national percentage of African Americans in the United States.

PTSD trials have been a notable exception in the inclusion of minority participants. One of the largest randomized treatment outcome studies (N = 284) involved female veterans recruited from 9 veterans administration centers, with African American participation¹⁵ at 33%. Foa et al¹⁶ also reported impressive minority participation in their study of female assault survivors (N = 171)—43.6%. Other studies have focused on minority differences in PTSD, including expression of symptoms, service utilization, and treatment outcome (eg¹⁷).

In July 1989, the National Institutes of Health (NIH) Memorandum on Inclusion encouraged research solicitations to include women and minorities and provide a rationale if they were excluded. To ensure 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 must be included and, by 1995, the NIH refused to fund any project that did not adhere to these policies.¹⁸

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 women or men or members of minority groups and their subpopulations differently.”¹⁸ Unless it is clear that no important public health questions can be resolved by the inclusion of minorities, the study design must include “sufficient and appropriate representation of minority groups to permit valid analyses of differential intervention effect.”¹⁸ 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. As of the last available NIH report, minorities constituted 26.5% of enrollment across all US domestic clinical studies. For domestic phase III trials, there were an average of 22.6% minority subjects enrolled in protocols from 2002 to 2007, and 9.6% were African American.¹⁹ The number of African Americans is less than representative of the US population, but high enough to illustrate that African Americans can and do participate in clinical research.

Mistrust of the larger medical system is often implicated as the major cause of low minority participation.²⁰ According to the US surgeon general, “research documents that many members of minority groups fear, or feel ill at ease with, the mental health system.”²¹ African Americans appear to have greater distrust of the medical and psychological health system, many believing that these institutions hold racist attitudes.^{22,23} Negative perceptions may be rooted in historical abuses of black slaves for purposes of medical experimentation; slaves could neither consent nor refuse to participate by virtue of their low social status.²⁴ Government-sanctioned abuses such as the US Public Health Service Syphilis Study at Tuskegee (Tuskegee study), serves as a grim reminder and warning to many African Americans about the dangers of research participation.²⁵ Correspondingly, it has been hypothesized that for these reasons African Americans are extremely suspicious of medical and psychological research.²²

African Americans who regularly encounter prejudice may develop what has been described as *healthy paranoia*, or cultural mistrust, a response style based on experiences of racism and oppression in US society.²⁶ There is research to support the idea that African Americans underutilize medical and psychological services out of fear of mistreatment, being hospitalized involuntarily, or being used as “guinea pigs.”^{26,27} The Tuskegee Legacy Project surveyed 1133 racially diverse adults in 4 US cities. The findings revealed no difference in self-reported willingness to participate in research between groups, yet black participants were significantly more likely than white participants to have a higher fear of participation (OR, 1.8) based on the Guinea Pig Fear Factor scale.²⁸ However, despite history of documented research abuses of African Americans, there are few studies that validate mistrust as a causal factor in their exclusion from many research trials. Furthermore, the reasons African Americans underutilize medical and psychological care may not be the same factors that prevent participation in research.

There are few reports in the literature to inform researchers and public health officials about effective outreach strategies for minorities into medical and psychological studies.²⁹ Nonetheless, several studies have successfully recruited African Americans, despite the obstacles described previously. For example, Meinert et al²⁹ reported a successful experience by organizing a conference for African American women focused on depression. The authors felt the key elements to success were their direct appeal to the African American community, encouragement of self-determination, respect of the participants' spiritual tradition, and strong collaboration with community groups.

The National Survey of American Life is a major epidemiological study focused on mental health issues and differences among black and white Americans.³⁰ Keys to successful recruitment of the large sample of African and Caribbean Americans (N = 3570 and N = 1623, respectively) included racial and cultural matching of interviewers and participants (this necessitated hiring and training 300 new African American indigenous interviewers), press releases and interviews in the local media, sending the best interviewers to the most difficult regions, and flexibility to utilize phone interviews when necessary. Clay et al³¹ recruited 150 African American women for a study of childhood factors related to psychosocial adjustment. They cited targeted advertising with midcourse corrections, networking with members of the African American community, and regular tracking of callers as essential ingredients to success. Thus, it has been demonstrated that recruitment of African Americans is possible for the determined researcher.

Among those who have successfully recruited African Americans, very few have systematically examined motivations for minority participation. Hatchett et al³² describe their experience in the recruitment of African Americans in Detroit, Michigan, for a behavioral study of thoughts and feelings over the lifespan. Early in the study it was found that race-targeted telephone solicitation was not an effective strategy. Successful recruitment strategies included forging relationships with trusted members of the African American community, personal contact with church leaders, presentations to African American organizations, and advertisements in African American venues. Most participants (70%) ultimately cited word of mouth as their source of information about the study. In a rare follow-up study, the authors assessed motivation for participation with a poststudy survey. Reported reasons included participant payments (45%), interest in the research (35%), opportunity to contribute (21%), informational/educational (14%), and other (7%). The authors concluded that lack of African American participation was not due to the Tuskegee study as previously thought, but rather a lack of knowledge about the study and its goals.³²

Stigma and stereotyping were previously explored in a series of quantitative studies as potentially confounding factors in the assessment of anxiety in African Americans.^{6,33} African Americans reported significantly more contamination anxiety than European Americans that was later explained by nonpathological cultural attitudes about cleanliness and animals.^{6,34} Interestingly, African Americans also reported significantly more negative affect in the testing situation than white participants, regardless of the race of the interviewer.³⁵ This indicates that there may have been some aversive aspect of the research experience unique to African Americans.

The current study further examines these issues by drawing upon in-depth interviews about the subjective experiences of 6 African Americans who participated in a larger study of anxiety disorders. Examined are participant experiences with the assessment process, opinions about why African Americans might be reluctant to participate in such studies, and participant-generated ideas about how to improve African American representation. It was hypothesized that African Americans would report mistrust of the medical and psychological health care system, including concerns that the study results might reflect negatively upon African Americans.

Methods

Procedures

More than 600 students and community members living in Virginia completed a study of ethnic differences in the expression of anxiety. The study was approved in advance by the university's institutional review board. Participants were recruited through direct mail, telephone solicitation, flyers, word of mouth, and the local university subject pool. Several measures were implemented to maximize the participation of African Americans. Targeted mailings advertising the study were sent out to neighborhoods that were demographically at least 50% African American. These were followed by phone calls from a diverse staff of research assistants. Posted around the community were color flyers about the study featuring a photo of an attractive African American person. Announcements about the study were made at black churches and community organizations. To address potential concerns about confidentiality, subjects were not required to provide names or identifying information to participate. Students received course credit for participation and community subjects were paid \$25. Personal information required by the university for financial compensation was collected separately to preserve anonymity.

Additional measures were put in place to alleviate potential discomfort of African American participants once the study had begun. Approximately half of the research assistants who administered assessments were African American. Further details about this study and the battery of measures administered are reported elsewhere.³⁵ Participants were reminded that their participation was completely voluntary, that they could skip any questions they preferred not to answer, and that they would be fully compensated whether or not they continued to participate. From this larger sample, 6 subjects were offered the opportunity to participate in semistructured interviews to gain a better understanding of participant experiences with the interview process and their opinions on how African Americans might respond to mental health issues. Participants agreeing to the interview were paid an additional \$35 for their participation. All who were approached agreed to participate. Interviews took place within 24 hours of debriefing from the initial study and occurred in a private, comfortable interviewing room.

Participants

Participants were 6 African American adults living in Virginia. Excluded were those reporting current or recent symptoms of OCD, participants whose racial identification did not fit into the black/African American category, and those who reported having lived in the United States for fewer than 5 years. The demographics of this group are described in the Table.

Measures

Prior to the interview, participants were given a battery of questionnaires designed to assess symptoms of anxiety and mood disorders, which included several measures administered by a study evaluator. Following this procedure, a semistructured interview was specifically designed to elicit information related to race, anxiety, help seeking, and participation in research studies. Participants were first orally debriefed about the procedure and also given a

separate written consent form. This was followed by several demographic questions about the participant's family, employment situation, and residence. Subjects were then asked about their experiences with illness, attitudes about mental health care issues, and experience with the research process. Questions about the experience with the research process are detailed in the Box.

Questions specific to race as a potential factor were asked last to prevent biasing answers to preceding questions. Five of the 6 participants were interviewed by an African American researcher, and one was interviewed by a Hispanic American researcher. This was done intentionally to help reduce any potential discomfort participants might have felt about answering sensitive questions about race in the presence of a majority interviewer.

Qualitative Analysis

Videotaped interviews, lasting approximately 1 hour and using a semistructured format, were conducted to elicit a full description of participants' experiences with and perceived barriers to participating in psychological research studies. The interviews questions were designed to allow participants to share their views, attitudes, and opinions in a casual, nonthreatening manner and environment. The videotaped interviews were transcribed verbatim, reviewed for accuracy, and summarized by a member of the research team. Another member of the research team coded the transcripts by grouping similar data together. Process and analytic memos were maintained to document the research process and outline the decision making that led to the data being assigned to particular categories.³⁶ After all transcripts were coded, the research team as a whole reviewed the findings, and consensus was reached for final themes. Qualitative data analysis was conducted to identify major themes and patterns to enhance the findings from the quantitative segment of the overall study.³⁷ Quotes that represented each domain were extracted and examined for their contribution to theme development.

Results

In detailing the sociocultural factors related to attitudes about study participation, feelings of mistrust emerged as a dominant theme. Concerns fell under several categories, including: (1) not wanting to speak for others, (2) self and group presentation concerns, (3) potential covert purposes of the study, (4) confidentiality, (5) repercussions of disclosure, and (6) the desire to confide only in close others. Additionally, thoughts and suggestions for increasing African American participation were identified, including: (1) increased confidentiality, (2) remuneration and incentives, and (3) a comfortable environment.

Can't Speak for Others

Participants were asked if they believed that people from their ethnic/racial group might be uncomfortable participating in a study such as the one described here. The question had been asked in this way to account for the possibility that participants might be uncomfortable disclosing their own personal beliefs to an unknown researcher and therefore it might be easier to describe the attitudes of anonymous others in their social networks. Participants

were also asked for their ideas about why they thought black and white people might answer certain questions differently.

Paradoxically, presenting questions in this way made participants more guarded. Rather than offer suggestions or guesses, several said they could not speak for others. For example, participant 1 noted, “there's such a broad spectrum [within] every ethnicity. I feel like there's such a broad range of people that it'd be hard to decide how they would answer.” In terms of why black and white people might answer questions differently, participant 2 said, “I can't answer that question because I don't know the African American answer. I only know for myself...I don't know the white person answer.”

Self and Group Presentation Concerns

Participants also expressed concerns surrounding how other African Americans would potentially view study participation. For example, participant 2 said others may believe they “have to fill this out a certain way so it doesn't seem like it's a big difference or whatever—I think that would probably happen.” This response indicates a concern over what others might think of a participant's ethnic group as a whole, based on the responses of a single participant, and the need to censor responses accordingly.

Covert Purpose of Study

Participants subtly questioned the motivations of the experimenter by pointing out that many of the questions seemed repetitive (participant 3: “They're saying the same thing in a slightly different tone”) and suggesting that perhaps this was done “to see if you were paying attention,” as noted by participant 2. Participant 4 remarked that one of the measures “asks some secret question about race,” an indication of concerns about a covert purpose of the study not revealed to participants.

Confidentiality

Confidentiality and privacy concerns also emerged as important themes. For example, participant 6 said,

If it is supposed to be confidential...how can they be sure?... They are probably afraid that it is something that might entrap them, or be used against them, or they are suspicious; no trust...That's because they don't know who is running it. Suspicious like wondering why they are calling them or why they are here and what is it going to be about.

Participant 4 said, “A lot of people don't like answering anything that can identify them.”

Concern About Repercussions

Many concerns reflected worries about the repercussions of participation. Participant 4 indicated fears about being involuntarily hospitalized when, referring to the assessment measures, he said, “Wow, I thought if somebody answers all the time with this, they're gonna come pick them up [laughs]. The cops are gonna be at the door waiting for you when you get home.” Participant 6 said, “Not everybody is your friend so when you tell people things you can create more problems.”

Desire to Confide Only in Close Others

Several indicated that it was only safe to confide in others who were close friends or family. Embedded in their statements are additional concerns about the repercussions of disclosing mental health concerns. Participant 2 said, “I can't talk to people that I don't know because I don't know what they are going to do to me.” Participant 6 said, “People like to talk and gossip; most of the time they are far from the truth. But I might tell a best friend.”

Ideas to Increase Study Participation

Participants were asked for ideas to help increase study participation among African Americans. One important issue, connected to the theme of mistrust described previously, included assurances of anonymity and confidentiality. Participant 2 noted that people “throw that term around these days, ‘everything's confidential,’ you know, but...people rarely believe that it is, you know. They just have to feel safe in order to do it.” Participant 4 suggested that “maybe if they didn't have to put their name anywhere...the fewer people they see the better.” Participant 5 felt participation would be improved among African Americans “if they felt they were put at ease and that, you know, this wasn't going to be something where their name would be publicized.”

Compensation and incentives were also listed as a means to improve participation. Participant 2 felt that financial remuneration was important, stating, “once they see that dollar sign, they go ahead and do it.” A comfortable environment was also cited as a critical factor. Participant 3 said, “Maybe hold it somewhere that's safe, in their neighborhood and lure them in—we have free food or something and then you'll get some money too, something like that...They don't want to feel like guinea pigs; they feel safe in their environment.”

Discussion

Although African Americans report the same willingness to participate in medical and psychological research as other groups,²⁸ it cannot be assumed that such statements reflect actual behaviors given the low rates of participation in many studies (ie^{12,45}). Our findings indicate that cultural mistrust may be an actual barrier to African American participation in psychological research studies. Participants were concerned about privacy due to potential negative repercussions, both small (ie, gossip) and large (ie, involuntarily hospitalization). This related to statements made by participants that it was best to confide only in close friends or family. This is consistent with findings from a focus group study by Thompson et al³⁸ about African American attitudes about psychotherapy; in that study, Africans Americans were found to have “strong prohibitions on sharing information with those outside of a circle of family and trusted friends.” Mistrust sometimes manifested as an unwillingness to speak for others. The reason for this is not completely clear, but participants clearly found this line of questioning uncomfortable.

Our findings are consistent with reports that African Americans are concerned that participation in medical and psychological research may result in being harmed or otherwise

exploited as guinea pigs.³⁹ For psychological research, the concerns may be amplified by worries about being involuntarily hospitalized.

There are several possible explanations for the degree of mistrust expressed by participants. Although not all African Americans are aware of the Tuskegee study, there is a collective memory of past and recent research abuses that continues to influence attitudes and behaviors.²⁰ Research abuses that disproportionately affect people of color were not isolated to the Tuskegee study and continue to into recent times (ie, John's Hopkins Lead Paint Study⁴⁰). Given this unfortunate reality, it is not surprising that concerns emerged about possible secret motives of the researcher.

Participants expressed general worries that are likely based in ongoing experiences of prejudice and discrimination, which broadly affect perceptions and expectations (ie, healthy cultural paranoia²³). African Americans may experience fears of validating negative stereotypes about their group and be reluctant to disclose information that might make themselves or their group compare unfavorably to others (ie, stereotype compensation^{7,33}). Participants expressed worries about potential direct harm—for example, loss of freedom through involuntarily hospitalization. However, this concern is not unrealistic, as African Americans are more likely to be involuntarily hospitalized.^{20,26,41}

Interestingly, we found that participants were mistrustful even when being interviewed by another African American. This is consistent with findings that African Americans have a more negative experience during the interview process, with both a black and white interviewer.³⁵ This is also consistent with the clinical observation that some African Americans may not be willing to discuss symptoms until they feel comfortable with their therapist, even when the interviewer is from the same ethnic/racial background.^{26,38,42} Although the reasons African Americans underutilize medical and psychological services may not be the same factors that prevent participation in research, concerns related to these issues are activated during study participation and may introduce additional anxiety and guardedness.

Dovetailing the theme of mistrust, confidentiality was described as an important factor in facilitating participation. Many studies require the collection of names and birth dates for routine purposes, but allowing participants to participate anonymously—without providing a name or other identifying information—may enhance recruitment and make participants feel more at ease. Additionally, participants may feel deceived when told that their participation is private, but in order to generate a check, their name, address, and social security number are requested. One method we used in this study was to provide gift credit cards so that it was not necessary to produce or mail a check; however, we were still required to collect names and social security numbers. Institutions with greater flexibility should compensate participants anonymously and with cash, when possible.

Participants indicated that meaningful financial compensation was an important factor in eliciting participation. 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.^{31,32} Compensation helps to offset practical

barriers, such as wages lost from missing work, the cost of child care, and the cost of transportation.⁴³

A comfortable study environment was cited as an important factor by participants. Participants can be put at ease if the study is conducted in private, peaceful environment that is clean and well-maintained. Consider making participants feel welcome by including African Americans magazines and artwork in the waiting room. If the study can be conducted in the participant's community, this is preferable, because participants may feel nervous or out of place venturing into a university research laboratory if this is not a part of their regular experience. Williams et al⁴⁴ reported difficulty in recruiting African Americans for an OCD outcome trial conducted in Washington, DC, an area with a large African American population. The authors believed that black participants felt uncomfortable venturing into an affluent, white section of the city. Additionally, having the study in an African American community—and thereby collaborating with community members—demonstrates that study organizers have an actual connection with the that community, which will help engender trust and improve recruitment through increased awareness.^{29,32}

One strength of this study is that participants shared their thoughts after actually participating in an anxiety research study, rather than discussing their beliefs about a hypothetical study (ie²⁸). Another strength is the comprehensive interview, designed specifically to address assessment experience and recruitment issues. Finally, the interviewer for this study was an African American in the majority of cases, which may have helped participants feel somewhat more comfortable answering sensitive questions about race.

Limitations of this study include that this sample was from central Virginia and may not generalize to all African Americans. There were no affluent African Americans in the sample, and higher-income individuals may not be motivated by incentives such as financial compensation. A potentially biasing factor during the interview is that participants knew the study was investigating race and stereotypes in report of anxiety disorder symptoms; the interview contained direct questions about sensitive racial and mental health issues, which may have been difficult to answer. Finally, this sample included only those who felt comfortable enough to participate and so we do not know what the opinions are of those who were too fearful to participate.

Conclusion

Based on the findings of his study, the following recommendations are suggested for future researchers:

- Emphasize privacy and confidentiality.
- Allow subjects to participate anonymously, if possible.
- Make the purpose of the study very clear in recruitment materials, during initial contacts, and during informed consent.
- Provide meaningful, timely financial compensation.

- Provide a comfortable study environment—within the community when possible.

These suggestions are a starting point as it has yet to be determined if such steps will actually increase African American participation.

Despite our best efforts at making study participants comfortable, a significant degree of mistrust remained. More research is needed to determine what additional strategies can be employed to elicit trust of participants and improve African American recruitment. Factors such as acculturation, age, education, past experiences of racism, and attitudes about mental health care probably all interact in a complex manner. More work is needed to quantify the factors that cause mistrust and their relative contribution to anxiety in the research setting and assessment process.

Acknowledgments

The author would like to acknowledge Wende Marshall, PhD, for assistance with the design of the semistructured interview for participants.

Funding/Support: This study was supported by the National Institutes of Health National Research Service Award Pre-Doctoral Training grant (1 F31 MH70175-01A1 awarded to Dr Williams, principal investigator), and the National Institutes of Health, National Institute of Mental Health grant, Research Supplement to Promote Diversity in Health-Related Research for Maximizing Treatment Outcome in OCD (3 R01 MH045404-17S1 awarded to principal investigator E. Foa for Dr Williams).

References

1. Kessler RC, Berglund P, Demler O. Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the national comorbidity survey replication. *Arch Gen Psychiatry*. 2005; 62(6):593–602. [PubMed: 15939837]
2. Carter MM, Sbrocco T, Carter C. African Americans and anxiety disorders research: Development of a testable theoretical framework. *Psychol Psychother Theor Res Pract*. 1996; 33:449–463.
3. Breslau J, Aguilar-Gaxiola S, Kendler KS, et al. Specifying race-ethnic differences in risk for psychiatric disorder in a USA national sample. *Psychol Med*. 2006; 36(1):57–68. [PubMed: 16202191]
4. American Psychiatric Association. *Diagnostic and Statistical Manual for Mental Disorders*. Fourth. Washington, DC: American Psychiatric Press; 2000. Text Revision
5. Guarnaccia, PJ. A cross-cultural perspective on anxiety disorders. In: Friedman, S., editor. *Cultural issues in the treatment of anxiety*. New York, NY: The Guilford Press; 1997. p. 3-20.
6. Williams MT, Turkheimer E. Identification and Explanation of Racial Differences on Contamination Measures. *Behav Res Ther*. 2007; 45(12):3041–3050. [PubMed: 17935695]
7. Hunter LR, Schmidt NB. Anxiety psychopathology in African American adults: literature review and development of an empirically informed sociocultural model. *Psychol Bull*. 2010; 136(2):211–235. [PubMed: 20192561]
8. Keyes KM, Hatzenbuehler ML, Alberti P, et al. Service utilization differences for axis I psychiatric and substance use disorders between White and Black adults. *Psychiatr Serv*. 2008; 59:893–901. [PubMed: 18678687]
9. Barlow DH, Gorman JM, Shear MK, et al. Cognitive-behavioral therapy, imipramine, or their combination for panic disorder: a randomized controlled trial. *JAMA*. 2000; 283:2529–2536. [PubMed: 10815116]
10. Rollman BL, Belnap BH, Mazumdar S, et al. A randomized trial to improve the quality of treatment for panic and generalized anxiety disorders in primary care. *Arch Gen Psychiatry*. 2005; 62:1332–1341. [PubMed: 16330721]

11. Greist J, Marks IM, Baer L, et al. Behavior therapy for obsessive-compulsive disorder guided by a computer or by a clinician compared with relaxation as a control. *J Clin Psychiatry*. 2002; 63(2): 138–145. [PubMed: 11874215]
12. Williams M, Powers M, Yun YG, et al. Minority representation in clinical trials for obsessive-compulsive disorder. *J Anxiety Disord*. 2010; 24:171–177. [PubMed: 20143498]
13. Roy-Byrne PP, Perera P, Pitts CD, et al. Paroxetine response and tolerability among ethnic minority patients with mood or anxiety disorders: a pooled analysis. *J Clin Psychiatry*. 2005; 66:1228–1233. [PubMed: 16259535]
14. Walkup JT, Albano AM, Piacentini J, et al. Cognitive-behavioral therapy, sertraline and their combination for children and adolescents with anxiety disorders: acute phase efficacy and safety. *N Engl J Med*. 2008; 359(26):2753–2766. [PubMed: 18974308]
15. Schnurr PP, Friedman MJ, Engel CC, et al. Cognitive behavioral therapy for posttraumatic stress disorder in women: A randomized controlled trial. *JAMA*. 2007; 297:820–830. [PubMed: 17327524]
16. Foa EB, Hembree EA, Cahill SP, et al. Randomized trial of prolonged exposure for posttraumatic stress disorder with and without cognitive restructuring: outcome at academic and community clinics. *J Consult Clin Psychol*. 2005; 73(5):953–964. [PubMed: 16287395]
17. Zoellner LA, Feeny NC, Fitzgibbons LA, et al. Response of African American and Caucasian women to cognitive behavioral therapy for PTSD. *Behav Ther*. 1999; 30:581–595.
18. Outreach Notebook for the NIH Guidelines on Inclusion of Women and Minorities as Subjects in Clinical Research. Bethesda, MD: National Institutes of Health; 2002. Department of Health and Human Services, Public Health Service NIH 03-7036
19. 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. Table 9. US Department of Health and Human Services; Fall. 2008 <http://orwh.od.nih.gov/inclusion/FinalAnnualReport> [Accessed February 26, 2009]
20. Suite DH, La Bril R, Primm A, et al. Beyond misdiagnosis, misunderstanding and mistrust: relevance of the historical perspective in the medical and mental health treatment of people of color. *J Natl Med Assoc*. 2007; 99(8):879–885. [PubMed: 17722664]
21. Mental Health: A Report of the Surgeon General. Vol. Ch 2. Rockville, MD: US 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; 1999. The fundamentals of mental health and mental illness.
22. Gamble VN. A legacy of distrust: African Americans and medical research. *Am J Prev Med*. 1993; 9(6 suppl):35–38. [PubMed: 8123285]
23. Whaley AL. Cultural mistrust and mental health services for African Americans: a review and meta-analysis. *Counsel Psychol*. 2001; 29(4):513–531.
24. Gamble VN. Under the shadow of Tuskegee: African Americans and health care. *Am J Public Health*. 1997; 87(11):1773–1778. [PubMed: 9366634]
25. Freimuth VS, Quinn SC, Thomas SB. African American's views on research and the Tuskegee syphilis study. *Soc Sci Med*. 2001; 52(5):797–808. [PubMed: 11218181]
26. Whaley AL. Cultural mistrust of white mental health clinicians among African Americans with severe mental illness. *Am J Orthopsychiatry*. 2001; 71(2):252–256. [PubMed: 11347366]
27. Ayalon L, Alvidrez J. The experience of Black consumers in the mental health system—Identifying barriers to and facilitators of mental health treatment using the consumers' perspective. *Issues Ment Health Nurs*. 2007; 28:1323–1340. [PubMed: 18058337]
28. Katz RV, Kegeles SS, Kressin NR, et al. The Tuskegee legacy project: willingness of minorities to participate in biomedical research. *J Health Care Poor Underserved*. 2006; 17:698–715. [PubMed: 17242525]
29. Meinert JA, Blehar MC, Peindl KS, et al. Bridging the gap: Recruitment of African-American women into mental health research studies. *Acad Psychiatr*. 2003; 27(1):21–28.
30. Jackson JS, Torres M, Caldwell CH, et al. The National Survey of American Life: A study of racial, ethnic and cultural influences on mental disorders and mental health. *Int J Meth Psychiatr Res*. 2004; 13(4):196–207.

31. Clay C, Ellis MA, Amodeo M, et al. Recruiting a community sample of African American subjects: The nuts and bolts of a successful effort. *Families in Society*. 2003; 84(3):396–404.
32. Hatchett BF, Holmes K, Duran DA, et al. African Americans and research participation: The recruitment process. *J Black Stud*. 2000; 30(5):664–675.
33. Williams MT, Turkheimer E, Magee E, et al. The effects of race and racial priming on self-report of contamination anxiety. *Pers Indiv Differ*. 2008; 44:746–757.
34. Williams MT, Turkheimer E, Schmidt K, et al. Ethnic identification biases responses to the Padua Inventory for obsessive-compulsive disorder. *Assessment*. 2005; 12(2):174–185. [PubMed: 15914719]
35. Williams, MT.; Turkheimer, E. The effects of interviewer race on anxiety in African Americans. In: Sebeki, LV., editor. *Leading-Edge Health Education Issues*. New York, NY: Nova Publishers; 2008.
36. Marshall, C.; Rossman, G. *Designing qualitative research*. 3rd. Thousand Oaks, CA: Sage; 1999.
37. Tashakkori, A.; Teddle, C. *Handbook of mixed methods in social and behavioral research*. Thousand Oaks, CA: Sage; 2003.
38. Thompson VL, Bazile A, Akbar M. African Americans' perceptions of psychotherapy and psychotherapists. *Prof Psychol Res Pract*. 2004; 35(1):19–26.
39. Corbie-Smith G, Thomas SB, Williams MV, et al. Attitudes and beliefs of African Americans toward participation in medical research. *J Gen Intern Med*. 1999; 14:537–546. [PubMed: 10491242]
40. Spriggs M. Canaries in the mines: children, risk, non-therapeutic research, and justice. *J Med Ethics*. 2004; 30:176–181. [PubMed: 15082813]
41. Snowden LR, Hastings JF, Alvidrez J. Overrepresentation of Black Americans in Psychiatric Inpatient Care. *Psychiatr Serv*. 2009; 60(6):779–785. [PubMed: 19487347]
42. Friedman S, Smith LC, Halpern B, et al. Obsessive-compulsive disorder in a multi-ethnic urban outpatient clinic: initial presentation and treatment outcome with exposure and ritual prevention. *Behav Ther*. 2003; 34:397–410.
43. Gallagher-Thompson D, Solano N, Coon D, et al. Recruitment and Retention of Latino Dementia Family Caregivers in Intervention Research: Issues to Face, Lessons to Learn. *Gerontologist*. 2003; 43(1):45–51. [PubMed: 12604745]
44. Williams KE, Chambless DL, Steketee G. Behavioral treatment of obsessive-compulsive disorder in African Americans: clinical issues. *J Behav Ther Exp Psychiatry*. 1998; 29:163–170. [PubMed: 9762593]
45. Mendoza DB, Williams MT, Chapman LK, Powers M. Minority Inclusion and Ethnic Differences in Randomized Controlled Trials of Panic Disorder. *J Anxiety Disord*. 2012; 26(5):574–582. [PubMed: 22445317]

Interview Questions About Study Attitudes and Experiences

- Before the survey, what kinds of questions did you think you would be asked?
- Did you think that the survey questions were appropriate to you?
- How did you think this information about you might be used?
- How did the instructions given by the experimenter make you feel?
- How comfortable were you with the experimenter?
- Were you concerned that your responses might reflect poorly on you or your ethnic/racial group?
- Do you think people from your ethnic/racial group might feel uncomfortable participating in a study like this one? Why or why not?
- What sorts of things might make them/you feel more comfortable?

Table

Demographics of Study Sample

ID	Occupation	Student Status	Sex	Age	Marital Status	Referral Source
1	University student	Full-time	Female	18	Never married	Subject pool
2	Manual laborer	Unknown	Male	22	Never married	US mail
3	Disabled, volunteer	Part-time	Female	46	Never married	Flyer
4	Human resources	Not student	Female	34	Married	Word of mouth
5	Clerical worker	Not student	Female	33	Married	Word of mouth
6	Hospital worker	Not student	Male	50	Married	US mail