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Recruitment of a hidden population: African Americans with obsessive–compulsive disorder

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ABSTRACT

Obsessive–compulsive disorder (OCD) is a leading cause of disability worldwide, however for reasons that are poorly understood ethnic minority groups are not well represented in clinical research studies. Thus, although African Americans experience equivalent rates of OCD according to epidemiological surveys, the generalizability of findings from clinical trials remains unknown. Research designed to improve identification, assessment and treatment of OCD is an important public health priority. The purpose of this study is to report outreach methods used to recruit African American adults for participation in an OCD research study. A variety of methods were employed, including radio advertisements, public transportation advertising, community outreach, and online advertising. A total of 83 African American adult participants were recruited over a 9.5 month period at the University of Pennsylvania in Philadelphia, and given comprehensive psychiatric assessments. African Americans with OCD symptoms were reliably identified and assessed, for a total of 75 with lifetime OCD (4 past and 71 current diagnoses). There was variability in the success and cost effectiveness of study recruitment methods. Radio ads were the most expensive means of recruitment, newspaper ads accounted for the largest number of eligible participants, and no cost methods such as Craig's List and word of mouth were also effective. The authors conclude that, with focused efforts, there are many effective methods for recruiting African Americans with OCD. Guidelines for recruitment are discussed, with a focus on cultural considerations.

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1. Introduction

1.1. African Americans and OCD

Obsessive–Compulsive Disorder (OCD) is a disabling and distressing disorder, which has made it one of the top ten leading causes of disability worldwide [1]. OCD afflicts 1.6% of the population, causing significant and pervasive impairment in

multiple domains [2,3]. Research designed to improve identification, assessment, and treatment of OCD is an important public health priority.

African Americans experience OCD at equivalent rates as the general population [3–5], but are underrepresented in OCD treatment clinics and research studies [6,7]. This disparity may be due to any number of factors, including inadequate outreach methods, cost of treatment, institutional mistrust, and/or lack of knowledge about OCD [8,9]. The non-minority population suffering from OCD takes 7–10 years before getting help, due in part to feelings of shame [10]; institutional mistrust and other factors that differentially affect African Americans may result in longer delays, resulting in greater symptom severity and impairment.

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1.2. Importance of cross-cultural OCD research

OCD is a heterogeneous disorder, and it is important to understand symptom differences in African Americans, because patients who do not meet the most common presentations may not be identified [11]. There may be cross-cultural differences in obsessive-compulsive symptoms [12–14], and it is possible that African Americans with the most severe form of the disorder, especially those with uncommon symptoms, may be misdiagnosed as psychotic [15,16].

African Americans report greater concerns about contamination on OCD inventories [17,18]. However, it is not known how effective screening measures of OCD are, since only non-clinical samples of African Americans have been included in psychometric studies. Other questions to be answered include understanding barriers to treatment and the acceptability of validated treatments for OCD among African Americans.

1.3. Racial differences in symptoms and treatment

The paucity of empirical work with African Americans with OCD has garnered some interesting findings. In the first epidemiological examination of OCD among African Americans and Caribbean blacks, the National Survey of American Life (NSAL) study found that African Americans are more likely to have an adult onset compared to late adolescence, as reported in the National Comorbidity Survey Replication (NCS-R) [4,3]. Later onset was correlated with greater severity and poorer insight, and higher comorbidity in the NCS-R study, which was primarily European American [3]. If this is also true for African Americans it would be an important cultural difference, as earlier identification could help remediate the adverse affects of this later onset. Additionally, treatments may affect different groups variably due to physiological reasons, acceptability of treatment, and cultural differences in the expression of psychopathology [19]. Identification of potential differences underscores the importance of OCD research focused on minority groups such as African Americans.

1.4. Recruitment of African Americans into research studies

Due to some unpleasant history involving African Americans in clinical research (i.e., the US Public Health Service Syphilis Study at Tuskegee), there is considerable pessimism surrounding recruitment and retention of African Americans for many types of research [20,9]. However, African Americans have been recruited successfully for other types of clinical studies, and it is believed successes have been achieved through attention to detail in planning, use of relevant incentives, and focused community outreach efforts [20,21].

Through active synthesis of past research and novel ideas, we describe effective recruitment methods for African Americans with OCD.

2. Methods

2.1. Demographics

Eighty-three African American participants were recruited for the study over a 9.5-month period during 2009–2010 at the Center for the Treatment and Study of Anxiety at the

University of Pennsylvania in Philadelphia. Of these, 75 were determined to have a diagnosis of past or current OCD by trained evaluators. The demographics of the lifetime OCD sample by gender are shown in Table 1.

2.2. Advertising and outreach

All advertising materials were approved in advance by the university Institutional Review Board. The study used an assortment of advertising options to maximize recruitment, including newspapers, radio, public transportation, Internet, and flyers. Visual advertisements prominently featured images of African Americans and verbiage that represented a direct appeal (e.g. “Seeking African Americans with OCD”). The term “research” was avoided in favor of other less incendiary terms such as “project” and “study” to distance these recruitment efforts from associations with historical research abuses against African Americans. Most advertisements were psycho-educational and described specific classes of OCD symptoms; for example one advertisement focused on washing symptoms, one focused on hoarding, and one focused on unwanted thoughts. This was done to help reach the widest range of OCD sufferers, with the idea that many may not realize their symptoms are typical of OCD.

Large postcards describing the study and inclusion criteria were mailed to local psychiatrists and community mental health clinics in an attempt to obtain professional referrals. Psychiatrists were identified through insurance company online directories, and community mental health clinics were found on publically available lists of community services.

A radio campaign was launched that included several 30-second ads about the study. The content of the radio ads included questions such as “Do you have fears that keep coming back?” and “Do you find yourself doing certain things over again and again to make the worry go away?” The first author also did a short interview about the study with a local radio personality, which was aired on a Sunday morning. Listeners were directed to visit the study website for more information and call for a confidential phone screening.

A major emphasis was placed on community outreach, which included connections with African American institutions, community leaders, and word of mouth. The first author joined the board of directors of three local organizations to facilitate these efforts. The organizations included a local chapter of a national mental health advocacy organization, a church-sponsored inner-city health clinic, and a local organization for black psychologists. This expanded the available network of community contacts and provided several opportunities to publicize the study.

All advertising and outreach efforts and related costs were logged for later analysis.

2.3. Telephone screening

Outreach and advertising efforts directed prospective participants to contact the study research assistant (RA) who screened individuals for eligibility by telephone. If the caller left a message, the RA tried no less than 3 times to make contact with the prospective participant. Once the screening process began, it was guided by a computerized database that prompted the RA to ask a specific series of questions that

Table 1
Demographics for all participants.

| | Marital status | | | | Age | | | | | |
|------------------------|----------------------------|-------------|--------------------|----------------------|-------------------|--------------|---------------|---------|-------------------|----------|
| | Married/lives with partner | Widowed | Divorced/separated | Single/never married | Mean | SD | | | | |
| Male | 7 | 0 | 10 | 21 | 44.81 | 10.12 | | | | |
| Female | 7 | 2 | 9 | 27 | 39.22 | 12.94 | | | | |
| Total | 14 | 2 | 19 | 48 | 41.71 | 12.03 | | | | |
| Employment data | | | | | | | | | | |
| | Full Time | Part Time | Homemaker | Full Time Student | Part Time Student | Temp Unempl | Unempl +6 mos | Retired | Public Assistance | Disabled |
| Male | 11 | 5 | 0 | 0 | 0 | 5 | 8 | 1 | 0 | 7 |
| Female | 11 | 4 | 1 | 5 | 5 | 3 | 11 | 0 | 1 | 5 |
| Total | 22 | 9 | 1 | 5 | 5 | 8 | 19 | 1 | 1 | 12 |
| Educational background | | | | | | | | | | |
| | Grade 7–12 | HS grad/GED | Part college | Two year college | Four year college | Some grad ed | Grad degree | | | |
| Male | 5 | 11 | 11 | 4 | 4 | 0 | 2 | | | |
| Female | 5 | 4 | 15 | 9 | 5 | 2 | 6 | | | |
| Total | 10 | 15 | 26 | 13 | 9 | 2 | 8 | | | |
| Household income | | | | | | | | | | |
| | Under 10 K | 10 K–19 K | 20–39 k | 40–59 K | 60–79 K | 80–100 K | 100 K+ | | | |
| Male | 10 | 6 | 8 | 2 | 1 | 2 | 3 | | | |
| Female | 11 | 9 | 10 | 8 | 0 | 1 | 2 | | | |
| Total | 21 | 15 | 18 | 10 | 1 | 3 | 5 | | | |

N = 73 for household income category due to missing data for 10 participants.

were entered into the database as the screening progressed. The RA collected contact information and demographic information first, followed by questions about mood symptoms, psychotic symptoms, anxiety symptoms, and OCD-specific symptoms. If the caller reported significant distress or impairment due to any symptom of OCD (i.e., any of those appearing on the YBOCS checklist), they were scheduled for an interview. The RA also collected information about how prospective participants found out about the study to assess the success of recruitment techniques. RAs were coached in cultural sensitivity issues to make participants feel comfortable. For example, RAs were instructed to address participants by surnames rather than first names, as it can be considered a lack of respect to be addressed by first names.

Prospective participants who were deemed ineligible by the screener were offered referrals to other facilities, as needed. Callers who passed the telephone screen were scheduled for the evaluation within 1 week. Scheduled participants were contacted by phone 1–2 days in advance of the assessment, to confirm the appointment time and location, and review the participant's current OCD symptoms.

2.4. Assessment

Upon arrival, the eligible participant was consented into the program by one of the masters or doctoral-level study personnel. Participants signed a written form that detailed the study procedures and their rights as a participant. It was explained to participants that by signing the consent form they were not waiving any of their rights.

Participants were provided with a packet of written measures to complete, or were given the option to complete the measures on a computer. Participants also had the option of having the questionnaires read aloud to accommodate anyone with literacy difficulties. The following self-report measures were administered to all participants in the following order:

- The Obsessive–Compulsive Inventory, short version (OCI-R) [22] is an 18-item self-report measure that yields a profile of distress for each symptom area in six subscales: washing, checking, ordering, obsessing, hoarding, and neutralizing.
- The Obsessive Belief Questionnaire – Brief Version (OBQ-44) [23] is a 44-item measure that assesses cognitive beliefs in OCD.
- The Barriers to Treatment Questionnaire (BTQ) [10] measures the participants' perceived barriers to seeking OCD treatment, based on similar questionnaires from the broader barriers to treatment literature. The BTQ assesses barriers in the following domains: logistic and financial, stigma, shame and discrimination barriers, treatment perception, and satisfaction barriers.
- The Disgust Sensitivity Scale, revised (DS-R)[24,25], is a 27-item self-report personality scale that was developed as a general tool for the study of disgust.
- The Beck Anxiety Inventory (BAI) [26] is a widely used instrument designed to discriminate anxiety from depression in individuals. The scale consists of 21-items, each describing a common symptom of anxiety.
- The Beck Depression Inventory (BDI-II) [27] is a popular 21-item self-report measure of depressive symptoms.

- The McMaster Family Assessment Device (FAD) [28] is 53-item self-report questionnaire assessing family functioning. The subscales include problem solving, communication, affect, affective involvement, behavioral control, roles, and general functioning. Lower scores on the FAD indicate healthier family functioning. A retrospective version is used [29].
- The Multigroup Ethnic Identity Measure (MEIM) [30] is suitable for use with any ethnic group. It contains 20 items about degree of ethnic identification and acculturation, with 3 fill-in questions about the subject's race. An extended version of this measure was used.
- The Hoarding Rating Scale-Self-Report (HRS-SR) [31] consists of five questions rated from 0 (none) to 8 (extreme) of clutter, difficulty discarding, excessive acquisition, distress, and impairment. This measure was administered on a separate occasion, after the main battery was completed.

For paper measures, the RA examined all pages to ensure that no items were missed, and the measures were subsequently entered into a database designed for this study and then double entered for accuracy. Measures completed on the computer were reviewed to ensure that they were completed correctly.

The clinician administered a comprehensive psychiatric diagnostic interview to participants, which took approximately 3 hours. Evaluators rephrased questions as appropriate to the participant's educational level as necessary. Clinician administered measures included the following:

- The Structured Clinical Interview for DSM-IV Axis I Disorders (SCID) [32], a widely used semi-structured clinical interview, designed to aid clinicians and researchers in making reliable DSM-IV psychiatric diagnoses.
- The Yale–Brown Obsessive Compulsive Check-List and Severity Scale (YBOCS)[33] was administered to assess the phenomenology and severity of OCD symptoms.
- The Brown Assessment of Beliefs Scale (BABS)[34] is a seven-item, semi-structured interview that assesses the degree of conviction and insight patients have concerning the beliefs underlying their obsessional thinking.
- The Clinical Global Impression Scale (CGI) [35] was used to rate overall level of psychopathology severity. This rating was made specifically with regards to dysfunction due to OCD symptoms.
- The Barriers to Treatment Participation Scale (BTPS) [36] is a scale that has been used successfully in prior studies to identify factors that prevent patients from obtaining mental health services. Originally developed to assess children, we used a version modified for our sample [37].

A Post Assessment Interview was used to summarize the result of the clinical assessment. The clinician reviewed her diagnostic impressions with the participant and answered any questions. Participants with a DSM-IV-TR diagnosis of any anxiety disorder who were not already receiving treatment were referred for treatment through the university or elsewhere. This included options at a fee-for-service clinic connected with the study, which offers a reduced fee for practicum student therapists, and an outpatient psychiatric center affiliated with the university, which accepts insurance, Medicaid and Medicare. For participants who declined these

opportunities for treatment, the reasons for their decision were explored and recorded. Eligible participants with OCD were also offered no-cost treatment through an NIMH treatment outcome study *Maximizing Treatment Outcome in OCD* (PIs: Edna Foa and H. Blair Simpson).

2.5. Incentives

Compensation, professional assessment, and treatment opportunities were offered to participants as incentives for participation. After completion of the study, participants received \$100 cash for their participation, plus reasonable transportation costs up to \$10. Eighteen participants were randomly selected received an additional \$40 for completing a second YBOCS for reliability purposes.

2.6. Follow-up

All participants received a follow-up phone call after at least 4 weeks to determine if they were successful in obtaining effective treatment for their OCD. Additional referral information was provided to the participant at that time, if desired. Participants not available by phone were mailed a letter instructing them to contact the center for a follow-up phone call.

2.7. Evaluators

Community evaluators were hired to conduct assessments with study participants. Because cultivation of trust is an important factor as indicated by prior research, whenever possible, African American evaluators were used to create a comfortable and familiar environment where participants could feel at ease [20]. Because some research has indicated that participants may be uncomfortable in a university-setting [38], evaluators were therapists who were practicing in the local community and not associated with the university at which the study was conducted. All community evaluators received extensive training before assessing study participants, observing a minimum of two OCD evaluations conducted by the PI and conducting two study evaluations with the PI present before being considered trained for the purpose of this study. Evaluators attended reliability meetings regularly and a training workshop about assessment and treatment of OCD. Evaluators met regularly with the PI for study supervision.

Although a total of five African American evaluators were hired for this study over the recruitment period, there were also two university-affiliated European Americans who were trained as evaluators to assess participants when the primary evaluators were unavailable. Of the 83 participants who were seen, 5 assessments were conducted by European American evaluators, and 2 were conducted by a team consisting of one European American and one African American evaluator. The remaining 76 assessments were conducted by African American master's or doctoral-level evaluators. All evaluators were female.

2.8. Reliability

Approximately one-third of the first 29 completed interviews were randomly reviewed from audio or video recordings

for reliability by a doctoral-level clinician with expert knowledge of OCD. Study evaluators reviewed the feedback about the interviews and met with the PI if there were any questions. From participant number 30 forward the protocol was changed (for reasons to be explained in the next section) to assess reliability with a live second rating; thus, one-third of participants received a second YBOCS from a doctoral-level expert clinician within a week of the initial interview. In cases of disagreement between raters, the PI reviewed the findings from both interviews to make a determination and/or an additional YBOCS was conducted.

3. Results

3.1. Advertising and outreach

A variety of advertising methods were used to reach the broadest audience possible. The methods and costs associated with each method are shown in Table 2. Newspaper ads were the most successful recruitment technique, yielding 27 participants (32.5% of all participants). These ads were placed in four different free local newspapers with high African American readership. Internet-based ads were responsible for 22 eligible participants when combining general internet pay-per-click advertising (i.e., Google, Facebook, Interactive One), discussion forums, and Craig's List. Though Craig's List is free to post, this modality was enhanced by being linked to the study website; it resulted in one more participant than paid Internet advertising which cost \$295 per participant.

Radio ads were aired by Clear Channel Philadelphia for \$787 per participant and generated 9 eligible participants, though there were a total of 35 inquiries. Radio ads represented the highest total individual cost among the various recruitment methods and accounted for approximately 11% of participants.

Public transportation ads were placed on local buses. Behind newspaper ads, public transportation generated the largest amount of inquiries at 41; however, only 7 of these inquiries ultimately participated (31 did not have OCD symptoms, 3 were scheduled but did not show, 2 were not interested, 1 was not African American).

Flyers were posted in high pedestrian traffic locations such as Drexel University, University of Pennsylvania, and Community College of Philadelphia campuses. While flyers were only responsible for 9 eligible participants, they were

relatively inexpensive at \$78 per participant, and accounted for as many participants as the most expensive recruitment method, radio ads. Word of mouth did not cost anything and generated 4 eligible participants. This entails members of the community sharing information about the study with each other. All recruitment methods contribute to a higher probability of word of mouth participants.

Professional referrals and undergraduate lectures were both low cost and together are responsible for approximately 10% of the eligible participants. Professional referral includes therapists, counselors and psychologists from both inside and out of the university health system suggesting or supplying information to their clients about the study. Several undergraduate lectures about the study were given at a historically African American institution by the first author.

3.2. Recruitment process

The study received a total of 383 inquiries. Of these, over a third (34.46%) were unreachable when study staff attempted a call back. Among the 251 who participated in telephone screenings, 83 were deemed eligible and completed the in-person assessment visit. Of these, 2 were excluded for providing inconsistent responses. Of the remaining 81, 75 were determined to have past or current OCD (4 and 71 respectively). Of the 251 screened, 33.07% participated in the study and 29.88% had lifetime OCD. We enrolled 7.89 participants per month with lifetime OCD. The recruitment process is detailed in the CONSORT diagram shown in Fig. 1.

3.3. Assessment data

Interrater agreement for an OCD diagnosis was determined by clinicians using the YBOCS checklist and severity scale and the portion of the SCID that assessed for OCD. After administering these instruments, each rater recorded if the selected participant was positive or negative for OCD based on their best determination. For the selected assessments, among the first 29 interviews, it was not possible to calculate interrater agreement as the expert raters had difficulty following the recorded assessments. This led to a procedural change, whereby remaining interviews were assessed via a live second interview, for proportion of agreement of 94.4% and a kappa coefficient of .77 ($p = .001$), an indication of substantial agreement. These findings are shown in Table 3. Among those with a lifetime diagnosis of OCD, the

Table 2
Advertising venues and associated costs.

| Referral source | Total inquires | % of all inquiries | Enrolled in study | % subjects from source | Total cost | Cost per subject |
|---------------------------|----------------|--------------------|-------------------|------------------------|-------------|------------------|
| Newspaper ads | 85 | 33.9% | 27 | 32.53% | \$ 2,582.24 | \$95.64 |
| Public transport ads | 41 | 16.3% | 7 | 8.43% | \$ 3,275.00 | \$467.86 |
| Radio ads/interview | 35 | 13.9% | 7 | 8.43% | \$ 7,083.00 | \$787.00 |
| Internet advertising | 20 | 8.0% | 10 | 12.05% | \$ 1702.92 | \$170.29 |
| Color 8 × 10 flyers | 19 | 7.6% | 9 | 10.84% | \$ 702.40 | \$78.04 |
| Craig's list | 19 | 7.6% | 11 | 13.25% | NA | NA |
| Word of mouth | 14 | 5.6% | 4 | 4.82% | NA | NA |
| Undergraduate lectures | 9 | 3.6% | 3 | 3.61% | \$ 45.00 | \$15.00 |
| Prof. referrals/postcards | 6 | 2.4% | 5 | 6.02% | \$ 372.55 | \$74.51 |
| Unknown | 3 | 1.2% | | | | |
| Totals | 251 | 100.00% | 83 | 100.00% | | |

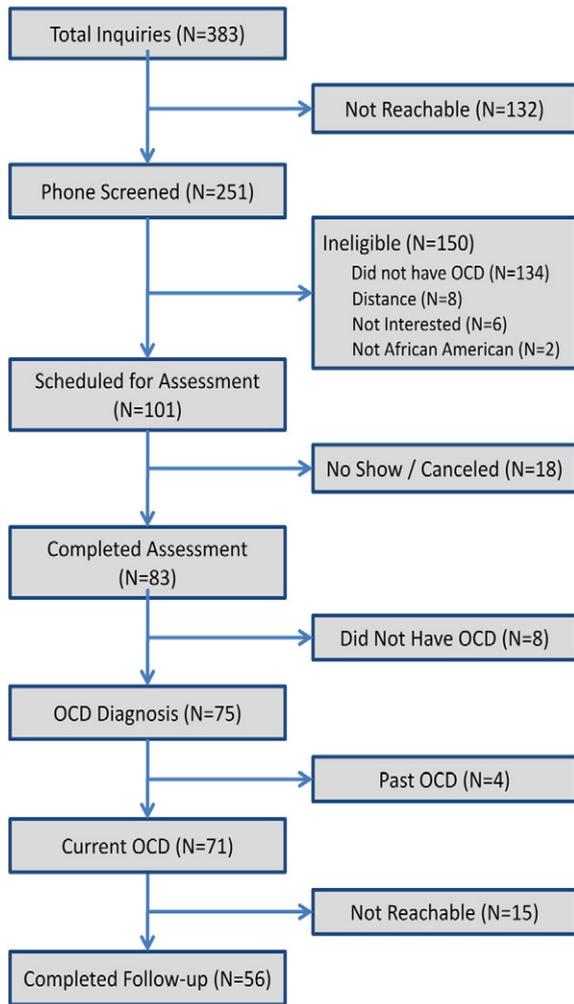


Fig. 1. Consort diagram.

mean age of onset was 22.8 years (SD 14.0). Among those with a current OCD diagnosis, the mean YBOCS score was 23.5 (SD 6.3) and overall GAF was 61.3 (SD 12.6).

3.4. Treatment data

Among those who were determined to have current OCD (N = 71), 87.3% expressed interest in receiving treatment for the disorder, 5.6% said they were not interested at this time, and 7.0% said they were not sure. After the follow-up period (at least 4 weeks), participants were contacted to determine if they received treatment. Among those with current OCD, 22.5% (16/71) were unable to be reached. Of the remainder, 41.8% (23/55) reported attempting to obtain

treatment, 38.2% (21/55) found/scheduled treatment, and 21.8% (12/55) had started treatment. None of the participants were eligible for the OCD treatment study being conducted at the study site, as inclusion criteria required participants to be on a stable and adequate dose on a serotonin reuptake inhibitor, and none of the participants met this criterion.

4. Discussion

4.1. African Americans in OCD treatment studies

Previous studies of OCD have been unsuccessful in their recruitment of minorities, with randomized clinical trials (RCTs) found to have an inclusion rate of only 1.3% for African Americans [7]. For example, the OCD RCT with the largest number of African Americans participants reported in North America included 5 African Americans out of a total of 224 participants [39]. Recruitment took place at 21 sites and participants were involved for 80 months. The length of the recruitment period was not specified, but if it lasted for 6 months at each site, it may be inferred that investigators found less than one African American participant per month, across 21 sites (0.04 African Americans per month, per site). In contrast, we recruited over 7 African American participants per month at a single site.

Although ours was primarily an assessment study, the vast majority expressed an interest in being treated; a notable proportion attempted to obtain or even started treatment during the follow-up period. Unfortunately, many who expressed interest were unable to obtain treatment, thus an important avenue of future research will be determining what barriers prevent African Americans from receiving treatment for OCD.

One possible barrier to research inclusion is the requirement for previous treatment, such as study criteria that require participants to be on a certain dose of an anti-obsessional medication before entry. Since African Americans with OCD rarely receive effective treatment [4], such criteria will exclude almost all African Americans with OCD.

4.2. Successful recruitment

The variety of advertisement styles is believed to have been an important factor in successful recruitment. Many OCD studies merely use people already coming to clinics that served predominately European American populations. Thus, it is important to have a targeted recruitment strategy and an adequate advertising budget to reach beyond the main clinical setting. Advertisements should make a direct appeal to the target audience and feature racially and ethnically diverse images.

Community outreach work generated invitations to provide educational lectures and trainings in various venues

Table 3
Reliability for all participants for an OCD diagnosis.

| | N | Agree | Disagree | Inconclusive | Total checked | Percentage checked |
|-----------------|----|-------|----------|--------------|---------------|--------------------|
| Recordings | 28 | 4 | 2 | 5 | 11 | 39.2% |
| Live assessment | 52 | 17 | 1 | 0 | 18 | 34.6% |

Total N = 80 due to 3 missing YBOCS.

sponsored by local organizations, and the efforts were well-received by leaders in the community. Thus there was a reciprocal relationship that benefited both the study and the community. Although several members of the study team were involved in community outreach, advertising generated more participants. The efforts of a few people could not compare to the wide exposure garnered by mass advertising in a large urban environment. Nonetheless, community outreach was an important part of the recruitment effort as a positive word in the community about the project enhanced advertising efforts. We did not have a minority recruitment coordinator due to budget limitations, but would recommend this for future studies as a dedicated recruiter could more easily leverage community contacts and increase word of mouth. This might be especially important in rural and smaller locales where community perception is particularly important. A genuine commitment to the well-being of the target community is essential.

Another important component of the study was adequate participant compensation. Compensation was offered for both study time and travel expenses, demonstrating respect and appreciation of the participant effort. As the average income of African Americans is lower than that of European Americans, compensation can also help to offset barriers such as wages lost from work, especially when studies are conducted during business hours, and child care costs [20].

Many studies compensate participants with gift certificates rather than cash, but a gift certificate can be perceived as patronizing if it forces participants to spend their compensation at an investigator-approved venue. Some university bureaucracies make cash payments to participants difficult, and in this situation we recommend a cash card that can be used anywhere a regular credit card can be used [40].

4.3. Costs and effectiveness

Ads in local newspapers led to the largest number of inquiries and participants. Craig's List, a zero cost recruitment method, reached the next largest number of participants, although as noted earlier, this effect may have been enhanced by linking these ads to the more detailed study website. In terms of cost effectiveness, undergraduate lectures were also effective. Although there was no advertising cost, per se, these did involve travel time and expense, as well as time-consuming sorting of screening packets. Nonetheless, it was a worthwhile source of eligible participants and diversified the SES of the sample. Although these particular lectures were conducted at a predominantly African American university, there may be some value to giving such lectures at majority European American universities that have racially and ethnically diverse student bodies.

Of note, less than a third of those screened ultimately had lifetime OCD. RAs expended considerable effort contacting and screening potential participants, and a high number of ineligible participants poses a financial and practical burden that must also be taken into account. Ideally, prospective participants will screen themselves out if not eligible, but the relatively higher cost of newspaper ads precluded the space needed to relay details about eligibility, resulting in many disappointed callers who were ineligible. Conversely, flyers, bus ads, the website, and postcards sent to clinicians contained

more details about study criteria, theoretically resulting in a lower proportion of unqualified participants. This, however, was not the case for bus ads, perhaps due to the fact that riders did not have enough time to carefully read the ad while in transit. The high cost and low recruitment of eligible participants from radio ads makes this a less desirable strategy that deserves careful consideration for future studies.

4.4. Characteristics of sample

In comparing our findings to those of previous investigators, there were many similarities but also some important differences. For example, the age of onset of OCD symptoms (22.8 years) was lower than previously reported for African Americans in the NSAL study (31.8 years), but closer to findings from NCS-R (19.5 years). We believe that the higher number found by NSAL may be due to the abbreviated assessment utilized to diagnose OCD.

4.5. Study challenges

One of the greatest difficulties in recruitment involved responding to potential participants who left a message for study personnel. Many of these calls were not returned as participants often left non-working phone numbers, numbers with no voice mail, or no numbers at all. To improve the acquisition of eligible participants, it is recommended that a qualified screener be available at all times to take such calls.

Accurate and current contact information was also a problem for actual participants. Study personnel were unable to perform follow-up evaluations for several participants due to changing phone numbers and addresses. The study protocol was changed halfway through the study to acquire additional phone numbers and email addresses from participants to facilitate follow-up. Another difficulty with follow-up calls was that some participants were unwilling to cooperate further. At least one participant who had comorbid PTSD declined the follow-up interview, citing stress resulting from recounting her symptoms.

One potential source of participants that was underutilized was the local organization for African American mental health professionals. Although the first author attempted to access the mailing list to disseminate information about the study to local providers, the leadership of the organization refused access for reasons that were not completely clear. The response was disappointing as it represented an untapped resource for the study. Nonetheless, it was this effort that facilitated access to students at a local African American institution, thus the community outreach efforts proved worthwhile.

One unexpected challenge was the high turnover of community evaluators. All were working on the study part-time, and as they found full-time positions they became unavailable. New community evaluators had to be hired and thoroughly trained before they were able to interview participants, which turned out to be a lengthy process that extended the timetable of the project.

Compensation-seeking among prospective participants was an important issue that required careful consideration. Most individuals who were not qualified were screened out by the research assistants, but two participants penetrated our screening process and were discontinued from the

study halfway through the evaluation process once it was deemed by evaluators that the answers given by the participants were inconsistent. This underscores the importance of rigorous training of phone screening staff.

In the initial design of the study, participants were compensated after consenting but before the evaluation to facilitate trust and ensure participants felt free to answer questions as accurately as possible [40]. However, this procedure was changed early into the study process after three participants did not complete their assessments (one said he did not want to be audio recorded and two others promised to return later to complete the assessment but did not). Providing compensation at the end of the assessment turned out to be a more effective means to ensure complete data collection.

4.6. Limitations

We believe that one strength of the study was the use of community African American evaluators. However, we did not formally assess whether community African American evaluators were more effective with this population (i.e., elicited more accurate information, engendered greater trust) than the university-affiliated European Americans.

Although the study expenses were carefully tracked, the actual cost of certain recruitment methods is unclear due to overlap and patients citing multiple recruitment sources.

5. Conclusions

African Americans have been consistently underrepresented in OCD research studies [7]. This study demonstrates that, when focused efforts are placed on recruitment, it is possible to have a successful result. As research into the causes and treatments for OCD continues, it will be critically important for the sake of the generalizability that all groups are represented.

It was previously assumed that African Americans would not participate in OCD research, but the results of this study show that is not the case. Given the lack of research with this group, new work is needed to address pressing problems such as causes of barriers to treatment and the phenomenology of symptoms in African Americans, which may pose diagnostic challenges thereby representing another barrier to inclusion. The validation of OCD screening measures among African Americans is also necessary, which will require a large sample of African Americans with and without OCD. The procedures documented in this study can aid in the preparatory phase of any study invested in diversifying their sample.

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