Recruitment of African Americans for Obsessive Compulsive Disorder Treatment Research

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Abstract

A systematic review of recruitment approaches was conducted as a step towards creating a culturally sensitive approach to enhance participation of African Americans into our Obsessive Compulsive Disorder (OCD) treatment research. From this review, a recruitment plan providing a collaborative partnership between the African American community and the clinical investigators was adopted. We sought to increase participation in OCD research by developing culturally sensitive educational materials, implementing strategies such as recruiter ethnic match, encouraging individuals to participate by a pastor, and providing education in the community that attempted to decrease stigmatization of mental illness and target cultural suspicion of institutional research. Despite positive responses from direct community involvement at churches and efforts to increase minority participation by utilizing recruiters and recruitment materials representative of the population, difficulties in recruitment remained.

Key Words: Minority research, Obsessive Compulsive Disorder, Subject recruitment, African Americans
INTRODUCTION

Obsessive-compulsive disorder (OCD) has been increasingly recognized as a severe and chronically disabling illness that affects two to three percent of the population (Flament et al. 1988; Vallenl- Basile et al. 1994; Hanna 1995; MacMaster et al. 2006). In as many as eighty percent of all cases, onset of OCD is in childhood and adolescence (Pauls et al. 1995). While the incidence of OCD in African Americans is similar to or greater than in the general population (Friedman et al. 1993; Williams et al. 1998), few African Americans present for OCD treatment (Hatch et al. 1996). Reasons often cited by researchers for this lack of presentation for treatment, when socio-economic variables are controlled, is that African Americans tend to consult members of their informal social network, including clergy, in times of emotional stress (Neal and Turner 1991; Neighbors et al. 1998). In addition, the stigma of mental illness and fear of being seen as ‘mentally ill’ or ‘losing their minds’ may be accompanied by the belief that they will be involuntarily hospitalized or falsely arrested for their behavior (Friedman et al. 2003).

There is a virtual absence of African Americans in OCD research studies, rendering potential differences in treatment effect undetected and benefits of findings not generalizable to the population (Williams et al. 1998; Shavers et al. 2001; Howerton et al. 2007). This under-representation of African Americans has made recruitment a very critical issue in experimental design, especially when OCD research is already limited in scope due to small sample sizes. Increasing representation of minorities is an important component of improving evidence-based health services to these populations (Bolen et al. 2006). Moreover, federal mandate requires that minorities be included in National Institutes of Health funded research (NIH Revitalization Act PL 103-43). Experts in minority research agree that the successful recruitment and retention of minorities into research must go beyond traditional methods in order to overcome barriers related to fear and mistrust of science and mental health services, stigma of mental illness, and participant burden (Areán et al. 2003).

Traditionally, methods of recruitment into research studies have utilized doctor referrals, mass mailings, and media advertisements. When traditional methods of recruitment are compared to patient-centered methods, the literature reports patient-centered methods result in greater recruitment and retention rates (Areán et al. 2003; Levkoff and Sanchez 2003, Fouad et al. 2004). Patient-centered methods utilize face-to-face recruitment, culturally appropriate recruitment materials and recruiter ethnic match. Virtually all studies confirm the importance of tempering research objectives by making authentic connections with the participants in their research, being present in the community of interest, and being perceived as a positive force by community gatekeepers (Levkoff and Sanchez 2003).

To enhance recruitment and retention of African-American participants in our clinical research programs, a recruitment plan providing a collaborative partnership between the African-American community and the clinical
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investigators was adopted (Pletsch, Howe, & Tenney 1995). We hypothesized participation of African Americans in OCD research would increase when the following recruitment strategies are utilized: adaptation of culturally sensitive educational materials, utilizing African-American recruiters, and development of partnerships with inner-city church leaders.

METHODS

Participants

The African-American church often occupies a central place in the lives of African Americans (Chatters, Levin, & Ellison, 1998). Public health practitioners, researchers, and policy makers recognize this role and are increasingly using the church to access African Americans for health improvement efforts (Chatters, Levin, & Ellison, 1998; Chatters, 2000). Moreover, there is growing evidence that religious involvement, in addition to providing greater access to health intervention, exerts positive and diverse health benefits for African Americans (Aaron, Levine & Burstin, 2003). In the city of Detroit, 83% of the population report themselves as African Americans (US Census Bureau, 2006). Therefore, participant recruitment for this project focused on individuals attending Sunday mass at fifteen Detroit inner-city Baptist churches that primarily serve African Americans.

Materials

A brochure was adopted from the National Institute of Mental Health (US National Institute of Mental Health 2000; Steketee and White, 1990) and modified to a 4th grade reading level using the SMOG readability formula (McLaughlin, 1969). This formula was selected because it is used widely in analyzing health literature and is a quick and easy method for estimating readability.

Design

A recruitment plan model, as described by Pletsch et al. (1995) was adopted for this study and included a feasibility analysis, selection and development of recruitment strategies, and evaluation. Feasibility analysis entailed gathering information from literature review of previous research, key members of the community, and data from needs assessments to define relevant characteristics of the target group such as the incidence of OCD in this population, attitudes toward mental illness, treatment seeking behavior as well as community agencies that could be subject recruitment sites. Selection and development of recruitment strategies entailed face-to-face discussions with African-American community church pastors and with service providers at various health clinics. Overall goals of the meetings were to build community relationships, initiate support from the leaders, to provide a general overview of the research studies with a particular focus on OCD diagnosis and treatment, to establish recruitment goals, planning the recruitment time frame, and establishing access to the institution.
A team of clinicians and researchers with African-American representation were involved in creating culturally sensitive materials. An OCD educational brochure was created to represent African-American culture and experience using the Pan-African colors of black, red, gold and green and featuring African-American children and adults on the cover. Based on focus group discussion, the content included lists of OCD behaviors that pertained to African Americans such as fixing hair, making pony tails exact, avoiding particular colors in clothing, avoiding bus rides, etc.

The recruitment evaluation plan consisted of weekly assessment meetings with all members of the research team including the principal investigator, the research coordinator, research assistants, post-doctoral fellow, and recruiters. The assessment meetings focused on reviewing contacts made with participating churches, numbers recruited, and identification of recruitment successes and failures. As a result of these meetings, modifications such as involving both female and male African-American recruiters as well as adjusting the reading level of the brochure were implemented to reach more participants.

Procedure

Recruiters met with church leaders throughout the city of Detroit. With support received from the Health Ministries Division of the Baptist National Convention, partnerships with fifteen churches were developed. Letters of agreement were obtained allowing the recruiter access to the population. Announcements were placed on bulletin boards of the churches. The recruiters and research study were introduced during the Sunday service.

Steps were also taken to standardize the recruiter’s method of approaching church leaders and potential research participants, as well as to develop a method of presenting topics such as confidentiality and voluntary participation. The presentation was structured and timed to be no more than ten minutes in length. When possible, the presentation was given as a powerpoint slideshow using a laptop and projector. If this mode was unavailable, the presentation utilized an overhead projector and paper handouts. A script was developed to standardize the method of brochure distribution and all participants were asked to complete and return the survey regardless of whether or not they experienced anxiety or OCD symptoms. The script, which was read aloud to potential participants read as follows:

‘The Department of Psychiatry at Wayne State University is conducting a free screen for Obsessive Compulsive Disorder. OCD is a mental health condition that is characterized by a person experiencing uncontrollable thoughts and behaviors over and over again. Although it is receiving significant attention within the mental health community, African Americans have been underrepresented in both research and treatment of OCD, and researchers at Wayne State are attempting to learn more about this.

In a moment, you will receive a packet containing two pieces of information. First, you will receive an informational brochure that describes
symptoms and treatment of OCD. Second, you will receive information on how to participate in a free OCD screen offered by Wayne State University. The screen takes only a few minutes to complete, and your privacy is assured. In addition to helping improve mental health research within your community, your participation in this screen could qualify you to receive free treatment for OCD. 

Please join your fellow community members who are already helping to make a difference in mental health research in Detroit by completing this OCD screen. Even if you do not believe you have OCD, your completed screen is important in helping us determine the extent of this condition in our community.

All participants received an OCD brochure and an OCD pre-screen which were presented as a single packet in a concealed envelope. The brochure was printed with two different covers, one featuring Caucasians, the other featuring African Americans (distribution of the two brochures varied). The screening tool could be returned by traditional (self-addressed stamped envelope or a telephone number where respondents could call in to complete the survey) or non-traditional (a web-site address so the survey could be completed via the internet) modes of responding. At the end of the presentation, the recruiter completed a face-to-face presentation form to assure presentations were conducted the same way in every meeting.

Measures

A brief non-standardized screening assessment was designed based on a literature review, issues of importance to the assessment and diagnosis of OCD, and the experience of the OCD treatment specialist team that consisted of a board-certified child psychiatrist, licensed clinical psychologists, social workers, and post-doctoral fellows. The OCD screen consisted of questions such as, ‘I feel compelled to count while I am doing things’, ‘I repeatedly check door, windows, drawers, etc.’ ‘I frequently get nasty thoughts and have difficulty getting rid of them’. A score of fifty or higher qualified participants for a comprehensive diagnostic evaluation by a psychiatrist or a doctoral level psychologist in the OCD treatment specialist team to determine whether the participant meets DSM-IV diagnostic criteria to participate in OCD treatment research.

The comprehensive evaluation for those participants who scored fifty or higher on the initial OCD screen, included the administration of objective psychological measures as well as standardized structured and semi-structured interviews such as the Children’s Yale-Brown Obsessive Compulsive Scale (CY-BOCS) (Scahill et al. 1997) and the Kiddie-Schedule for Affective Disorders and Schizophrenia (K-SADS) (Kaufman et al. 1997). The description of the study that was presented to potential research participants and the OCD screen met Wayne State University and state of Michigan Institutional Review Board approval.
Data collection and analysis

A coding scheme and database were constructed for the recording of survey data. Data included date of birth, ethnicity, gender, socio-economic status, recruitment source, and score on the OCD screen. The intent of the project was to perform a between subjects design [two (Ethnic Match - Caucasian vs. African American-covered brochure) x three (Response Mode - mail, internet or telephone)]. The behavioral outcome measure was the number of OCD screens returned by participants. However, given the paucity of participation only descriptive statistics were performed on each item to calculate frequency of responses.

RESULTS

Intentional Recruitment

Only one OCD screen out of 200 distributed was completed and returned. The completed OCD screen was from a fifty three year old female African American who utilized the mail-in version of the survey. This participant received a score of thirty two, not qualifying for comprehensive diagnostic assessment nor research participation. No surveys returned were from participants who received Caucasian brochures. No surveys were completed via the internet or telephone response modes.

Incidental Recruitment

Unsolicited and via open access to the OCD screen on the internet, fourteen individuals completed our posted OCD screen. Of these, eight self-report (or adult) surveys and six child/adolescent report versions of the OCD screen were completed. See Table 1 for a detailed description.

Table 1. Participant Characteristics from Incidental Recruitment via the Internet

<table>
<thead>
<tr>
<th></th>
<th>Child</th>
<th>Adult</th>
</tr>
</thead>
<tbody>
<tr>
<td>OCD screens completed</td>
<td>N = 6</td>
<td>N = 8</td>
</tr>
<tr>
<td>Age (range and mean)</td>
<td>3-10; X=7.7</td>
<td>24-31;X=44</td>
</tr>
<tr>
<td>Female</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>Race</td>
<td>50% Caucasian; 50% Hispanic</td>
<td>100% Caucasian</td>
</tr>
<tr>
<td>Less than $20,000 per year</td>
<td>0%</td>
<td>43%</td>
</tr>
<tr>
<td>Private Insurance</td>
<td>67%</td>
<td>50%</td>
</tr>
</tbody>
</table>
DISCUSSION

A consumer-centered recruitment plan providing a collaborative partnership between the African-American community and the clinical investigators was adopted to enhance recruitment and retention of minority participants into our clinical research programs. The results confirm the difficulties in recruitment of African Americans into mental health research trials even after implementing models of recruitment proposed in the literature such as developing culturally sensitive education materials, utilizing a recruiter representative of the community, and attaining positive responses from direct community involvement at churches (Areán et al. 2003).

Out of 200 packets distributed to participants, only one survey was returned via standard mail. This was an unexpected and disappointing outcome in light of the fact that church leaders had embraced the research study. With pastoral support of the research, parishioners were encouraged to participate with announcements of support from the pulpit during Sunday service, advertisement of the project information on the church bulletin boards, published announcements in the church programs, and information disseminated during health fairs. The lack of response from the targeted African-American cohort did not allow for comparison among the various methods of recruitment.

Another unexpected finding was the unsolicited completion of surveys on the internet. Interestingly, none of the fourteen unsolicited surveys were completed by African Americans. Half of completed internet surveys received scores qualifying the respondent for a comprehensive diagnostic assessment and potential research participation. All parental reports on the internet surveys indicated a desire for their child to participate in the existing OCD research protocols. Unintentional recruitment via the internet was encouraging yet still failed in the attainment of African Americans.

In a study of the Detroit area (the same catchment area for this recruitment study) sixty-four percent of African-American participants indicated that they did not believe that all racial/ethnic groups share the risks of medical research equally (Shavers et al. 2001). Qualitative review of comments made directly by participants during presentations or comments communicated through community leaders revealed a multitude of interrelated factors including lack of awareness about research studies, distrust, fear of being used as guinea pigs, and knowledge of the Tuskegee Study. The recruiters for this study heard comments such as ‘What are they going to do with us now?’ Such negative perceptions of research were also reported in one study that found African Americans are generally familiar with the concept of experimental study, but defined its purpose as an ‘experiment where people are used as guinea pigs’ (Corbie-Smith et al. 1999). Any one of these factors experienced or encountered by African Americans poses a serious challenge to investigator efforts to meet the mandates to include minorities in research.
Other recruitment failures stemmed from recent experience wherein organizations had participated in research only to be abandoned by the research institution when the project ended. The recruiter fielded questions such as, ‘Are the researchers going to disappear after they get what they want?’ Drawing on historical evidence of exploitation of African Americans in medical research to validate their fear of ethical misconduct, participants’ fear and mistrust may have impeded their willingness to complete the distributed surveys (see Shavers-Hornaday et al. 1997; Shavers et al. 2001; and Shavers et al. 2002 for an extensive review of this literature).

Psychiatric disorders may also have greater stigma in ethnic minority populations. Compared to Caucasians, African Americans hold more negative views of mental illness and are more likely to believe that mentally ill individuals are morally inferior or should be isolated from others (Silva de Crane and Spielberger 1981; Alvidrez 1999). Low-income and less educated individuals are also more likely to express concern about the reactions of friends and family if they get help for psychiatric problems than are middle class and more educated individuals (Leaf et al. 1987; Alvidrez 1999). The strong social stigma that African Americans ascribe to mental illness serves as a deterrent to seeking treatment, many seek treatment only when symptoms become severe and community and family support systems fail (Rogler et al. 1991).

An alternative explanation for the lack of response by the African-American cohort may be a low incidence of OCD. The literature, however, indicates the incidence of OCD in African Americans is similar to or greater than in the general population. An epidemiological catchment study that examined lifetime prevalence of specific psychiatric disorders found the percentage of African Americans (0.04 to 0.08) satisfying DSM criteria for lifetime incidence of OCD meets or exceeds the percentage of the non African-American population (0.03-0.04) (Robins et al. 1984; Williams et al. 1998).

It has also been postulated that disparities in research participation may exist because educational materials and outreach programs target African-American groups less often and less effectively. A recent study published in Minorities in Health Research examined the consent rates among persons asked to participate in health research studies and found very small differences in the overall willingness of minorities to participate in health research compared with Caucasians (Wendler et al. 2006). However, they also found that many of the studies invited fewer minority individuals than would be representative of the US population. By developing culturally sensitive educational materials, implementing strategies such as recruiter ethnic match, encouraging individuals to participate by a pastor, and providing education to minority groups in the community, we still were not successful in recruiting African Americans into research protocols.

While the recruiters were able to establish positive relationships with some churches, initially the identification of community recruitment sites willing to participate was difficult. The large churches were layered with bureau-
cracy and contacting the nurses to disseminate health information within the churches proved difficult. Recruiters were informed in some communities of faith, mental illness is perceived as ‘evidence of sinfulness’ and ‘seeking clinical treatment of such illness perceived of as a lack of faith in God and the community’.

This project attempted to mitigate these problems by reaching out to African-American church leaders to increase education, counteracting suspicion of institutional research and decreasing stigmatization of mental illness. The recruiters were successful in reaching out to African-American groups and were embraced by the community leaders who understood the importance of African American participation in research and supported the recruiter’s efforts. These efforts alone did not result in higher participation in the research. It was suggested in discussion sessions with community representatives that the use of incentives might have had a positive effect. The need to involve community members in the designing and execution of studies also remains a significant factor. This study would have benefited through the use of focus groups to further identify ways to improve mental health care and education in the African-American community. It was not within the scope of this project, however, to provide incentives or conduct focus groups.

This study had various methodological flaws. This study used a non-standardized instrument to screen for OCD. Lack of standardization hinders the ability to make cross-study comparisons. And, although the method of information presentation was standardized, it cannot be assumed that instructions for completing the survey were clear. Participants were instructed to complete the surveys regardless of the presence or absence of known anxiety or OCD symptoms. The presentation of the information to large groups of people may also have resulted in a low turn-out. If individuals had been approached on an individual basis in a private setting they may be more apt to participate.

Another methodological limitation was the randomization of response mode. Randomization of the response method (telephone, internet, or standard mail) would have allowed for comparison and evaluation of each method. However, providing participants with only one response mode option, limited the participant choice and neglected to account for participant’s comfort with, or access to, a particular response mode.

Despite these limitations, this study highlights the complex nature of recruiting African Americans into research studies and the necessity of developing community partnerships through focus group development beyond the scope of research project involvement. Each partnership needs to consider what type of community participation is feasible. Partnerships must also identify cultural barriers and work towards alleviating African-American participant fears. African Americans may participate more readily on focused projects that are taking actions that provide tangible benefits, such as child care and transportation. Building in time and resources to allow the participa-
tory process to happen is essential. Community members need time to attend meetings and learn about the benefits of participation. Moreover, use of qualitative and ethnographic methods (individual case studies, interview, histories) would help researchers “get underneath” these findings, offer more to the literature, and provide a greater understanding of cultural and community barriers, the stigma of mental illness for African Americans, and the history of African American oppression and discrimination that leads away from study participation.

This study highlights the complex nature of recruitment and sheds light on areas to be addressed in future research. Clearly, developing a partnership with the African American community is vital to building trust and facilitating understanding of the benefit of African American participation in research. Identifying appropriate and meaningful incentives tailored to specific community-identified needs is imperative. Most importantly, soliciting significant input from the African-American community from the onset and beyond the scope of the research project is crucial.

REFERENCES


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