J Child Fam Stud (2012) 21:273–280
DOI 10.1007/s10826-011-9472-1

ORIGINAL PAPER

# The Significance of Strategic Community Engagement in Recruiting African American Youth & Families for Clinical Research

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**Abstract** We present baseline data and describe the utility of a community engaged, culturally relevant approach to recruiting African American youth and families for phase I of The AAKOMA Project. The AAKOMA Project is a two phase treatment development study to improve mental health service use among depressed African American youth. We completed capacity building activities using a community engaged framework and Community Based Participatory Research (CBPR) methods. Replicating the (Alvarez et al. in West J Nurs Res 28:541–560, 2006) model of systematic community outreach enhanced our ability to effectively recruit partners and evaluate outreach efforts as demonstrated by our Recruitment Success Factor (RSF—i.e. 'an adjusted ratio of eligible participant yield to contacts made'). Using the chi-square goodness-of-fit statistic; we compared the RSFs of the various modes of participant study entry to determine which was most effective. Our target enrollment was 56 persons. We recruited 130 and enrolled 57. Our baseline data is drawn from a gender balanced and socioeconomically diverse sample who participated in youth focus groups and individual interviews and adult focus groups. We identified 3 study participant referral modes (self-referral, provider referral and participant-to-participant referral) with multiple sources per mode and an overall RSF of 0.41. Study findings support the effectiveness of assiduous and systematic community interaction, reflective review of recruitment efforts and the importance of disseminating information on strategic recruitment processes for engaging diverse populations in clinical research.

**Keywords** CBPR · Research recruitment · African American youth · African American families · Depression

## Introduction

African American youth and families face significant barriers to mental health care and research participation. One of the earlier and significant assessments of this concern was provided by McMiller and Weisz (1996) who asked parents of African American, Latino and White youth what steps they took to address youth mental health issues prior to formal mental health clinical intake. What they discovered laid a strong foundation for the access to care barriers

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described in the literature today. Specifically, they found African-American and Latino families to be 0.37 as likely as White families to seek mental health help from a professional or agency as a first step. More recent research has evaluated African American parental and youth perceptions of what is necessary for them to consider utilizing traditional forms of mental health treatment (Breland-Noble et al. 2010; Breland-Noble et al. (in press); Lindsey et al. 2010). With limited exception, (e.g. Breland-Noble et al. 2010) most research in this area focuses on impoverished youth and families who report seeking initial help from family and clergy to provide insight into youth mental health problems. Overall, African American youth who seek mental health help face poorer quality of care and poorer outcomes which contributes to a disproportionate burden of disability from mental illness (Breland-Noble et al. 2005; National Research Council & Institute of Medicine 2009).

In recent years, health disparities researchers have quantified and described the multitude of barriers that African Americans face in mental health research participation. Generally speaking, research in this area points to the pervasive nature of African American underrepresentation in clinical research. In 2003, Guerrier and colleagues reviewed the inclusion of diverse youth in anxiety and depression clinical trials and found that race was often under reported and that recruitment methods for diverse youth were generally unspecified (Guerrier et al. 2003, 2007). Examples of research engagement barriers for African Americans abound and include concerns like lack of transportation, limited or non-existent child care, poor compensation, time constraints related to parental work schedules and general life crises that interfere with study participation (Gibson and Abrams 2003; Lee et al. 2006). In addition, socio-historical factors like the United States Public Health Service Tuskegee Syphilis Study and enduring perceptions that African Americans disproportionately shoulder the burden of illnesses without receiving any of the benefits of medical research, contribute to researcher difficulties in the engagement of African Americans in biomedical and mental health research (Hamilton et al. 2006; Whaley 2001). Recent reports of United States Public Health Service misconduct, via the deliberate infection of Guatemalan prisoners with the sexually transmitted disease syphilis in the 1940s, are likely to reinforce such historical fears and concerns (Reverby 2011). With the multitude of barriers to mental health care and research faced by African American youth and families, it is not surprising that members of this group remain underrepresented in mental health research. Therefore, The AAKOMA Project team presents the results of our pilot treatment development study as a means of better understanding and addressing African American research and care engagement barriers.

Researchers have developed a body of literature related to best practices for engaging African American participants in research (Bell and McKay 2004; Gibson and Abrams 2003; Gilliss et al. 2001; Smith et al. 2007; Thompson et al. 1996; Yancey et al. 2006). Thompson et al. (1996) outlined the importance of "intensive-preliminary interaction" with community members and immersion in the local environment. Smith et al. (2007) described ten trends relevant for researchers interested in creating and maintaining positive regard in African American communities. The trends include community involvement by research team members and having persons of color represented in leadership and other roles on the research team. While Thompson and Smith focused primarily on research conducted with African American adults, researchers at the Community Mental Health Council, Inc. (CMHC) of Chicago, IL led by Dr. Carl Bell, developed The Seven Field Principles of community psychiatry based on The Theory of Triadic Influence (TTI). Their focus was to implement a mental health and wellness infrastructure relevant for child and adolescent mental health research for youth and families (Bell and McKay 2004; Flay et al. 2009). Stated succinctly, the seven principles include, rebuilding the village, providing access to health care, increasing connectedness, increasing social skills, reestablishing the adult protective shield, increasing self-esteem and minimizing trauma (Bell and McKay 2004).

While research on barriers to African American participation in research has consistently focused on the historical, institutional and individual impediments to engagement, current best practices refer to the necessity of utilizing local experts (i.e. community leaders) to facilitate and enhance engagement (Breland-Noble et al. 2006; Laborde et al. 2007). Overall, the unifying theme in effective approaches to community engaged research practices with African Americans includes a rigorous, empirically based, strategic approach to relationship building and direct, sustained involvement with community members (Jones et al. 2006).

Though research and treatment engagement of African Americans has developed into a topic of interest among researchers, little of this research focuses on the engagement of African American youth. Of the literature in this regard, most focuses on small studies designed to better understand adolescent perceptions of mental health help-seeking behaviors and attitudes about mental illness and mental health professionals (Cauce et al. 2002; Jacobs et al. 2008; Lindsey et al. 2006; Molock et al. 2007). With this manuscript, we propose to add to the behavioral clinical trials literature by describing the utility of a community engaged, systematic approach to the successful recruitment and engagement of African American adolescents and families into a multiphase treatment development pilot trial for depressed teens. We will describe the factors that supported successful community involvement and collaboration within a socioeconomically diverse African American community sample for our study, The AAKOMA Project. Via the replication of the Alvarez et al. (2006) model of strategic community outreach, we provide evidence of the efficacy of outreach efforts (as measured in part by study patient yield) and describe our systematic approach to community capacity building.

The AAKOMA Project, described by Breland-Noble et al. (2006), is a multi-phase clinical intervention development study (for depressed African American adolescents and their families) for the identification and reduction of psychological barriers to mental health treatment. Referring to the Seven Field Principles mentioned earlier, our research team focused on three in our community engagement efforts including (1) re-establishing the village, (2) providing access to health care and (3) improving bonding, attachment and connectedness dynamics. We operationalized these principles by developing and expanding our community partnerships and coalitions within a broad socio-cultural framework (i.e. re-establishing the village) ensuring that where possible, we provided current healthcare resource contact information for study families (i.e. providing access to health care) and our development of strong, mutually beneficial relationships among the investigators, local community members, clinicians and stake holders (i.e. improving bonding, attachment and connectedness dynamics).

Phase I of The AAKOMA Project included a mixed methods approach to collecting background data. Phase II included a treatment development, pilot randomized controlled trial focused on a novel approach to adolescent treatment engagement. We report data from phase I, which included qualitative data collection through focus groups and survey research with African American adolescents (primary target population) and primarily African American adults (including 1 white adult participant) (see Breland-Noble et al. 2006 for a detailed description).

## Methods

### Procedures

### *Building Community Relationships: The Adult Advisory Board*

In accordance with standard practice for community engaged research (Horowitz et al. 2004; Minkler and Wallerstein 2008), our research team agreed that a community advisory board was essential to our efforts to gain insight into best practices for collaborating with our local community. To develop the adult advisory board, we employed multiplicity sampling (i.e. asking persons initially contacted by a researcher to nominate others in their 'networks' who might fit the criteria of interest to the researcher) to identify potentially interested African American community leaders (e.g. clergy, school personnel, healthcare providers, etc.) (Sudman et al. 1988). Our methods yielded a final board of 14 members with whom we communicated via regular face-to-face meetings, email and phone to enlist their support for community information, assessment of the cultural relevance of our study protocol and implementation of our research methods. Primary among the board's initial recommendations was the development and articulation of a post-study sustainability plan. Recommendations for the plan included updating the AAKOMA Memorandum of Understanding at study ending, continuation of the study newsletter and website, formalizing community-university linkages for grant submissions and training for community members in CBPR and clinical research. The advisory board also asked us to consider ways to acknowledge our local community's contribution to our efforts by offering training and employment opportunities to community youth.

### *Recruitment*

The Duke University Health System Institutional Review Board for Clinical Investigations reviewed and approved our study protocol and our research team obtained a Certificate of Confidentiality from the National Institutes of Health for the study. Subsequent to recruitment, enrollment in the study phase consisted of participants providing feedback to the research team via focus groups and individual interviews.

We supported the recruitment efforts of our advisory board by recruiting study participants through community outreach events (seminars), utilizing a senior study/community liaison (also a member of the adult advisory board), the principal investigator's (PI) community network, participant to participant referrals, our University Health System website and local media appearances by the study team and adult advisory board members.

Regarding specific recruitment strategies, we collaborated with our lead community liaison (a suicide survivor) to develop and disseminate a culturally relevant adolescent depression awareness and suicide prevention package of literature along with our research study literature at every community outreach event we participated in (in keeping with the field principle of *providing access to health care*). As we shared literature with potential study families at all outreach events, we collected contact information from those families who verbally (at an outreach event) or in written form (e.g. via a sign-up sheet or in an email to the PI) expressed interest in study participation. Our study team continually compiled and updated a contact list of all individuals expressing interest in the study and maintained contact with these persons via the mailing of our study newsletter, published 2–3 times per year. This process allowed us to maintain a potential study patient database which we could then actively use in a strategic manner. In essence, our research team met periodically to discuss whom to contact from our list and to share any personal experiences with study families that might provide clues as to when and how to best initiate contact with them. This process follows the Alvarez model and helped our research team to economize our time by easily eliminating the names of families whom we assessed as disinterested or unavailable (e.g. had outdated contact information or were interested only in direct clinical services from the PI).

Initial contact with study families followed their stated, preferred mode of contact (e.g. phone or email) to either set up a time to complete the formal phone screen or to immediately complete the initial phone screen. For all persons who met initial inclusion criteria via the phone screen, we immediately followed up with them with a letter of invitation to the study followed by a confirmatory phone call. Once confirmed for the study, study families completed the enrollment process via an in-person consent/assent review and assessment with a trained clinician-researcher followed by a focus group or individual interview. Results from the youth focus groups and individual interviews, and the separate adult focus groups, are described in other manuscripts (Breland-Noble, Burriss, Bell, & The AAKOMA Project Adult Advisory Board, Under Review; Breland-Noble et al. 2010).

### *Inclusion/Exclusion Criteria*

Recalling the focus of Phase I (a qualitative examination of African American youth and adults' perceptions of the barriers to depression treatment and research engagement), we included persons of direct relevance to our topic of interest using systematic non-probabilistic sampling. As described by Mays and Pope (1995), non-probabilistic sampling ensures that, "specific groups of people who either possess characteristics or live in circumstances relevant to the social phenomenon being studied," (Mays and Pope 1995, p. 110) are included. For this study, these individuals included African American persons who either declined or accepted offers to participate in mental health treatment and/or research. Adolescent inclusion criteria were youth (a) between the ages of 11 and 17 at the time of recruitment; (b) self-identified as Black or African American (non Latino); (c) ever offered mental health care and/or research participation and (d) with demonstrated cognitive ability to understand the study and be an active participant. Adult inclusion criteria were adults who a) parent an African American adolescent (at present or in the past) with suspected or diagnosed depression or (b) have relevant and significant professional experience working with African American adolescents with suspected or diagnosed depression. We deliberately included non-parent adults, as well as any non African American adult who met the inclusion criteria, as we believe that individuals who interact regularly with African American adolescents (e.g. clergy, counselors and teachers) have insight relevant for the study. We hosted separate adult and youth focus groups and we separated youth focus groups into older (ages 14–17) and younger (ages 11–13) cohorts.

### Measures

In the Alvarez et al. (2006), quantitative data of recruitment effectiveness is traced via a Recruitment Process Log Form (RPL), a written form on which the study team records the multiple sources of recruitment, the number of contacts made to each source and the number of study referrals received per source. Relevant qualitative data is garnered from compiling notes on potential community partners and research team member discussions of the successfulness of outreach efforts.

## **Results**

We used the Recruitment Success Factor (RSF) to quantify the recruitment yield in relation to outreach efforts via the following formula: $(\mathrm{RSF} = (\mathrm{P} + 1)/(\mathrm{C} + 1)$ where $\mathrm{P} =$ participants yielded and $\mathrm{C} =$ contacts made, (See Alvarez et al. 2006 for more information). Referral sources included faith based organizations, local public school administrators and student services personnel, our University Health System website, our senior community liaison, community seminars, the PI, participant-to-participant referrals, and media appearances (radio and television). Referrals were classified as (a) self-referral (generally from a community outreach event/presentation), (b) provider referral (generally via word of mouth from a clinician/provider to potential study patients) and (c) participant-to-participant referral (i.e. learned about the current study from another study participant).

Table 1 includes the number (and percentage) of participants enrolled, the total number of contacts, the percentage of effort exerted, the RSF and the referral mode for each source. Since ours was a pilot study, we acknowledge our small sample size but note the socioeconomic diversity of study families with only 23% of the sample living at or below the poverty level, a finding consistent with reports of national samples of African Americans (Breland-Noble et al. 2005).

We anticipated enrolling 56 individuals for Phase I of our research. We recruited and contacted 130 study

**Table 1** Recruitment yield by community referral source

| Community referral source | Number of participants enrolled | % of Total participants enrolled | Number of contacts | % of logged efforts | RSF[a] | Major referral mode[b] |
|---|---|---|---|---|---|---|
| Faith based | 2 | 3.51 | 4 | 2.86 | 0.60 | SR |
| Local school administration | 4 | 7.02 | 9 | 6.43 | 0.50 | SR |
| Student services | 1 | 1.75 | 2 | 1.43 | 0.67 | PR |
| Adult advisory board | 3 | 5.26 | 7 | 5.00 | 0.50 | PR |
| University health system website | 6 | 10.53 | 13 | 9.29 | 0.50 | SR |
| Community liaison | 12 | 21.05 | 13 | 9.29 | 0.93 | PR |
| Community seminars | 15 | 26.32 | 61 | 43.57 | 0.26 | SR |
| Principal investigator | 4 | 7.02 | 10 | 7.14 | 0.45 | PR |
| Participant—participant referral | 6 | 10.53 | 7 | 5.00 | 0.88 | TR |
| Locally owned business | 3 | 5.26 | 11 | 7.86 | 0.33 | SR |
| Media 1: Radio | 0 | 0 | 2 | 1.43 | 0.33 | SR |
| Media 2: Television | 1 | 1.75 | 1 | 0.71 | 1.00 | SR |
| Total | 57 | 100.00 | 140 | 100.00 | 0.41 | |

[a] *RSF* Recruitment success factor

[b] *SR* Self referral, *PR* Provider referral, *TR* Participant to participant referral

families and enrolled 57 via 12 referral sources and 3 referral modes thereby exceeding our enrollment goal. In order of recruitment yield high to low, our study families were referred from community seminars (26.32%), our community liaison (21.05%), the Duke University Health System Website (10.53%) and participant to participant referrals (10.53%). Effective recruitment sources, defined as percentage of human effort exerted by the research team compared to patient yield from that source were community seminars (43.57%), the Duke University Health System Website (9.29%) and the community liaison (9.22%).

### Recruitment Success Factor (RSF)

Based on the RSF score, our senior community liaison produced the highest recruitment yield per outreach effort (RSF = 0.93). Although we recruited 21.1% of the study's participants from our community liaison, only 9.29% of our recruitment efforts were directed there. In contrast, the community outreach events yielded the most participants (26.3%) but also required considerable outreach efforts (43.6%) thus resulting in a much lower recruitment success factor (RSF = 0.26). Media produced the lowest recruitment yield in relation to outreach efforts (RSF = 0.25). Only one participant was recruited via media resulting in an RSF of 1 and an RSF of 0.33 for radio. We completed a *Chi-square goodness-of-fit test* between the mean RSFs (Recruitment Success Factors) of the major referral modes (i.e. SR-Self-Referral; PR–Provider Referral; TR–Participant to Participant Referral) and found the results to be non-significant $\chi^2$ (2, $N = 3$) = 0.000, $p = 1$.

## Discussion

Our study data revealed that intensive-preliminary interaction was essential for our engagement of African American youth and families. This level of interaction was reflected in the sustained efforts of our senior community liaison, an African American professional school counselor trained in suicide prevention. As a suicide survivor whose son completed suicide at the age of 15, she was passionate about the need for African Americans to be educated about suicide. In fact, it was on her advice that we incorporated suicide prevention information into our outreach informational packets and our community seminars. We believe that her effectiveness was enhanced by the fact that she matches the race of our target population, is a longstanding, well-respected member of the community and was a member of our adult advisory board. Additionally, we believe that the integration of suicide prevention and depression education was an effective tool for highlighting the importance of addressing adolescent mental health concerns. In fact, it was often the case that local families first identified the possibility of their adolescent being depressed after attending an AAKOMA Project community seminar (H. K. Poole, personal communication, June 2008).

In our evaluation of the efficacy of our outreach efforts, we found that of the 12 recruitment sources we utilized, our senior community liaison and community outreach seminars produced the highest recruitment yield. The remaining referral sources yielded approximately half the number of participants as were yielded by our community liaison and community outreach seminars. For example, our University Health System Website had the same number of contacts and percent of effort as the community liaison; however, from 13 contacts, only 6 participants were enrolled. In contrast, of the 13 contacts from the community liaison, 12 participants were enrolled. Media involvement produced the lowest recruitment yield with less than 2% of recruitment efforts directed there. In the growing body of literature on best practices for engaging the African American community in research, having persons of color represented in substantial leadership roles on the research team is considered essential (Bell and McKay 2004; Gibson and Abrams 2003; Gilliss et al. 2001; Smith et al. 2007; Thompson et al. 1996; Yancey et al. 2006). Given that our research team was multiracial and included African Americans in leadership roles, we believe that our findings support the effectiveness of this idea. In other words, it is possible that the opportunities for potential study families to physically view the multiracial composition of our team provided better recruitment yields than when they were unable to view us. Future studies might examine the significance (or lack thereof) of racial and ethnic diversity in research teams conducting clinical research with African Americans.

Recall that because this study focused on understanding how to engage depressed African American youth in research and clinical care one of the inclusion criteria was that potential participants not currently be in treatment for depression. Our research team encountered little difficulty locating and enrolling socioeconomically diverse, insured and uninsured youth who met this criterion lending validity to the idea that psychological factors (as opposed to solely financial barriers) may contribute to African American underrepresentation in mental health clinical research and care. While it was clear to many enrolled study families that their teens might be at risk for depression, or were actually depressed, most had not sought any type of treatment nor participated in any local clinical trial for adolescent depression. Given that many of these families were insured and/or had been approached to participate in research even via the research team's home institution, most remained reluctant to initiate contact with local providers or clinical researchers. Nevertheless, our research team successfully recruited this typically hard to reach sample and engaged them in a research study.

Interestingly, most research in the area of African American adolescent depression research and clinical care focuses on financial and logistical barriers to care as they impact predominantly impoverished, resource poor, urban families (Breland-Noble 2004; Lindsey et al. 2006; Thurston and Phares 2008). We believe that our pilot study is novel with regard to the socioeconomic diversity of the families and the focus on non-financial potential barriers to research participation and clinical care use. Though the focus of this manuscript was not on the relationship between clinical care use and familial and cultural factors among African Americans, the research team has published findings in this regard elsewhere (Breland-Noble et al. 2010).

There are a few limitations to discuss regarding our study, primary among which is the small sample size. Though small, the sample size for this study approximates the sample sizes of African American youth in 2 of the most recent adolescent depression multisite trials using community and clinical samples (the Treatment of Adolescents with Depression Study—TADS—13 sites, 57 African American youth randomized and the Youth Partners in Care Study—YPIC—6 sites 54 African American youth randomized). An additional limitation is that this study utilized a volunteer sample. Though the sample was recruited using culturally relevant and systematic means, essentially all persons who participated in the study did so of their own, or their parents', volition. A replication of our study might include collecting data from primary care, school or juvenile justice samples. Such diversity in setting might still yield larger numbers of African American families while also further reflecting the socioeconomic diversity of this population. Finally, we acknowledge the significance of our partnership with our senior community liaison and advisory board members with specific interests in reducing health disparities in mental health. Though we are aware of the utility of such groups for other heath conditions and settings within the African American community (Ammerman et al. 2003; Chene et al. 2005) further research is necessary for us to better understand the constellation of factors that make this type of advisory board useful for mental health research.

Overall, our findings exemplify the utility of a systematic approach, relationship building and direct interaction as vital to engaging African American families in clinical treatment research. The findings contribute to the literature by demonstrating the importance of sustained community interaction and the value of a systematic documentation and review of the recruitment process for diverse populations. The existing literature addressing recruitment among underserved populations has largely been descriptive in nature (Yancey et al. 2006). However, there is a burgeoning literature which outlines the importance of integrating rigorous science and community engaged practices (Breland-Noble et al. 2010; Jones and Wells 2007; Wells et al. 2006). The systematic recruitment approach described in this manuscript is based on an integrated theoretical framework supported by a quantifiable approach to tracking and evaluating recruitment efforts. Alvarez et al. (2006) model was critical to our ability to monitor our efforts and report on our successes. As this model was straightforward to implement and generated important knowledge yields for our study team, we believe it reasonable to suggest that the model should be further adapted and implemented with other populations underrepresented in clinical research.

**Acknowledgment** Dr. Breland-Noble is funded by a career (K) award from the National Institute of Mental Health (NIMH) (MH073814) and was funded by the Loan Repayment Program via the National Center for Minority Health and Health Disparities (NCMHD) during data collection for the study reported herein. The AAKOMA Project Adult Advisory Board Members include Reverend Clarence Burke, Beacon Light Missionary Baptist Church; Ms. Cynthia Clinton, J.D. Duke University Medical Center; Dr. Karon Dawkins, UNC Department of Psychiatry and Behavioral Sciences; Mrs. Cynthia Laws-Davis, Passage Home; Dr. Angela Lee, North Carolina Central University Counseling Center; Dr. Theresa Lewis, private practice; Mrs. H. Kathy Poole, retiree, Durham Public Schools; Mrs. Janis Quarles, Wake County Schools; Mrs. Karen Sansom-Goodman, Haven House; Judge Joe Webster, NC Office of Administrative Law; Dr. Delbert Wigfall, Duke University Medical Center, Department of Nephrology; Mr. Allan Younger, retiree, IBM; and Mrs. Marjorie Younger, retiree, Wake County Schools.

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