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Understanding the African American Research Experience (KAARE): Implications for HIV Prevention

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SUMMARY

Despite recognition that the African American population is underrepresented in studies of health and mental health treatment and prevention efforts, few investigations have systematically examined barriers to African American research participation. Without their participation, treatment and prevention strategies designed to curtail the spread of HIV in their communities will be bound to achieve less than optimal outcomes. Based on the assumption that successful recruitment of African Americans requires knowledge of (a) their beliefs about research, (b) their perceptions of the research process and researchers, (c) their motivations to participate, and (d) the historical and social factors that may be the source of at least some ambivalence, the current study undertook semi-structured interviews with 157 African American, low-income mothers residing in a large urban community where they and their children were at high risk for HIV. Given the sensitive nature of the research topic, members of the community were trained to conduct the interviews. Qualitative and quantitative analyses of the interview content suggest that despite having been consented, many participants (a) are not aware of their rights under informed consent and (b) lack knowledge of how the research will be used. Despite this and the subtle suspicion of White researchers held by some, many decide to participate for altruistic reasons. The implications for recruitment of participants in general and African Americans in particular into HIV prevention studies are discussed as are the implications for service providers directly or indirectly involved in the development and delivery of these interventions.

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Keywords

Examine barriers to participation; implications of recruitment; implications for service; providers; under representation of African American population; low-income mothers at high risk

Research aimed at creating and testing preventative interventions in social work or allied professions depends on the recruitment of participants from the communities and populations for which these interventions are intended. Additionally, ethical conduct of research calls for sensitivity to the needs and circumstances of ethnically diverse populations (Gil and Bob, 1999; Fisher, Hoagwood, Boyce, Duster, Grisso et al., 2002). Noting the under-representation of African Americans in psychosocial research and with the ultimate goal of devising strategies to encourage African American enrollment in research projects, the current study aims to identify impediments to recruiting African American research participants and to understand their experiences as participants in research.

To date, few studies have addressed the issue. Of those that have, the majority have considered the under-representation of African Americans in medically-oriented research, particularly clinical trials (e.g., Gorkin, Schron, Handshaw, Shea, McKinney, Branyon et al., 1996; Roberson, 1997; Green, Partridge, Fouad, Kohler, Crayton, and Alexander, 2000). Based on reviews of the literature or extrapolation from publications on cultural competence (Shavers-Hornaday, Lynch, Burmeister, and Torner, 1997; Dennis and Neese, 2000; Alvidrez and Arian, 2002), the feedback of focus groups (Freimuth, Quinn, Thomas, Cole, Zook, and Duncan, 2001), or evaluations of samples of less than 75 participants (Freedman, 1982; Freimuth, Quinn, Thomas, Cole, Zook, and Duncan, 2001), most have suggested that social, political, and historical factors and widely held beliefs and attitudes about research impede African Americans adults from participating in health-oriented projects.

Salient themes in this body of literature have included the impact of knowledge of the Tuskegee Syphilis Study (Brawley, 1998; Shavers, Lynch, and Burmeister, 2000), African American distrust of White researchers and institutions (Corbie-Smith, Thomas, and St. George, 2002), the importance of culture-specific recruitment strategies (Bonner and Miles, 1997; Ashing-Giwa, 1999), and motivations to participate (Sengupta, Strauss, DeVillis, Quinn, DeVillis, and Ware, 1999).

These studies have yielded conflicting and often surprising results. For example, when asked in one study if knowledge of Tuskegee influenced decisions to participate in a clinical trial, interviews with thirteen African American women suggested that it would not (Freedman, 1998). In another study, African Americans were significantly more likely than Whites to say that knowledge of Tuskegee caused them to be less trustful of the researchers, but were not more likely than Whites to cite the event as a deterrent to participation (Shavers, Lynch, and Burmeister, 2000). Others (Bonner and Miles, 1997; Ashing-Giwa, 1999) have concluded that culturally compatible recruitment strategies, while important, do not guarantee increased enrollment among African Americans and urge exploration of additional impediments. In a few existing studies, explanations of African Americans' decisions to participate have included altruism (Sengupta, Strauss, DeVillis et al., 2000; van Stuijvenberg, Suur, de Vos, Tijiang, Steyerberg, Derksen-Lubsen, and Moll, 1998) and volunteerism (Corbie-Smith, Viscoli, Kernan, Brass, Sarrel, and Horwitz, 2003).

While this research provides insights into African Americans' thinking regarding research, the hypothetical or actual context of the clinical trial or medical research typically differs dramatically from the contexts of psychosocial research where participants are not being confronted with the possibility of death or negative health consequences. Unfortunately, a

relatively limited number of studies address recruitment or the participation of African Americans in research on health-related behaviors, psychosocial issues, or interventions. Examples include studies of recruitment of African Americans into research on a smoking cessation program (Woods, Harris, Mayo et al., 2002), a HIV-prevention program, and mental health (Thompson, Neighbors, and Munday, 1996; Alvidrez and Area, 2002). Each of these studies raise questions about the generalizability of findings regarding research participation in medical settings to research participation in studies concerned with psycho-social issues or behavior change. Discussions of the recruitment and experiences of African American research participants in the social work literature (Hatchett, Holmes, Duran, and Davis, 2000) are especially rare.

The current study adds to the literature pertaining to African American research participation in several ways. First, it addresses African Americans' thoughts about and knowledge of research and research participation outside the medical context. Second, to increase the reliability and validity of results, it draws upon a socio-economically homogeneous group of 157 African American individuals from a large mid-western city, utilizes a semi-structured interview and trained African American interviewers from the participants' community, and relies upon both quantitative and qualitative analysis. Finally, all members of the sample were parents of children under eighteen years of age and had agreed to participate and to allow their children to participate in this study.

METHOD

The authors of this study employed grounded theory. This approach, rather than beginning with a hypothesis to test, develops concepts based on the data and hypotheses grounded in the data (Charmaz, 1990; Glaser and Strauss, 1967; Strauss & Corbin, 1990). The approach, therefore, highlights the perspective of the client and, in doing so, remains consistent with a full range of social work values and values in the field of psychosocial research (Arnoff and Bailey, 2003). Quantitative analyses supplemented this approach and served as a useful source of contrast and comparison.

Measures

The basic study instrument, the Research Information Questionnaire, consisted of 15 open-ended questions meant to tap previous experience with research, attitudes about research activities, barriers to participation (Stevenson, 1994), and understanding of previous research events in African American communities (e.g., The Tuskegee Syphilis Experiment). The questions typically called for brief explanations of (a) the participants' reasons for participating and (b) their attitudes and perceptions related to the research endeavor. Because of the sensitive nature of the interview questions, all interviews were conducted by trained members of the community to reduce the likelihood that participants would censor their responses.

DATA COLLECTION PROCEDURES

Sample

The sample for the KAARE project consisted of 157 adult caregivers who were selected to participate in the Chicago HIV and Adolescent Mental Health Project (CHAMP), a multiple family group program aimed at increasing family communication to reduce the risk of children contracting HIV. The sample was randomly drawn from schools located adjacent to or on Chicago public housing projects and within 11 blocks of each other. These schools serve elementary school children and are 99% African American. Approximately 70% of families are supported by Public Assistance; 75% are single, female-headed households; 63% of adult caregivers had not worked in the last year. Selection of these schools from which to draw the

sample of adult caregivers allowed the authors to draw a relatively homogeneous sample, to help control for factors of community, poverty, and ethnicity.

Informed consent was obtained from all participants following IRB approval of the protocol from the University of Illinois, Chicago. The protocol entailed reading the informed consent aloud with participants and answering questions. In addition, interviewers asked a set of questions to insure that participants understood.

DATA ANALYSIS

The researchers reviewed the completed interviews, identified response patterns distinct to each question, and developed a preliminary coding scheme that would allow for quantitative analysis of the data and permit detection of general trends that could inform the qualitative review. The inter-rater reliability, based on a two way random effects inter class correlation, revealed an alpha value of .85.

The researchers adopted Campbell's (1978) mixed methods approach to analyze the data based on the belief that it is important to express qualitative perspectives, methods, perceptions, and conclusions while also communicating findings that are at least partially amenable to quantitative representation and, therefore, quantitative analysis.

The coded interviews and the complete qualitative responses to each question were entered into an SPSS database. Qualitative analysis involved isolating the text that corresponded to each question, noting common themes, and interpreting the responses against the backdrop of the scaled response created for the quantitative analysis. This approach enhanced the possibility of distinguishing participants' explicit and implicit responses.

The first step in the quantitative analysis involved calculating the frequencies of responses as coded through the qualitative analysis. Then, correlations and multiple regressions were used to determine the relationship between motivations to participate in research and the tensions between community residents and outside researchers. Because variables measuring the understanding of the research experience were dichotomous, one-way ANOVAs and logistic regressions were employed to determine the relationship between the motivation to participate in research and knowledge of the research process.

RESULTS

Univariate Results

Motivations to participate in research—Nearly one in four participants maintained that they would not agree to be in a research study if they would not get anything out of it. While many did not expound on their negative responses, far more indicated that they expected to learn something as a result of participation or to contribute to the welfare of their children and/or community. None cited money or in-kind reimbursement as a motivation. Interestingly, those saying that they would agree to be in a research study, regardless of what they would receive in return, implied that they were motivated by what they assumed to be intrinsic to the research participation experience: learning something or contributing to the welfare of others. The remainder of those who replied “yes” conditioned their participation on the nature of the study itself. One individual's comments, “just verbal, not physical, no medicine, no needles”, summed up the general rationale of these participants.

Tensions between community residents and outside researchers—The overwhelming majority of participants claimed that being interviewed by someone who was not from their neighborhood would not be a problem (83.4%, $n = 132$). Reasons varied. Some

said they thought it would be easier to talk to an interviewer from outside the neighborhood. Others' responses were consistent with the statement, "It will be okay; a researcher is just a researcher." The minority of participants, asserting that they would be less comfortable with an interviewer who did not reside in the neighborhood, almost unanimously cited the interviewer's lack of familiarity with the neighborhood as the reason for their uneasiness.

Participants were similarly indifferent to being interviewed by a White researcher. 92.4% ($n = 145$) said they would feel comfortable being interviewed by a White researcher. While some simply said that it wouldn't bother them and implied that the White researcher was the equivalent of the interviewer from outside the neighborhood, many specifically noted that they were "not racist," "not prejudice," or "it does not matter of the color of your skin." Others attributed this comfort with the White interviewer to characteristics that distinguished them as individuals.

It wouldn't make a difference because I am biracial.

I was brought up Christian.

A few implied that the race of the interviewer did not matter because "help come from Black or White," the research was being conducted "for a good cause," or interviewers were just "here to do a job."

Seventy-two percent ($n = 113$) of respondents believed that African American's can be treated fairly by White researchers. Those who did not trust White researchers cited reasons including:

We've never been treated fairly.

They (White researchers) are the devil. I can't trust these people.

White people think they are all that and treat black people like slaves.

Similarly, roughly two-thirds ($n = 103$) of participants did not believe that Whites would use information any differently than Blacks. Their explanations can be captured in three categories: (1) Whites and Blacks are really no different, (2) the subject of the research threatened the White community as well; racism was not the focus of the study, and (3) Whites who are researchers are different. The third of participants who expected that Whites would utilize the data differently suggested that Whites, not sharing the same worldview, would misinterpret, or less often twist, the words of Black participants. A small subset answered that the White researcher's use of the data "depends on" the individual interviewer, his/her professional affiliation, or the purpose of the research.

When asked about their views regarding the possibility of research hurting their community, 72% ($n = 113$) said that research could not hurt their community. Most participants replied that research would not be used to hurt people because their own responses were intended to help people or would not include information that could implicate or harm someone else.

Another group asserted that research would not be harmful because its aim was to help the people and community or because it was confidential. When elaborating on their responses, the nearly one-third of participants who said that they thought research could be hurtful, cited lapses in confidentiality and the nature of information that people gave to researchers as the reason. Overall, in answering this question, participants did not refer to research as an impersonal, objective process. Rather, their responses quite consistently concerned the individual effects of what they said or what researchers divulged, rather than the nature or results of the scientific investigation itself, as the potentially hurtful consequence of research.

Knowledge of the research process—For the purpose of this study, knowledge of the research process refers to the extent to which participants are knowledgeable about the purpose

of the study, clear about the expectations associated with participation, and accurate about the risks and benefits associated with the proposed study prior to deciding to involve themselves.

Twenty one percent ($n = 33$) were unaware that a researcher must obtain written consent before a person can participate in a research study:

It would depend on the nature of the research as long as it is not negative [they don't need to know they are participating].

[They don't need to consent] because there is a lot they can be done to help African Americans. Some of them have a lot of problems.

Participants with knowledge of the informed consent process cited the following reasons for its importance:

Too much has happened to us already.

It's illegal not to get their consent.

So Black people will know what White people are saying about them.

When asked if they worried that a researcher was not informing them of all the information they needed to know before they consented to the study, 45.2% ($n = 71$) said they had some level of concern. Those who answered "no" seemed to fall into one of two groups. The first group who said they would not worry about the researcher disclosing important information about the research suggested that they did not worry because they trusted the researcher. These participants often conveyed a willingness to "suspend" judgment or belief in the researchers' good intentions:

I wouldn't worry 'cause I'm hoping they're telling the truth.

The second group, conveying more suspicion and a greater sense of control, said they would not worry because their participation would be contingent upon having their own set of questions satisfactorily answered by the researchers.

The participants who said "yes," they would worry about the researchers' divulgence of all necessary information usually explained that they did not trust people as a general rule. Fewer suggested that, if one was not suspicious of the research and did not ask questions, he/she was acting irresponsibly. Just five singled out researchers as people not to be trusted.

Participants' responses to the question about their concerns about their information being kept private closely resembled their explanations of why they would or would not worry about being told everything they needed to know about the research. 42.7% ($n = 67$) said that they did worry that all information was not being kept private. However, more ($n = 78$) simply chose to take their chances and believe what they were told:

[I don't worry] because it's supposed to be confidential.

Others were not concerned about privacy because they controlled their responses as in:

I wouldn't tell nothing that I would be scared for somebody else to see.

The majority of those who stated that they did have concerns about privacy, like those who worried about being told everything they needed to know, implied that they generally viewed others with skepticism. Fewer of them distinguished the characteristics of the research environment with its easily accessible information that might get lost or viewed by unauthorized eyes as the basis of their concerns or the sensitivity of the information they provided. Most of these individuals regarded "leaks" of information as inevitable. For some, the sensitivity of the subject matter affected their concerns.

When asked what they thought researchers would do with the information they were given, participants often referred to specific aspects of the research endeavor—“analyze it,” “compare it,” “study it,” “combine it with other information.” The majority “[did] not know,” were not sure, or “hoped” that researchers would use all of the data. In fact, more participants skeptically predicted that researchers would do nothing with the information than draw upon it to improve the community or people in general.

To tap into the participants’ knowledge of the history of the African American experience within the context of research, questions were included about their knowledge of the Tuskegee Project. Thirty-five participants had heard of Tuskegee. Of these, ten correctly noted that the Tuskegee experiment involved Black men and syphilis, fourteen remarked only on the study’s focus on syphilis, four mentioned only that the experiment involved Black men, and the remainder associated it with sexually transmitted diseases, did not know, or did not respond at all. Four of the 35 respondents had learned about Tuskegee from the television movie, “Miss Evers Boys.” Just three of the 35 provided explanations of the Tuskegee Experiment that accurately captured what occurred. While a few mentioned that the cure for syphilis or the “disease” had been withheld, just one individual noted that the subjects in the study were not aware of their role in the experiment. Refer to Table 1 for a summary of descriptive statistics.

Bivariate Results

Motivations to participate in research—At the bivariate level, Pearsons correlations revealed that there was a positive relationship between the belief that information from research could be used to help people and that African Americans can be treated fairly by Whites ($r = .17, p < .05$).

Tensions between community residents and outside researchers—A negative relationship existed between the belief that White researchers will use information differently and feelings about researchers who are not from the neighborhood ($r = -.15, p < .05$). This relationship indicates that the more comfortable individuals were with the researcher not being from their neighborhood, the less likely they were to believe that a White researcher would use information differently than a black researcher. Conversely, those who were not comfortable with the “outside” researcher tended to believe that Whites would utilize the information differently than African Americans.

Knowledge of the research process—Numerous relationships existed between the variables measuring knowledge of the research process. Pearson’s correlations revealed a relationship between the belief that White researchers will use information differently than black researchers and the fear that researchers do not tell participants all pertinent information about the study ($r = .16, p < .05$). The fear that researchers do share pertinent information with participants was also associated with the worry that information from the study is not kept confidential ($r = .21, p < .01$). Results from an analysis of variance showed that people who had heard of Tuskegee also believed that research could be hurtful to them or their neighborhood ($F = 5.95, p < .05$) and that White researchers would use the information differently than African American researchers ($F = 3.72, p < .05$), but that they would still be willing to participate in a research study even if they would not benefit directly ($F = 6.40, p < .01$). Table 2 describes these bivariate relationships.

Multivariate Results

Motivations to participate in research—Logistic regression revealed that when controlling for the fear that White researchers will do something different with research data than black researchers and the fear that the research could harm their neighborhood, people

who had heard of Tuskegee were significantly more likely to participate in research even if they did not personally gain from it ($\text{Exp}(B) = 2.165, p < .05$).

Tensions between community residents and outside researchers—Multiple regression analysis indicated that when controlling for comfort of being asked questions by a researcher, people who worried the information they provided would not be kept private also worried that the researcher was telling them all the information they needed to know about the study ($F = 5.60, p < .01$). Refer to Table 3 for a complete description of the multivariate analysis.

DISCUSSION

Motivation and Trust

The majority (67.5%) of respondents' comments suggested that they would agree to participate in research studies if, in doing so, they would learn something or would help their children or the African American community. Even higher percentages indicated they would have no problem answering questions posed by an interviewer from outside the neighborhood (83.4%) or who were White (92%). Both the willingness to participate without assurance of tangible gain and the level of comfort with non-community interviewers were surprising given that substantial, albeit smaller, numbers conveyed some level of distrust. For example, 12.3% ($n = 17$) did not think African Americans could be treated fairly by Whites, 10% ($n = 14$) believed that Whites would use the data differently, 43% ($n = 59$) expressed at least some concerns about the researchers' divulgence of all important information about the research, and 41.3% ($n = 57$) worried about researchers maintaining confidentiality.

While the univariate analyses generally portray African Americans as trusting of researchers and Whites, bivariate analyses imply that, for at least a subset of the African American population, racial tensions or distrust are associated with negative views of research. African Americans who believed that African Americans could not be treated fairly by Whites were more likely to support the view that research information could be used to hurt people. Likewise, those believing that Whites researchers would use information differently were more inclined to worry that all pertinent information about the research was not being shared and less inclined to be comfortable with a researcher from outside the community.

In explaining why research could not be used to harm their communities, most participants suggested that, by giving well-intended answers or by refraining from divulging potentially hurtful information, they were preventing this from happening. Implicitly, such comments indicate that many participants maintained a sense of what could be said without risking someone else's welfare and, at the same time, suggest that, in spite of professing their trust in researchers and their altruistic motivations, many may be guarded and/or unconsciously self-censor.

Knowledge of Research

Forty-five percent of the current sample worried that a researcher might not share important information about the research, nearly 43% worried about privacy, and 21% thought that one could be involved in a study without his/her permission. These results highlight the extent to which current approaches to informed consent may be inadequate or inappropriate. Misinformed or uninformed, prospective participants may elect not to enroll, those enrolled may censor what they say, and many may engage in research without a clear understanding of its potential risks, their rights as participants, and its purpose.

Participants' vague depictions of what researchers actually do with the information (e.g., "study it") and the more common response of "I don't know" also speak to how little is understood about the research endeavor.

Tuskegee

Those who had heard of Tuskegee tended to be more cognizant of the potential of research to hurt individuals or communities and to be more likely to believe that Whites could use information differently. However, even with this awareness of the potentially harmful effects of research and the sense that Whites will use data differently than African Americans, those who knew of Tuskegee appeared more willing to participate in research without any direct benefit.

IMPLICATIONS

The study's findings draw attention to (a) the visceral nature of distrust that may exist between the African American community and outside White investigators and (b) the lack of accurate knowledge regarding research in general and informed consent in particular. These results have clear implications for social work researchers and clinicians.

First, the results underscore the need to remain attuned to racial tensions and distrust that, unacknowledged, may lead to sub-optimal treatment and prevention interventions. Without such sensitivity, researchers increase the likelihood that some groups of African Americans, possibly those most disenfranchised and in need of services, will remain un-represented and/or reluctantly engage in clinical research projects. Although participants in the current study were more likely to deny a preference for African American researchers or interviewers, their qualified explanations suggest otherwise. Indeed, speaking with a community-based interviewer who represented a White researcher, may not have been, by itself, enough to keep participants from censoring their comments.

Second, both researchers and clinicians must take steps to assure that African Americans, presented with opportunities to join clinical research projects, truly understand their rights and the potential risks and rewards of participating. Far too many in the current study lacked accurate information about basic aspects of informed consent, confidentiality, and other aspects of typical research protocols. Clarifying the terms of recruitment and the goals and nature of the research process, while certainly an ethical responsibility, may also assuage misgivings about divulging sensitive information and empower participants in ways that make them more inclined to sustain enrollment in a project and become involved in future research.

Ultimately, by empowering those they aim to assist, clearly specifying their intentions and how and why they aim to achieve them, and acknowledging the distinct perspectives of potential research participants, social work researchers and clinicians will mitigate distrust, enrich the quality of research they produce, and enhance the fidelity of interventions.

In the words of one participant:

[Research data from African Americans] may give other researchers a better idea on how to do things because everybody mind is not the same.

In focusing on a homogeneous stratum of the African American population, the current study offers insights regarding one group's knowledge and perceptions of psychosocial research participation and permits some comparison with similar surveys of more heterogeneous or older African American samples. However, to validate the study's conclusions about the perceptions and knowledge of one group of African Americans, future research on the topic should include more diverse groups of African Americans and other ethnic-minorities.

Additionally, the study's findings that participants lacked basic information about research protocol and outcomes highlight the need to explore the knowledge of research participants from other ethnic-minority groups as well as whites.

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TABLE 1

Univariate Analysis

Variable	Percentage	<i>n</i>	<i>n</i> missing
Fear researcher is not sharing all information about the study	45.2	71	
Would participate even if there was no personal benefit	67.5	106	
Worry that information is not private	42.7	67	2
Comfortable speaking to a researcher	88.6	139	2
Research can hurt my neighborhood	24.8	39	2
Comfortable with a researcher not from the neighborhood	83.4	132	
Research information can be used to help people	86.0	135	
Comfortable with White researchers	92.4	145	
White researchers will use information differently than black researchers	10.8	17	
Had heard of Tuskegee	22.3	35	2
Research should be done with African Americans without their knowledge	5.7	9	4
African Americans can be treated fairly by White researchers	72.0	113	6
People can be involved in a study without written consent	21.0	33	11

TABLE 2

Bivariate Analysis

Motivation to participate in research variable	r
Information could be used to help people(x)	.17*
African Americans can be treated fairly by Whites	
Tensions between community residents and outside researchers	r
Feelings if researcher is not from the community(x)	-.15*
Whites will use information different than black researchers	
Knowledge of the research process	r
Fear that information is not private(x)	.21**
Worry that researcher is not sharing all information	
Worry that researcher is not sharing all information(x)	.16*
Whites will use information different than black researchers	

*
p < .05,

**
p < .01

TABLE 3**Multivariate Analysis**

<u>Ordinary Least Squares Regression “Privacy of information provided”</u>				
<u>Variable</u>	<u>B</u>	<u>SE B</u>	<u>β</u>	
Comfortable speaking to a researcher	−.13	.07	−.15	
Fear researcher is not sharing all information about the study	.09	.03	.21**	
R ² =.07, Adj. R ² = .05, df = 154, F = 5.30, p <.01				
<u>Logistic Regression “Heard of Tuskegee”</u>				
<u>Variable</u>	<u>B</u>	<u>SE B</u>	<u>Wald χ²</u>	<u>Odds Ratio</u>
Whites will use information differently than black researchers	.21	.14	2.47	1.24
Research can hurt the community	.21	.13	2.56	1.23
Would participate in research even if no personal gains	.77	.40	3.72	2.17*

*
p < .05,

**
p < .01