

African American Communities' Interest, Motivation, and Participation in Research Studies

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Abstract

Objective: Across the United States, chronic diseases, including cardiovascular and diabetes are having catastrophic effects on the health status of African Americans. To address health disparities in the United States, participation of African Americans in biomedical research studies and clinical trials is imperative. In Mississippi, this population leads the State in almost every negative health statistic. Thus, it is important to examine the indicators as to why many in the African American communities lack interest and motivation, and are reluctant to participate in research studies that can influence better health outcomes. **Method:** A qualitative study design was selected and focus groups were identified as the qualitative data collection method. A questionnaire designed to collect demographic data such as: county of residence; gender; age; income; education; and employment, also included three questions specific to the purpose of this study. Between May 2014 and February 2015, 70 participants were recruited from the same counties (Hinds, Madison and Rankin) as the JHS participants. They identified focus group sites and hosted a town hall meeting for the sessions. Analysis was conducted utilizing interpretive phenomenology. **Discussion:** Hinds and Madison County focus group participants perceived more disadvantages of research in their communities than advantages, while Rankin County focus group participants did not list any disadvantages, and they perceived a longer list of advantages than Hinds and Madison Counties. Primary among the disadvantages of research cited were four types of fears: fear of the unknown, fear of being mistreated, fear of having to pay to participate and fear of having to disclose personal financial information that could be misused. **Conclusions:** Researchers interested in recruiting and retaining African Americans in biomedical research studies must actively engage communities in the research process from the planning phase to implementation. This allows time for communities and researchers to “get to know” each other. Researchers will also find that community members have a wealth of knowledge and influence that can facilitate the success of the research more so than if the researchers chose to go it alone initiate the research without community involvement.

Keywords

African Americans, Participation in Research, Motivation, Advantages

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1. Introduction

Across the United States, chronic diseases, including cardiovascular and diabetes are having catastrophic effects on the health status of African Americans. To address health disparities in the United States, participation of African Americans in biomedical research studies and clinical trials is imperative. In Mississippi, this population leads the State in almost every negative health statistic. Thus, it is important to examine the indicators as to why many in the African American communities lack interest and motivation, and are reluctant to participate in research studies that can influence better health outcomes. Researchers and physician biases as barriers to recruitment of African Americans have been described by several authors. Some studies have reported that researchers may not actively recruit minority participation in clinical trials because of their personal beliefs that it may be more difficult to obtain compliance with study protocol, and African Americans may have higher attrition rates [1]. Studies on minority participation in research have described how researcher biases about barriers to recruiting certain populations are related to their own prejudices against populations. Another factor that may limit recruitment is the small number of minority researchers, and limited relationships between investigators and minority health care providers and caregivers [2].

Additionally, despite nationwide participant recruitment for the Cancer Prevention Study 3, it was noted that the number of participants from Mississippi and in the Southern part of the country in general, was small. Nationwide, only 13% of African Americans participated in this exercise from 2006 until 2011 (Spring 2011 CPS-3). Their lack of participation in medical research, limits the ability of researchers to generalize data from clinical trials to African Americans and may ultimately contribute to the presence of health disparities in this population [3, 4].

Some researchers believe that there is a great degree of negative attitudes toward research and mistrust of scientists in African American communities [5]. This finding was not just applicable to medical research alone, but was a barrier commonly found in African American communities toward any research. Mistrust of medical research and scientists was rooted in the African American community long before the United States Public Health Services Syphilis Study (1942-1972). This study has led to the decades of continued mistrust of research by African Americans [6]. Another example of research abuse involves Dr. J. Marion Sims (known as the Father of modern gynecology). Dr. Sims of Alabama used three African American slave women, between 1835 and 1846, to develop an operation to repair

vescio-vaginal fistulas. These women underwent up to 30 painful operations without the use of an anesthesia. Only after he perfected his technique on the slave women did he attempt the procedure on white women with painkillers [7].

A series of national-level projects were initiated in the past two decades from the National Institutes of Health (NIH), the Federal Drug Administration (FDA) and the Centers for Medicare and Medicaid Services (CMS), and they confirmed that racial and ethnic minorities still remain underrepresented in clinical research [8]. These studies all suggested that in order to improve research participation rates, attitudinal change, respect for informed consent throughout the study process, and trust with research investigators are paramount. The purpose of this study was to investigate participation in research studies, motivation to participate, and participants' views about advantages and disadvantages of research studies conducted in their respective communities.

2. Methods

Through a grant funded to the Center of Excellence in Minority Health and Health Disparities (CEMHD), School of Public Health, Jackson State University, the Community Engagement Core (CEO) initiated a multi-disciplinary working group (MWG). The MWG was developed as a collaboration between the Center of Excellence on Minority Health and Health Disparities (CEMHD) and Jackson Heart Study (JHS) Community Outreach Center.

A qualitative study design was selected because qualitative designs tend to be holistic, allowing researchers to strive for an understanding of the whole [9]. Qualitative research allows researchers to involve the people of the community in a self-study of their own needs and aspirations [10]. Additionally, a qualitative design emphasizes several principles of CBPR; these principles acknowledge the community as a unit of identity. CBPR builds on the strengths and resources within the community, facilitates a collaborative, equitable partnership in all phases of research, involving an empowering and power-sharing process that attends to social inequalities, and fosters co-learning and capacity building among all partners [11].

Focus groups were identified as the qualitative data collection method because this method allows multiple voices to be heard at one sitting, drawing a larger sample into a smaller number of data collection events" [12]. Additionally, "One of the strengths of focus groups is that they give participants the opportunity to discuss issues and question and build upon one another's answers and the collective construction of knowledge, which is the jewel of the focus group method" [13]. The primary goal of the MWG

was to convene focus groups to explore the issues related to the participation of local area African American residents in research studies. They sought to understand the respondents' willingness to participate in research studies, motivation to participate, and their views about the advantages and disadvantages of research studies conducted in their respective communities. Focus groups were identified as the data collection method for this study because they allow multiple voices to be heard at one sitting, drawing a larger sample into a smaller number of data collection events" [12]. Additionally, "One of the strengths of focus groups is that they give participants the opportunity to discuss issues, ask questions, and build upon one another's answers.

The MWG developed a questionnaire designed to collect demographic data such as: county of residence; gender; age; income; education; and employment. Sixteen questions were developed for the entire focus group interviews, and three of those questions were specific to the purpose of this study. The MWG also developed the study's instruments, focus group guide, and recruitment materials, and determined the number of participants required for a population health needs assessment by conducting a power analysis. Between May 2014 and February 2015, 70 participants were recruited. They identified focus group sites and hosted a town hall meeting. The MWG decided that, at the end of the session, they would offer participants compensation with a \$25 Walmart gift card and a light snack for participating in the focus groups.

2.1. Participant Recruitment

Recruitment strategies included: networking with community partners, local churches, community-based organizations, fitness centers, and local government entities. Additional recruitment strategies included dissemination of flyers and announcements at churches, and community gatherings. Recruitment efforts focused on adults from rural and urban settings, at least twenty one years of age with different experiences relative to age, gender, income, education, and health status. Participants were recruited from the same counties (Hinds, Madison and Rankin) as the JHS participants.

The counties from which the participants were recruited are a combination of urban and rural communities. Hinds County, the largest county in the state is the location of the state capitol, and has a total population of 242,891, approximately 71.1% of whom are African American. Madison and Rankin Counties are rapidly growing rural and suburban counties with total populations of 103,465 (African American 38.4%), and 149,039 (African American (20.5%) respectively [14].

Table 1. Focus Group Questions.

Focus Group Questions on Research Participation	
1.	Have you ever been a participant in a research study?
2.	What do you believe will motivate more African Americans to participate in research projects being offered in your community?
3.	What do you consider to be the disadvantages and advantages of research being conducted in your community?

Experienced moderators and a doctoral candidate conducted the 7 focus group sessions. A digital recorder and a note-taker were utilized at each of the sessions. At the beginning of each session, participants completed informed consent documents and the demographic survey.

2.2. Procedure

The focus groups were conducted between May 2014 and February 2015 and lasted between one hour and thirty minutes and two hours. They consisted of 7-12 participants who were asked to comment on the questions developed, and the meetings took place at seven sites: Asbury, Canton, IBS, NTENSE, Progressive I, Progressive II and Sweet Rest. Participants completed informed consent documents, were informed that their participation was voluntary and were provided instructions regarding confidentiality. The focus group interviews were digitally recorded and a graduate student assisted by recording notes and nuances exhibited by participants. The recorded interviews were transcribed by a professional transcriptionist and analyzed by an expert qualitative research investigator.

2.3. Data Analysis

Each digitally recorded focus group session was transcribed verbatim. Analysis was conducted utilizing Interpretive Phenomenology. This method was chosen in order to arrive at interpretive descriptions of common practices and shared meanings that could reveal, enhance or extend our understanding of how participants perceived specific health practices and possibilities [9]. Diekelmann's seven stage process of data analysis was adapted [15]:

1. An expert Qualitative Research Consultant (QRC), experienced in the interpretive phenomenology approach to data analysis read each of the seven focus group transcripts and organized the responses under the three questions asked of each focus group resulting in a data file by question/response for focus group; Asbury, Canton, IBS, NTENSE, Progressive I, Progressive II and Sweet Rest.
2. Writing Group members reviewed the data files and suggested further grouping of the data according to their research questions and setting.
3. Writing Group members read through each County-specific focus group data file, and listed, on the worksheet,

their interpretations for use in developing key themes for each focus group, according to the response to the questions.

4. Writing Group members and the QRC reached consensus on their interpretations of the responses, and/or reconciled differences via discussion.

3. Results

3.1. Focus Group Demographics

A total of 70 focus group members participated in interviews. They were from the three counties that encompass the Jackson Heart Study: Hinds (N=27-18.9%); Madison (N=30-21%) and Rankin (N=13-9.1%). Of the 70 participants, 56 (39.2%) were female and 14 (19.8%) were male. Participants' ages ranged from 18-60 and over; most participants (N=30) were age 60 and over 57% were 59 years of age and younger. Income for slightly more than half of the participants ranged from \$21,000 to \$39,000 per year with 20% earning less than \$21,000 per year. Participants with incomes of \$40,000 to over \$60,000 per year totaled 16 (23%). Fifty-six participants (39.2%) had educational levels that ranged from some college to Masters' degree or higher, and 21% had a high school diploma. While 30 (21%) of the 70 focus group participants were retired, 34 (49%) were employed; less than 5% were unemployed, and two were students. The proportion of participants who were retired was equal to those who were employed (50.0%).

The Writing Group and QRC extracted common themes and patterns from the data file worksheets that described the essence of the experience for each County-specific focus group to the phenomena of interest, until they reached redundancy of content. Presented in this section, is the essence of the experience using exemplars and narrative descriptions that describe how the phenomenon was experienced by County-specific Focus Groups. We compared and contrasted the essence of the experiences between/among the focus groups.

3.2. Focus Group Responses

Focus group responses are reported according to three questions about participating in research as presented in Tables two, three and four.

Table 2. Participation in Research Study.

Question 1: Have you ever been a participant in a research study?
Hinds County Response: There was an equal number of focus group interviewees who had participated in a research study and those who had not. For Madison and Rankin Counties, more focus group participants had participated in a research study than had not.

Table 3. Motivation to Participate in Research.

Question 2: What do you believe will motivate more African Americans to participate in research projects being offered in your community?
Response: For Hinds County, five motivators emerged: information; willingness to participate; trust; a monetary incentive and sharing the results. In terms of information, Hinds County focus group participants recommended: "More information in the churches and information for the /African American Community". The willingness to participate must include" wanting to be healthy, wanting to stay healthy". Hinds County participants indicated that: "A lot of people don't trust these research organizations because they'll tell you, confidentiality and we know that that goes so far and you just don't ever know how it gonna be used against you in the long run." Sharing the results should include: "doing some follow-up at offering affordable medical care, affordable foods." Madison County focus group participants also noted; compensation such as monetary things that would help research participants. They most frequently mentioned making people more aware of research, increasing awareness about what is available, about how relevant it is and the benefits. Madison County respondents' related lack of trust to fear: "Back in the day when African Americans think about research, they think about Oh my God the Tuskegee Experiment and things of that nature". And, "They have found out that research links up together with all things as far as they want to ask about your economic background and getting assistance and they think that some of that is going to come out". An additional motivator contributed by the Madison County focus group participants was the sharing of examples of people who have reversed diabetes, and recovered from other illnesses. Rankin County focus group participants also mentioned money, being informed about the value and the benefits of research for future generations, personal interest and information, especially word of mouth.

Table 4. Perceptions of Disadvantages and Advantages of Research.

Question 3: What do you consider to be the disadvantages and advantages of research being conducted in your community?
Response: For Hinds County focus group participants, disadvantages of research included: "Not getting enough information so we can learn how to help our bodies, help our minds and help our souls". They also included fear of the unknown: "Fear, because a lot of time when we're afraid of knowing what might happen we don't follow-up on it because were afraid of what we might find out". And, there is the fear of being used: "Now you know back in the day they use us, the Black men's syphilis and all that stuff". Additionally: "We always afraid that there's some type of money...., that we're going to be charged to participate in research." Madison County participants also noted fear as a disadvantage to participating in research: "Afraid of what they call a guinea pig". Further; "In the Black race, a lot of people, they have not gone through any research and they sometimes think its something against them that they will harm them in the long run, they're not aware of the educational part of it". They also mentioned lack of time as well as the long amount of time for the research results to come out. Rankin County focus group participants' response was that they could not think of any disadvantages. In terms of advantages, Hinds County participants noted getting a feeling of what is going on out in the community, interacting with other people and getting feedback on a particular subject as advantages of participation in research. The saw it as the community coming together to get more information to help those who live in the community. For Madison County participants, a healthier life is an advantage of participating in research. As well they noted "To be able to voice your opinion of how you feel". For Rankin County focus group participants, self- advocacy was noted as an advantage of research along with self- responsibility. They also noted the benefits of prevention through research: "We would save lives. We would prevent debilitating illnesses with research done".

Hinds and Madison County focus group participants perceived more disadvantages of research in their

communities than advantages, while Rankin County focus group participants did not list any disadvantages, and they perceived a longer list of advantages than Hinds and Madison Counties. Primary among the disadvantages of research cited were four types of fears: fear of the unknown, fear of being mistreated, fear of having to pay to participate and fear of having to disclose personal financial information that could be misused. These are areas that researchers need to address and areas in order to motivate these communities to participate in research. Participants saw a major advantage of participation in research as improved individual health and improved health of the community. Motivation to participate in research included building trust, some monetary incentive, sharing the research results in a timely manner, and availability of more information, including awareness of resources and services available, their relevance and benefits. They felt that information should be distributed by multiple means such as the media, through churches and word of mouth.

While question 1 yielded a quantitative response as presented in Table two, the responses to questions 2 and 3, as presented in Tables three and four, help us to begin to explore the perceptions of a tri-county African American community about participating in research in their communities.

4. Discussion

This research study involved African American focus group participants seeking to examine the perceptions, opinions, knowledge and experiences regarding their participation in research studies, their motivation for their participation, and their perceptions of the advantages and disadvantages of participating in research studies. About 40% of the participants noted that they had at some point participated in a research study, while the majority acknowledged that this was their first time participating in a study. It may be worth noting that this group of participants, some of whom are participants in the Jackson Heart Study, expressed strong confidence and high esteem for JHS Community Outreach Center and the Center of Excellence on Minority Health and Health Disparities Community Engagement Core staff, and trusted and respected the investigators in these centers.

Motivation denotes different things to different people and this in fact was true with this group of participants. Word of mouth from others whom participants trust was important to members of these focus groups in committing to participate in this study. Common themes that came across as motivation for participating in research studies included trusting investigators, translation and dissemination of findings back to them, incentives (i.e. prizes, food, affordable medical care), benefit for future generations, and confidentiality

assurances that information gathered from these sessions will not be used against them. Many African Americans are not confident in engaging or participating in research because of lack of trust. They also expressed concerns that research study findings could stigmatize them in the future. Personal and altruistic interest, value and benefit of the study, and incentives are all participants' suggestions that could motivate African American communities to participate in a research study.

Some of the disadvantages of research conducted in the African American communities identified by the participants within this focus group study were: inadequate information about a research project; researchers are not taking their time to communicate the usefulness and importance of the study to the community; therefore, African American communities have concerns about the usefulness of them participating in an issue that does not concern them. Fear was another factor identified as a disadvantage because some people do not want to know what is wrong with them and are misinformed about the significance of the research study. Other disadvantages included: perceptions that it costs to participate in research, their information is not confidential, they are being used as guinea pigs fueled by the Tuskegee Experiment "Guinea pig syndrome", and that information obtained from them would be used against them in the future.

Advantages of participation in research identified by focus group participants included: improved African American community's health, gain in knowledge, awareness and opportunity to modify positive behavioral change from unhealthy lifestyle, potential to save lives, prevent illnesses, influence change in others, and providing a sense of being involved in your community. Participants also noted that it was important to interact with others to exchange ideas from others and brainstorm on what can make their communities better.

The major limitation of the study is that all of participants reside in the counties from which the JHS recruited its participants. Some were study participants and others may have benefitted from educational activities conducted in their counties or from any of the 3 major community-wide participatory educational events sponsored each year, by the JHS Community Outreach Center, formerly known as the Community Partnership/Outreach Office in the Jackson State University Jackson Heart Study Coordinating Center (2000-2013). Because of the small sample size of this study, the generalizability of the findings is limited. Another limitation is that all participants were from the counties where JHS participants were recruited; thus they may have had more exposure to health education information that promotes healthy lifestyles.

5. Conclusions

Researchers interested in recruiting and retaining African Americans in biomedical research studies must actively engage communities in the research process from the planning phase to implementation. This allows time for communities and researchers to “get to know” each other. Researchers will also find that community members have a wealth of knowledge and influence that can facilitate the success of the research more so than if the researchers chose to go it alone initiate the research without community involvement.

Author Contributions

All authors contributed substantially to data collection, analyses, and preparation of the manuscript for submission.

Competing Interests

The authors declare that they have no competing interests.

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