ORIGINAL REPORT, COMMENTARY: RESEARCH DESIGN

RESEARCH PARTICIPANTS' OPINIONS ON GENETIC RESEARCH AND REASONS FOR PARTICIPATION: A JACKSON HEART STUDY FOCUS GROUP ANALYSIS

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The Jackson Heart Study (JHS) convened focus groups to engage the community in dialogue on participation in the National, Heart, Lung and Blood Institute's Candidate Gene Resource (CARe) project. CARe, a genome wide association and candidate gene study, required the release of participant phenotypic and genotypic data with storage at NIH for widespread distribution to qualified researchers. The authors wanted to assess the willingness of an African American community to participate in the genetics research, given the past history of bioethical misconduct in ethnic minority communities. The discussion produced the following specific issues of interest: reasons for participants' interest in genetics research; participants' knowledge about the JHS; and participants' knowledge about genetics research and its advantages and disadvantages. Training on genetic issues was also developed for the JHS community and staff. (*Ethn Dis.* 2014;24[3]:290–297)

Key Words: Community-based Participatory Research, Genetics, Ethics, Community Education

BACKGROUND

The Jackson Heart Study (JHS) is a single site multi-center investigation of predictors of cardiovascular disease (CVD) in 5301 African Americans living in the Jackson, Mississippi, metropolitan area. The JHS represents an expansion of the Jackson Field Center of the Atherosclerosis Risk in Communities (ARIC Study).[1] The goal of the JHS is to broaden data collection in an African American population and to increase access and participation of African American populations and scientists in biomedical research and professions. Outreach activities to increase awareness and promote healthy lifestyles are other goals of the study.[2,3] The JHS is a collaborative effort among three Jackson-area academic institutions, the University of Mississippi Medical Center, Jackson State University and Tougaloo College. The JHS conducted three clinical examinations, baseline Exam 1 (2000–2004), Exam 2 (2005–2008), and Exam 3 (2009–2013). The design and data collection for the JHS are described elsewhere.[2] Access to the JHS data collection forms, manuals of operations and data summaries can be found on the JHS website.

The Tuskegee Syphilis Study is a notable contributor to today's fear of research exploitation among African American participants.[4] This historical experience with racism has created a legacy of mistrust.[5,6] Lack of knowledge about research or its procedures, and the lack of trust and rapport with researchers cause many minority communities to perceive the role of medicine, health care professionals and health care institutions differently than is the case for White communities.[7] Distrust and systemic racism in health care institutions continue to be barriers to minority population participation in research studies. [8,9]

Because mistrust is among the most commonly identified barriers to African Americans' participation in research, a Participant and Recruitment and Retention Survey (PRRS) was conducted during the JHS feasibility phase (1996–1997).[10] This survey, which included both individual and focus group interviews, was implemented as a result of challenges in recruitment of underserved populations for biomedical research and to determine the enhancing or impeding factors for the Jackson African American community's participation in research, including genetic research.[11] The PRRS data indicated that 90% of the interviewees were willing to participate in the JHS, with 88% willing to have their DNA analyzed.

The feedback from the PRRS resulted in the decision to plan and implement an approach to participant recruitment and retention that was community-driven using the community-based participatory research (CBPR) model. In CBPR the community is active in the full spectrum of the study, and therefore recognized as a partner who shares in the decision making of the study.[12]

In 2006, the JHS was invited, with nine other national cohort studies, to

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From Mississippi State Department of Health (ERW); and National Heart, Lung and Blood Institute, National Institutes of Health (CRN); and Jackson State University (DAL, DTO, DFS, AMS, ALS); and National Heart, Lung and Blood Institute, National Institutes of Health (MAP); and University of Mississippi Medical Center (FCH).

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participate in two new genetic research projects initiated by the NHLBI. These projects required the release of participant phenotypic and genotypic information to be stored in an NIH database for widespread distribution to qualified research investigators. In particular, the JHS would participate in the NHLBI Candidate Gene Resource (CARe), a genome wide association and candidate gene study.[13] Even though participating in these high impact projects was exciting, JHS staff were concerned that combining JHS genetics data with data from other population-based cohorts represented expanded use of the genetics data not directly addressed in the layered consent process. It is important to note that JHS participants were consented prior to the baseline examination in 2000–2004, five years before JHS received the invitation to participate in CARe. Therefore, staff was concerned about the willingness of JHS participants to take part in the NHLBI national genetics research project, in light of previous instances of bioethical misconduct (eg, the Tuskegee experiments). The JHS steering committee with consultation from the JHS ethics advisory board sent letters to the JHS participants explaining the NHLBI CARe project. The study committee also determined that focus groups of participants enrolled in the study would be an excellent way to query the JHS cohort about their thoughts and concerns and provide quantitative and qualitative data on the level of knowledge of genetics/genomics, as well as potential barriers and facilitators for African American participation in genetics studies. Further, a qualitative study design would provide insights by discovering meanings in the responses of focus group participants.

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METHODS

The JHS is a large, community-based, observational study whose participants were recruited from urban and rural areas of the three counties (Hinds, Madison and Rankin) that make up the Jackson Mississippi, metropolitan statistical area (MSA). Recruitment was limited to non-institutionalized adult African Americans aged 35–84 years, except in the family cohort where those aged 21 to 34 years were eligible. The final cohort of 5,301 participants included 6.59% of all African American Jackson MSA residents aged 35–84 (*N*-76,426, US Census 2000). Major components of each exam included medical history, physical examination, blood/urine analytes and interview questions (eg, physical activity; stress, coping and spirituality; racism and discrimination; socioeconomic position; and access to health care). At 12-month intervals after the baseline clinic visit (Exam 1), participants were contacted by telephone to: update information; confirm vital statistics; document interim medical events, hospitalizations, and functional status; and obtain additional sociocultural information. Questions about medical events, symptoms of cardiovascular disease and functional status were repeated annually. Ongoing cohort surveillance included abstraction of medical records and death certificates for relevant International Classification of Diseases (ICD) codes and adjudication of nonfatal events and deaths. The second clinical exam, Exam 2, occurred in 2005 followed by telephone contact at 12-month intervals, similar to those that occurred after the baseline visit. Exam 3 (2009) contained some repeated measures from the first two exams and new questionnaires for assessment of sleep history and cognitive function. Cardiac magnetic resonance imaging (MRI) scans of the structure and function of the heart, with and without gadolinium contrast were performed in an eligible, consenting subset of participants to identify silent myocardial infarctions.

Focus Group Participants

Research participants' opinions on genetics research and reasons for participation were contributed by a sample of participants enrolled in the JHS. The JHS cohort included general non-Family Study participants and Family Study participants, the latter were recruited based on contact information from their relatives identified as index participants recruited to JHS.[14] The JHS used a layered consent document to give participants clear choices regarding the use of their genetic materials. The layering allowed participants to withhold permission to use of their genetic materials, as well, participants could limit use to the study of JHS-focused diseases versus an option that allowed the study of any major diseases or health conditions. The JHS participants who consented to having their DNA extracted from their venous blood totaled 4725, which included 1499 members of 291 families enrolled in the Family Study embedded within the JHS. The sample population for the genetics focus group study was drawn from the total number of 5301 participants recruited to the JHS and included some who had contributed DNA specimens and some who had not.

Table 1. Focus group questions

1. Tell me in your own words what the Jackson Heart Study (JHS) is all about?
2. What were some of the reasons why you decided to participate in the study?
3. What made you want to hang in there and continue with the study?
4. What were some of your concerns?
5. Did you find it difficult to meet the demands of time or did you think about that in the beginning?
6. Did you have any concerns about family members participating in this?
7. What helped you not to be concerned about that? What would you tell that person?
8. Who do you think looks out for your interests?
9. If I asked you, who's looking out for you all to make sure what you said does not happen?
10. Now that you've heard about this new study, what are your thoughts about having given your blood sample to the JHS? What do you think about that now? How do you feel about it?
11. Do you think it is okay for you to tell the JHS Ethics Advisory Board you should go forward or not go forward with these kinds of studies, what would you tell them?
12. Tell me something about the genetic traits or conditions.
13. Remember, you gave your blood samples, what do you think they were for?
14. What are the benefits you say the JHS will result in?
15. What were negative things you thought might happen by participating in this?
16. Do you get a sense of what the JHS is thinking about doing and what do you think about it?
17. How does the JHS keep you informed?
18. Do you feel you basically understand what they are doing with the DNA sample and the data? Do you worry about it? And, why don't you worry about it?
19. Are you happy the board asked you to come in today?
20. What do you think about that blood that you contributed in that blood sample now? What do you think about it now?
21. How do you feel about participating in this SHARE/CARE research that is being proposed?
22. Do you have any concerns about anything that might not go right in terms of your data? About how they handled the information that they will get the JHS people will give?
23. Suppose some researchers tried to do something that was not right, who would look out for your interest?
24. So, would you recommend that this study go forward?

A sample of 140 participants was randomly selected using a randomized scheme in SAS (PROC PLAN)[15] from the 5301 JHS baseline Exam 1 cohort using a stratified sampling scheme: one pool of 40 Family Study participants and a second pool of 100 non-Family Study participants. The random sample was stratified by the Family Study status defined by the presence or absence of a family identification number. All of the 140 JHS participants were sent invitation letters to participate in a focus group and follow-up phone calls were made to determine interest. Twenty-five focus group participants were recruited. Thirteen were Family Study participants, while twelve were non-Family Study members. Four focus groups were formed with 7 members each in group A, B and D and 4 members in group C. The four focus groups were purposely homogenous, 2 Family Study member groups and 2 non-Family Study member groups.

The focus group session leader was an experienced facilitator who: 1) provided assurance of confidentiality of focus group participants' identities; 2) stressed that participation was voluntary; 3) defined what it meant to participate in a focus group; 4) informed members that the sessions were being audio recorded; and 5) explained how the recorded transcripts and data analysis would be handled and the results disseminated. Each of the four groups was asked the same questions (Table 1) about their knowledge of the JHS, participation in research in general, and specifically, participation in genetics research. JHS staff collected demographic data via a survey questionnaire prior to the beginning of the focus group interview. Additionally, the focus group leader administered a 16-item quiz on basic genetics terminology as a part of the focus group interview. The focus group facilitator was assisted by an observer and note taker. All focus group sessions were held at the Jackson Medical Mall JHS facility, each participant received a $25 incentive and child care service was provided if needed. The focus groups were conducted in 2007, seven years after initiation of JHS baseline Exam 1 data collection.

Analysis

Descriptive statistics were performed to quantify the demographic characteristics of the study sample. The qualitative data were transcribed by a professional transcriptionist and the content was analyzed to derive the emerging themes of the focus groups. Experts in hermeneutics (the science of text interpretation and verbal/nonverbal communication) and phenomenology (the study of phenomena or perception)[16,17] read each focus group transcript and organized the responses under each of the questions asked of the focus groups, resulting in data files for focus group A, B, C, and D. An interpretive team read each data file and extracted common themes until they reached redundancy of content for each of the four focus groups. Each of the focus groups' responses was organized into meaningful statements and descriptive narratives were developed supporting the following four issues of interest: 1) reasons for participants' interest in genetics research; 2) participants' knowledge about the goals and objectives of the JHS; 3) participants' knowledge about genetics research; and 4) participants' knowledge about the advantages and disadvantage of genetics research.

RESULTS

Focus Group Demographics

Focus group members were aged 21–84 years and fell within three age groups: 2 participants (8%) were aged 21–44; 17 (68%) aged 45–64, and 4 (16%) aged 65–84. Most participants, 14 (56%) classified themselves in the middle income group; 7 (28%) affluent and 2 (8%) were in the low income group.[18] Levels of educational attainment ranged from a bachelor's degree or higher for 13 (52%) participants with some college for 7 (28%) and 5 (20%) participants had earned a high school diploma or GED equivalent. Whereas the focus group participants were distributed across age, income and educational levels, most were aged 45 to 64 years, middle income with a bachelor's degree or higher.

Focus Group Responses

Focus group responses are reported according to the four issues of interest. Key themes reflect input from Family Study focus group participants and non-Family Study focus group participants. Whereas, Family Study participants specifically introduced input about improving the health of future generations and focus on hereditary illnesses that plague Blacks as a whole, non-Family Study participants also provided input about dealing with something common among families and improving the health of future generations. Key themes are presented for each of the four areas of interest as reflective of interpretations across focus groups, including appropriate illustrative quotes.

Reasons for Participants' Interest in Genetics Research

The interpretive results to several of the JHS focus group questions provide insight on the reasons for participants' interest in genetics research. Although the question "What were some of the reasons why you decided to participate in the study?" didn't specifically refer to the genetic component of the study, some respondents exhibited interest in genetics. Other questions regarding knowledge and benefits of the study also generated responses that indicated an interest in genetics research. Participants' reasons for their interest in genetics research varied from global and futuristic to family-centered and disease-specific.

The following responses best summarize the essence of one of the prevailing themes of the response interpretations, the desire to know more: 1) finding out what is causing our problem; 2) increasing awareness of disease; 3) learning about drugs geared toward your race; 4) information about the impact of genes on heart disease; 5) wanting to learn something about my family, why we don't live long; and 6) wanting to know why African Americans have more heart disease.

Responses also reflected a family connections theme and the desire to improve the health of future generations. There was also the sense that participation could lead to prevention of disease in future generations, and the satisfaction of contribution to this by participating in the study. Specific responses included: "I had a heart attack, ….so concerned that it passed down to my kids, my grandkids," "My father died from a massive heart attack," "I do have hypertension, whole family has it."

The expectation that the JHS would address the causes of heart disease and find solutions is seen in responses such as the following: "How to get research programs that are used to look into the links, or causes of and probable solutions," "Dealing with something common among families," and wanting to find out about the problems so that it "will help us more," "What can be done to offset it …focus on hereditary illnesses that tend to plague Blacks as a whole."

While some responses referenced well-known biomedical research studies - "experimented on people in Tuskegee and Parchman[19] [Mississippi's state penitentiary]" indications were that there could have been some hesitation or fear, but interest in participation was sustained, nonetheless. The three themes that emerged across focus group responses about their interest in genetics research were: 1) the desire to know more; 2) the desire to improve health of future generations and 3) the desire to address the causes of heart disease and find solutions.

Overall the focus group participants appeared to associate family with genetics. A strong desire to contribute to improving the health of their families and promoting disease prevention for future generations through an increased knowledge of the causes of heart disease speaks to the influence of family dynamics and family ties when considering genetics research.

Participants' Knowledge about the Goals and Objectives of the Jackson Heart Study

Focus group participants exhibited varied levels of knowledge about the goals and objectives of the JHS. The three prevailing themes were: 1) heart disease research; 2) reasons why so many Blacks die of heart disease; and 3) prevention, health awareness and improvement. The following response conveyed the fundamental objective of what the JHS was: "I thought it was all about heart disease research, studying a live segment of the population for concrete answers about the heart." For the most part the respondents exhibited the knowledge that the study's goals involved determining "Why so many Blacks die of heart disease."

Their responses reflected an unspoken hope for what the JHS might achieve as suggested in the statements "find ways to ward it off, or slow it down" "Hopefully from this study they will find things that Blacks can do to live longer especially males".

Other responses focused on goals that more specifically reflected the individual's health awareness and improvement. Comments such as the ones listed below indicated expectations of more immediate heart health benefits: "They can detect if you have heart trouble," "It's more to inform us …it's more to let us know about our heart problems…that will help us more".

The respondents' beliefs that the objectives of the JHS were to assemble and study a family, whether the broad family of African Americans or one's individual family, and to benefit these families, whether in the near future or at the time of the exam, clearly surfaced across focus groups. Respondents' statements reflected their perception of the uniqueness and specificity of the study's research focus: "It's a study of heart conditions in Blacks;" "to compare Blacks as opposed to other races;" "Find reasons why African Americans are plagued with heart disease."

It seemed evident to the focus group participants that the study's scope was dynamic enough to be narrowed beyond the larger family of Blacks to smaller, individual families: "It is a family study of the things that ran in families;" "About dealing with something common among families."

Also the theme of prevention as an objective was reflected in comments such as: "Hopefully get a handle on it as far as the future holds, we can live better and healthier lives," "Something that can be prevented," "What can be done to sort of eradicate so much of it from continuing to plague African American communities?"

Participants showed that they were knowledgeable that prevention activities for these diseases would not stop with the individuals being studied but could possibly benefit the overall Black community and future generations.

Participants' Knowledge about Genetics Research and Results of Genomics Literacy Quiz

The assessment of participants' knowledge about genetics terminology was determined using a 16-item genomics literacy quiz administered to each participant as a part of the focus group interview (Table 2).[20] The instructions for the questions about genetics were for the focus group participants to circle the letter next to the answer that was the best by choosing options a, b, c, d or e. If the participant had heard of the genetic knowledge term or topic but couldn't guess the answer they were instructed to choose option d or choose option e if they had never heard of the genetic knowledge term or topic and didn't have a clue about the answer. Responses to some questions indicated the focus group participants had some basic knowledge of genetics. Focus group participants provided correct responses for questions on basic level genetics: Every living thing has DNA (Question 2; 72% correct); each person has unique DNA (Question 4; 61% correct); What is a gene? (Question 5; 78% correct); having a gene doesn't mean disease (Question 10; 61% correct); and both nature and nurture makes you you (Question 11; 61% correct). However, for the more advanced level questions such as: question 1- "What does DNA stand for?", question 6 - "What is a genome?", question 7 - "What is the relationship between genes and chromosomes", and question 12 - "How much DNA is needed for genetic testing", respectively only 28%, 12%, 6% and 6% of the focus group participants provided correct responses, indicating a lack of knowledge regarding the science of genetics. "How many genes are in the human genome" (Question 9), was answered incorrectly by all participants.

Responses to the questions related to participants' genetic rights Question 15 and 16, indicated that 83% of the respondents were unaware of their genetic rights and the laws protecting individuals from discrimination by employers and by insurance companies, and 72% were not clear of their rights regarding participating in genetics research. However, the focus group participants clearly exhibited knowledge about the policies that safeguard the use of genetic data, as revealed in the statements: "There was a debate between the insurance companies and the DNA thing…," "Individuality will be protected…you are not having anyone named."

Awareness of genetic terminology and mechanisms was also exhibited by some group participants: "In families it is a carrier…some type of disease might have been into them and maybe somewhere down the line if we prevent it not to continue to be carried on in our inner families," "My mother back in 1988 had her first heart attack. I opted to look into it because obviously we are connected."

When asked about the genetic traits and conditions in their families, the responses were overwhelmingly limited to hypertension and diabetes. Although the participants' understanding of genetics is at a basic level, it is clear that genetics is seen as advancement in research and recognized as a comparative study, distinguishing why African Americans are different from other subpopulations. Thus, the two emerging themes from focus group responses related to participants' knowledge about genetics research: "It is going to help them improve the way they find diseases or heart problems," "We will get more on what is causing our problem."

Participants' Knowledge about the Advantages and Disadvantages of Genetics Research

Focus group participants' responses to questions regarding the advantages and disadvantages of genetics research generated more favorable than unfavorable responses.

Overall, participants indicated that participating in genetics research was a good idea. Among the favorable responses were increasing awareness, benefiting everybody, providing participants with information and getting to the cause of participants' problems, helping one's self and others, and helping to prevent disease.

The unfavorable responses or concerns raised included fear of losing one's health insurance or having to pay a higher premium, fear of being used as a guinea pig, questions on how the information would be used and who would have access to it.

Potential barriers to participation emerged in some responses. Examples included the fear that one would have to adhere to a special diet or exercise program, fear of changing one's medications, fear that some illness or abnormality would be found and doing something about it, having enough time for participation or having to take time off from work, and concern about experiments on people in Mississippi's State Penitentiary and Tuskegee.

Facilitators to research participation included active engagement by JHS staff manifested by making respondents feel welcome. Below are some remarks describing the staff: "nice" and "concerned," "They would call periodically to see if there had been any changes and just to see how they were doing;" "Persistent and dedicated," "…as evidenced by persistent phone calls, letters and the newsletters to keep them up on what they were doing." The participants attributed their continued JHS participation to feeling motivated by the staff, and to their feeling of a sense of trust with the staff, stating "You can feel that you can trust them."

The four emerging themes were: 1) increasing awareness; 2) benefiting everybody; 3) helping one's self and

Table 2. Test your genetics knowledge: what do you know?

1. What does DNA stand for?
    a. different natures in animals
    b. different nerve action
    c. deoxyribonucleic acid
2. Which of the following is *true*?
    a. only animals have DNA
    b. only plants have DNA
    c. every living thing has DNA
3. Where is your DNA?
    a. only in your gonads, the testes and ovaries
    b. in all your cells
    c. only in your blood
4. Who has the exact same DNA as you do?
    a. all human beings
    b. your children
    c. only you
5. What is a gene?
    a. the basic unit of heredity information
    b. a cell in the human body that causes disease
    c. a protein found in the human body
6. What is a genome?
    a. the part of a cell that makes proteins
    b. an organism's complete set of hereditary information
    c. all the cells in an organism
7. What is the relationship between genes and chromosomes?
    a. genes are found in every cell; chromosomes are found only in sex cells
    b. chromosomes determine gender; genes determine other cellular functions
    c. chromosomes are compact storage units for genes
8. What is the main goal of the Human Genome Project?
    a. to eliminate the genes that cause disease in humans
    b. to determine the complete set of hereditary information present in humans
    c. to enable us to genetically engineer and clone human beings
9. How many genes does the human genome contain?
    a. forty-six (46)
    b. between 20,000 and 25,000
    c. three billion (3,000,000,000)
10. If you have a gene for a disease, will you get that disease?
    a. yes
    b. only if both your parents have the gene.
    c. it depends.
11. What makes you you? What do most scientists think it is?
    a. only nature (what is determined by your genes)
    b. only nurture (what happens to you in your life, from the food you eat to just plain luck)
    c. both nature and nurture
12. How much of your DNA is needed in order to conduct a genetic test?
    a. a few cells
    b. a teaspoon
    c. a tissue sample
13. What conditions can currently be genetically tested for?
    a. only single-gene diseases like Tay-Sachs, Huntington's, and Sickle Cell Disease or chromosome aberration disorders like Down's syndrome
    b. certain cancers, including breast, ovarian, and colon
    c. both a and b.
14. What is the link between genes and complex social behaviors such as shyness and intelligence?
    a. behavior can represent a complex link between genes and environment
    b. genes determine specific behaviors in every individual
    c. genes have no influence on behavior, only physical traits
15. Which statement is correct about the genetic rights of individuals?
    a. the federal government protects its employees from discrimination by insurance companies and in hiring practices
    b. all states protect individuals from discrimination by employers and by insurance companies

Table 2. Continued

c. currently there are no explicit laws protecting individuals from genetic discrimination; the bill is pending in Congress.

16. When deciding whether to participate in genetic testing or genetic research, each individual has the following rights:
    a. to give informed consent after asking questions and understanding the issues and the benefits
    b. to have his or her privacy respected with respect to results but not if immediate family members ask for the results
    c. to expect confidentially unless the results have medical or commercial benefit for society, then the results must be released

others and helping prevent disease; and 4) feeling that you can trust (staff).

Participants' knowledge about the advantages and disadvantages of genetics research reinforced three themes regarding reasons for participants' interest in genetics research. Increased awareness is reflective of the desire to know more. Benefiting everybody is reflective of improving the health of future generations. Helping one's self and others and helping to prevent disease was reflective of the desire to find the causes of heart disease and find solutions.

DISCUSSION

The analysis of the focus group participants' responses revealed evidence that concern for individual and family health was a strong driver for participation in the JHS in general and participation in the genetics studies in particular. The assumption, and in some cases the desire, that the study might disclose some unknown health information appeared to enhance the motivation to participate. Furthermore, expressions of hope for the improved health of the individual's family, both currently and in future generations, stimulated many of the responses. The respondents overwhelmingly felt that participation in the study would help the common good, as a strong motivation to participate. Respondents also expressed the desire to be part of something that would help African Americans throughout the country.

The analysis of the focus group participants' responses revealed evidence that concern for individual and family health was a strong driver for participation in the JHS in general and participation in the genetics studies in particular.

Another recurring theme surrounding reasons for initial participation, and continued participation, was the confidence and trust that the respondents placed in the study's leaders and staff. They specifically referred to the kindness and genuine concern extended throughout each of their encounters with the study. In the participants' deductions, this caring environment translated into an earned trust.

The focus group findings, like the PRRS findings, were very informative, showing the JHS participants' high acceptance of genetics research and their willingness to participate. However, the focus groups also exposed the low to moderate level of genetic knowledge. Through the analysis of the focus group responses, as well as through review of the genomics quiz results, it is clear that more education is needed to enhance knowledge on the scope of genetics research. The specific heritability of hypertension, diabetes, and heart problems appeared clear to the group; however, evidence of knowledge that specific types of heart disease risk factors might run in families wasn't as clear. Additionally, knowledge about the fundamentals of genetics and issues surrounding the ethics and laws governing genetics research and results was minimal.

This new information was used by the JHS to identify, assess and establish training on genetic issues for the JHS staff and Jackson community. Genetic educational sessions were supported by the study, inviting genetic experts to speak with the JHS staff and at Jackson community events on topics such as ethics and confidentiality, medical genetics and role of genetics in clinical practice, ethical issues, genetic counseling, pharmacogenetics, gene environment interaction, the human genome project, genetic research and genetic diseases prevalent in African Americans. A JHS genetics brochure was developed and distributed to the study participants and a JHS genetics education resource library was established.

Strengths and Limitations

A major strength of the JHS is that it has effectively employed the principles of community-based participatory research through a community-driven approach to recruitment and retention to make the study participants and community an integral part of its protocol; thus it is likely that the information obtained has a high degree of reliability.

The generalizability of the findings of this focus group sub-study is limited by the small sample size. Although the focus group invitees were a stratified random subset of the JHS cohort, those who accepted may not have represented participants from both the general non-Family Study participants and Family Study components of the JHS. We did not perform a comparative analysis of the clinical characteristics (major medical conditions, BP, BMI, lipids) for the focus group and the overall JHS cohort. Therefore there may a bias due to the healthy participant effect. As well, the focus group participants may also be biased because of having more interest in participation in research and more positive feelings about the value of their contribution than the larger group.

RECOMMENDATIONS

Once the participants were in the JHS, the perception of trust was maintained through the caring attitudes and actions experienced throughout the course of the study which indicates the importance of an ongoing effort to create a caring participant-researcher relationship. Researchers seeking to recruit and retain ethnic minorities should consider: 1) implementing tailored activities for study participants and the community (non-participants) that engage and lead to developing trust and providing a sense of study ownership; 2) providing regular genetics education activities focusing not only on the participant's general genetics knowledge and a patient's probability of contracting a disease based on the family background and previous medical history, but also on the rights and the laws protecting individuals; and 3) providing a transparent operation to help the community overcome any fears and concerns they may have about providing biological specimens, particularly DNA, for genetic studies.

With these considerations in place, ethnic minorities are more likely to participate in research studies and remain engaged because they will believe and trust that the study investigators will do the right thing, both ethically and scientifically.

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