African-American Community Attitudes and Perceptions toward Schizophrenia and Medical Research: An Exploratory Study

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Introduction: Ensuring adequate representation of all demographic groups in medical research is necessary in order to ensure that the benefits associated with participation are equitably shared. Mental health research is unique in that the stigma associated with mental illness, such as schizophrenia, further hinders participation. Using focus groups, we set out to explore the attitudes and views of African Americans with regard to schizophrenia and medical research.

Methods: Four focus group discussions were conducted, with 23 participants divided into two groups of working and retired adults, and two groups of full- and part-time students selected from inner-city residents of Birmingham, AL, and surrounding counties. Data obtained were analyzed using the content analysis method.

Results: Diverse views were expressed about the cause of mental illness, and much of this was influenced by cultural beliefs. There was considerable misunderstanding of schizophrenia, and the majority of participants described the disease in terms of positive symptoms only. Whereas for older participants the Tuskegee syphilis study experience was an important factor in their reluctance to participate in medical research, younger participants expressed no knowledge of the study. Among younger participants an assumed level of social distrust was evident, with prominent fear of participating in research that employs physically intrusive methods.

Conclusion: The provision of accurate information through trusted community sources and open dialogue will help to dispel myths, correct faulty assumptions and increase African-American participation in schizophrenia research.

Key words: African Americans ■ schizophrenia ■ research ■ attitudes ■ focus groups

INTRODUCTION

Participant recruitment is an integral component of clinical research, with proportional representation of all demographic groups being necessary to ensure that any benefits associated with participation in medical research are equitably shared. However, ethnic minority groups are often not represented in medical research. In the United States, the nonrepresentation of African Americans in medical research has been attributed to a variety of reasons, including cultural barriers, limited knowledge of clinical trials, the effects of the Tuskegee syphilis study, societal distrust of medical researchers, poor access to primary medical care, the perceived risks of minimally invasive procedures, as well as the paucity of data to design, implement and evaluate recruitment strategies.[1-5]

Apart from the stigma associated with mental illness (which permeates all ethnic groups), additional barriers in mental health research in the African-American community are presented by unique factors, including the negative attitudes toward psychotherapy and the historical manipulation of mental illness to justify slavery.[6,7] It is therefore important to explore the perceptions and attitudes of African-American communities toward mental illness research in order to design appropriate interventions that will increase the likelihood of more racially inclusive mental health research.

In the last two decades, focus groups have been increasingly used as a qualitative research method and valuable data source.[8] Utilizing small-group dynamics and a more natural form of communication, focus groups are useful for exploring attitudes, norms and opinions on sensitive topics within populations.[9,10] Further, focus groups have been shown to be particularly useful among ethnic minority groups whose

members share similar personal experiences, beliefs and values.[8,11] The meaning of these experiences, beliefs and values may be compared across age and other socioeconomic variables.[12] The Project Among African Americans to Explore Risks for Schizophrenia (PAARTNERS) is a multisite NIMH-funded project that seeks to identify the genes that predispose to schizophrenia among African-American families, a hitherto understudied population. As one of the aims of the project, focus groups formulated by age and socioeconomic demographics were conducted to explore the attitudes, views and cultural beliefs of African Americans about schizophrenia and medical research. By doing so, we seek to gain an understanding of the factors that influence African Americans' decisions to participate in schizophrenia research, as well as improve recruitment and participation in our study, while adding to the literature in this understudied area. Such an understanding will also serve as a foundation on which future studies can build upon and thereby contribute to narrowing the prevailing ethnic disparities in mental health, especially through community education outreach efforts.

METHODS

Focus Group Participants

Participants for the focus group study (23 participants divided into four groups) were selected from inner-city residents of Birmingham, AL, and surrounding counties. One local community activist and one member of staff at the department of psychiatry, University of Alabama at Birmingham (UAB), selected a convenience sample based on the following characteristics: a) race, b) age, c) level of education, and d) employment status. In an attempt to access a range of opinions and attitudes across the local community, participants were selected from neighborhood centers, local school systems, law enforcement, social services and nursing agencies.

Twenty-three participants (nine males and 14 females) were asked to participate in a research study investigating perceptions and attitudes about schizophrenia and participation in biomedical research. Four focus groups of 5–7 participants were created, including men and women. Participants were of self-reported African-American descent, except for a single non-African American. However, in order to present a solely African-American perspective on schizophrenia and biomedical research, we decided to exclude observations by the non-African-American participant in our analysis and narrative.

Two groups (F1 and F2) included working and retired adults, ages 55–67 (mean age 63), while the other two groups (F3 and F4) included full-time and part-time students, ages 17–27 (mean age 21). Four

of these participants had previous knowledge and association with other group members. There were five participants in each of the first two groups (F1 and F2), seven members (four females) in the third group (F3) and six participants (two females) in the fourth group (F4). Groups F1 and F2 had a preponderance of female members (4 each).

Focus Group Format and Procedures

The format for the focus groups was designed to elicit candid beliefs, attitudes and opinions among African Americans about schizophrenia and medical research. While the study sought answers to specific questions, it was important to the researchers and the process that participants feel secure. The study design sought to offer participants an equal opportunity to express their true feelings about sensitive themes. In this regard, participants were informed that all discussions will be confidential, that no personal identifiers will be used in the transcripts and that all information obtained will be strictly used for research purposes. The informed consent process was conducted in a sensitive and respectful manner.

All focus groups were conducted by a female African-American facilitator with training in focus group development, question design and group process. Another staff member assisted with the audio/video recording and notetaking. Two focus groups were conducted at the Birmingham Public Library and two groups at the department of psychiatry, UAB. All sessions were facilitated in a conference room setting conducive to group discussions. Each focus group lasted 90 min. The PAARTNERS study is approved by the Institutional Review Board for Human Use at the University of Alabama at Birmingham.

Study Instrument and Data Collection

The topic guide for the focus group sessions was developed in advance at UAB following a review of the

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Table 1. Focus group questions/research themes

1. What is mental illness?
2. What is schizophrenia?
3. What are the cultural beliefs and stigmas about schizophrenia?
4. What are the feelings associated with being in medical research?
5. What is genetics?
6. What would prevent your participation in research?
7. What would increase your participation in research?
8. What are the feelings associated with "Blacks Only" research?

literature, with input from investigators working on the PAARTNERS study and from community members of a related ethics advisory committee. The guide consisted of open-ended questions and statements designed to explore eight research themes established by our study objectives (Table 1). After the welcome, introductory and opening comments, participants were asked a question and ample time was allowed for each participant to provide an answer. Participants were instructed to be candid and open. The moderator then guided and facilitated a detailed discussion of each question. Participant comments and responses were documented and visually displayed using a flipchart for clarity and further discussion. At the end of each group session, participants were asked what they thought about the process and the information shared.

Complete confidentiality was maintained throughout the study. At the end of the focus group session, a luncheon at the Birmingham Museum of Art was provided for older participants; a $25 honorarium was given to younger participants. Each focus group discussion was audio- and/or videotaped with the consent of the participants. Detailed notes were also taken during each session. All audio and video tapes arising from the focus groups were independently transcribed by two people: the focus group facilitator and a graduate student intern who had no former knowledge of the contents. The focus group facilitator verified written in-group participant responses from videotapes, audiocassettes and transcribed data.

Data Analysis

We used the content analysis method[13] to analyze data obtained. The transcripts of the focus group sessions were first coded and broken down into manageable categories on a variety of levels—word (e.g., "stress"), word sense (accepted meaning of a word), phrase (e.g., "multiple personality"), sentence (e.g., "It is paranoia") and theme subject matter (e.g., "cultural beliefs"). A numeric system was used to code the research themes and subthemes. We then manually quantified and analyzed the presence, context, meanings and relationships of certain words and concepts and made inferences about the messages conveyed. Each group constituted the unit of analysis, and analysis was undertaken in a group-by-group progression. A narrative was then developed that described the meaning, properties, connections and dimensions of the data under those categories, and the significance of the messages contained within. The narrative followed the eight categories delineated by our research themes (Table 1).

RESULTS

Views on the Causes of Mental Illness

The first theme of the study was related to exploring participants' beliefs regarding the cause of mental illness. Across the groups, diverse views were expressed on what causes mental illness. Such views included references to environmental, organic, biological/genetic and trauma-related factors.

Participants in the first two older age groups expressed the opinion that mental illness may be caused by a single factor or a combination of factors. Environmental conditions proffered included situationally induced stress, social factors such as poverty, reduced quality of life, poor nutrition and fanatical religious conviction. Biological factors were thought to be the result of genetic inheritance of a predisposition toward mental illness. Other factors listed included organic illness of the brain, chemical imbalances in the brain as well as injurious prenatal conditions and traumatic brain injury.

Since you have asked the question, I think stress can cause it. I mean, it has to be stress, because everybody is under stress. (F1)

Military issues, situational issues. Religion, sometimes people become fanatically religious, so involved .... (F1)

Illnesses of the brain ... like encephalitis. (F2)

There were some differences in the responses of the last two groups of younger participants who also mentioned alcohol and drug use (especially the extended use or "abuse" of these substances) as causes of mental illness in addition to stressful life situations, such as peer pressure, bullying, child abuse (i.e., sexual, physical, verbal, neglect), and trauma (i.e., emotional; witnessed or experienced):

Bullying or teasing, low self-esteem. (F4)

Substance abuse, like crack ... when it starts to affect you. (F3)

General Understanding of Schizophrenia

All groups expressed confusion about terms associated with mental disorders in general, and schizophrenia in particular. When described, schizophrenia was described in terms of positive symptoms only. The illness was described in terms of an individual having "two minds," paranoid thinking, abnormal behavior, being insane, deranged or pos-

sessing altered perception of reality. Collectively, these and other symptoms were thought to render an individual "crazy".

> Well, that is the term (crazy). It means out of the norm. You do not do what you normally do. You do things that are totally strange. (F1)

> It is paranoia. Seeing and hearing things that are not there. (F3)

> It is just crazy! Paranoid. (F4)

A prominent theme across the groups was the notion that schizophrenia meant "multiple" or "split" personalities. One participant (F3) suggested that in schizophrenia, where multiple personalities exist, the stronger personality was in control. Another member of the same group (F3) suggested that it is similar to "when a man starts wearing a dress." Schizophrenia was also interpreted as the manifestation of "demon possession" by older participants (F2).

> Having a bad spirit... multiple personalities. (F2)

> The demons ... when I was growing if you had a mental disorder they used the word "crazy" and "split personality." Some say "crazy," you say "schizophrenia," what is the difference? (F2)

Participants expressed disparate views about how the disorder may affect intelligence. Whereas older participants (F1, F2) suggested those affected are highly intelligent, younger participants (F3, F4) reported that persons with schizophrenia are of lower intelligence. One of the participants indicated that although persons with schizophrenia are intelligent, their mental abilities are restricted:

> They only can function in this little realm right here. They can't come out of that. (F1)

From the expression of younger respondents, there is evidence that the majority (n=7) believed that schizophrenia was neither a medical disease nor was it inherited. They expressed the view that affected individuals possessed some level of control over expressed symptoms. That is, behavioral manifestations of the disease could be turned on or off at will. One participant believed that affected individuals could heal themselves of the disorder by "just working it out".

> It is not a disease that you give to another. (F4)

> It is only in the mind. They can choose their actions ... it is under their control. (F4)

> Something they can turn on and off. They can control it. (F3)

> They can heal themselves. They just need to work it out. (F4)

Some older participants (n=4; groups F1, F2) tended to disagree with this view, asserting the disorder is a chronic disease that can be inherited and afflicted individuals are unaware of their abnormality. They believed that these individuals cannot control their symptoms and are not fully responsible for their actions.

A consensus among participants across all groups was that there is nothing positive about being affected with schizophrenia and that it has a chronic course, but is manageable when the individual is compliant with medication. There was the belief that an affected individual could not be healed ("cured") and must stay on prescribed medication. It was suggested that individuals could be *functional* if they remained medication compliant. In addition, there was agreement that individuals with schizophrenia can be successfully employed, be productive citizens, make decisions, vote and live independently. Despite these beliefs, three participants (groups F3 and F4) believed that a population of individuals with schizophrenia is less desirable to live near as they, collectively (such as a group home), represent a liability to the neighborhood or community.

The majority of participants across the groups (n=18) believed symptoms associated with the disease can make affected individuals inherently dangerous and prone to violence. Specifically, a participant explained this proneness to violence by proposing that paranoid symptoms render individuals with schizophrenia naturally more sensitive to life events and the actions of others.

> They are dangerous and violent ... because of paranoia. (F4)

> They are more prone to violence because they are more sensitive ... more likely to be overreacting. (F3)

Cultural Beliefs

Cultural themes were expressed across topics and groups. Spirituality and religiousness was prominently expressed in all group discussions. A view expressed by younger members was that schizophrenia is a taboo and not to be spoken of, while older par-

ticipants mentioned the notion of spell-casting (i.e., voodoo) or being hexed (inhabited by an evil spirit):

It is not really spoken of. (F3)

It can be like voodoo and being hexed .... (F2)

Group participants recalled the biblical reference to a man inhabited by an entity called "Legion" (meaning myriad evil spirits) who experienced symptoms and demonstrated self-destructive behaviors similar to those associated with schizophrenia. The possessed man found relief only when Legion was cast out by Jesus Christ. In contrast, there was no reference among the younger participants (F3, F4) to the belief that schizophrenia is an affliction by God or that it is a result of demonic possession. Although participants across all four groups expressed the view that full recovery from schizophrenia is not feasible, both older (F1, F2) and younger (F4) participants endorsed the view that certain religious beliefs could heal *any* condition.

Among participants expressing pride in family legacy and history, there was the feeling that mental illness, including schizophrenia, would not diminish the importance of affected family members or their inclusion. Individuals with a mental illness are therefore not shunned by such families or the local church. Older participants were more likely to hold such beliefs, asserting the importance of family. They did not endorse shame if they had an affected member in the family. In contrast, younger participants were more likely to associate mental illness with shame. Specifically, they concurred with the idea of being ashamed of a family member afflicted with schizophrenia. They were also more likely to restrict the individual's participation around immediate peers and at important social events.

I mean, if my friends were all coming over, I would feel shame... would not want them hanging out. But you still love them. If we go to a movie or something, that would be OK. (F4)

Attitudes toward Genetics

Participants expressed a superficial understanding of genetics. In attempting to explain the meaning of the term, participants made reference to the terms "genes," "heredity" and "DNA" (e.g., chromosomes, traits, hormones, types of cells). Genetics was also related to the idea of cloning, genetic mutation, offspring, Siamese twins, blood type, the human body, body makeup, chemicals of the body and relation to parents. None of the participants expressed awareness that genetics is also a profes-

sional field of study.

Regarding schizophrenia and genetics, the majority of participants (n=16) *did not* believe the condition is passed from generation to generation. However, some of the older participants (F1) expressed the belief that the disorder could be inherited or passed on to offspring. One of the participants mentioned the role of disparities in access to care as being responsible for any hereditary traits that may be seen among African Americans:

When you are looking at the south and the African-American community—many of our relatives come from the Deep South—and there was the lack of adequate medical care ... So, when you are talking genetic and heredity, it has passed on because black people are not receiving treatment and there is a lack of proper medical care ... (F1)

Barriers to Research Participation

While numerous views, concerns, beliefs and attitudes emerged across the four groups, several key barriers to participation in medical research emerged.

Tuskegee Syphilis Study. While discussing participation in medical research, older group participants had an immediate recall of the damaging experiment conducted on African Americans by the U.S. Public Health Service at Tuskegee Institute.[14] Knowledge about the experiment was immediately expressed:

There's reluctance and because, well, I am going to say why you don't get as many of us participating in medical research ... it is because of the Tuskegee experience and that's embedded in us ... The first thing that comes to mind is that something is going to happen to us, and we don't know if they are going to induce us with such medicines that cause us pain and we don't heal. That's what happened at Tuskegee and that's basically our thinking ... My belief is this is why you don't get it ... because it's there, it keeps coming up ... (F1)

As a result, the Tuskegee study experience was an important factor for older participants in their reluctance to participate in medical research. To emphasize this reluctance, an example was given about a recent study that used a placebo in a medication trial. This was negatively viewed and perceived as withholding vital medication for the research participants, a situation eerily reminiscent of Tuskegee:

Currently, I read a story in the newspaper this week that they are using a placebo to try ... I

forget now exactly what the study was, but I remember I immediately felt that the experiment itself, that if you are getting the placebo you are slowly dying … Regardless, the other person may be getting some real help, but you are being the guinea pig so that you are set for death … (F2)

Distrust. Younger participants on the other hand, expressed no knowledge of the Tuskegee study. But among these participants, there was still an assumed level of social distrust of Caucasians referred to as the "white–black issue." Older participants suggested that although younger generations of African Americans may not be as directly aware of what occurred at Tuskegee, their reluctance to participate in mental illness research may be associated with the notion that "little pictures have big ears," meaning that younger people have learned fear and distrust of Caucasians from overhearing the comments of adults. There was an additional concern that even in medical research performed by African-American investigators, skills of the researchers and staff may be inferior to current medical standards. Fear, reluctance and distrust, therefore can be associated with both Caucasian *and* African-American researchers.

Fear. As stated earlier, younger participants (F3, F4) expressed some reluctance to participate in medical research, but for reasons not immediately associated with the Tuskegee experiment. For these individuals, the *type* of research being conducted was important. There was a more prominent general fear of participating in research that employs specific methods. Several participants across all groups (n=11) expressed the view that they would not participate in any study (regardless of race/ethnicity of the researchers) that employed any type of physically intrusive method (ingesting medications, blood draws, injections, etc.) or involved potential exposure to a known infectious disease. Such individuals were willing to participate by only providing verbal information:

In my situation, I would be more reluctant to take something, you know, medically, into my body—an injection or whatever, from anybody as opposed to somebody telling me, "Come in, you just get to provide information. I am just taking history from you." I would be much less reluctant, from my standpoint, to just provide history or medical history … But, when somebody starts telling me, "Well, we want to try a new medication on you," then I start getting the same feeling you all are saying … this is going to hurt me down the line—you know what are you giving me … (F2)

There was some distrust of doctors, with one participant (F2) commenting that "… They would do unethical things for the greater good." For example, a participant (F3) negatively recalled a local herpes study and feared repeat tactics (i.e., unethical practices). Another young participant (F4) would not participate in medical research under any condition. This participant's aversion was further described as a simple "fear of the unknown."

Perceptions of research results. Another factor perceived by participants as influencing their decision to participate in research was the notion that published outcomes are overwhelmingly negative about African Americans. This was evident in the following remark where the participant expressed doubts about statistics that show increased disease risks in African Americans compared to other racial/ethnic groups:

And you know what disturbs me? When I see statistics and it's always Afro Americans are the number one of this … You mean to tell me that we are the only people with diabetes? We are the highest percent with hypertension? We all breathe the same air but we … That puts something back there—brings back to mind, "Well OK, I'm studied and it's always I am the one in the forefront. No one else experiences these things but us." That puts something on your mind … (F2)

Although there was a consensus that information-only research was acceptable, a participant expressed concern about what will be done with results arising from black-only research:

I don't want to participate because I don't know what you are going to do with this, and I don't know if it's going to negatively reflect on black people as a whole. People always want to do research on black people and then it ends up in *The New York Times*, and I don't want to contribute to that … (F1)

Rationales for Research Participation

While several participants expressed fear or distrust of participating in research, some participants were positive and encouraging. Positive reasons given for participating by older focus group members included: 1) strong desire and willingness to help others, 2) to improve medical treatments, 3) to gain personal knowledge or better understanding about an outcome, condition or drug, and 4) to assist in fighting diseases prevalent among African Americans.

Among younger participants, positive reasons for participating in research included: 1) financial incentives; 2) a desire to help save lives or to help others; 3) personal interest, to gain personal knowledge or better understanding about an outcome, condition or drug; 4) religious commitment or expectation to help others; 5) to specifically help a family member or spouse; and 6) to gain a sense of fulfillment, expressed as "I'm making a difference."

Some participants expressed the view that they would, in fact, participate without preconditions or direct material or monetary gain. Altruism appeared to be the reason here. Such individuals were willing to participate even if they or a loved one would not directly benefit, provided their doing so would help others.

Preconditions and Prohibitive Factors Influencing Research Participation

Conditions perceived as important to research participation by willing participants included factors such as if: 1) they were qualified to participate, 2) they were well informed about the study objectives, 3) the study employed and made visible qualified African-American principal investigators, 4) the study had oversight from a prominent authority or recognized entity (e.g., American Medical Association, American Psychological Association or the National Institutes of Health), 5) a significant financial incentive was given, >$100.00, and 6) there were no known adverse effects.

Some participants *would not* be willing to join if: 1) involvement was physically intrusive; 2) the logistics, such as transportation to or from a location, were difficult; 3) taking part required a significant time commitment (30 min to 1 hour was considered acceptable); or 4) participation occurred at an inconvenient time of day, affecting parenting and other responsibilities. Other reasons given by participants unwilling to take part in research were: 1) fear of the unknown; 2) fear of being infected with disease; and 3) fear of known adverse effects. Specific reasons given by one participant (F1) for not enrolling, beyond fear of experiments and distrust were: 1) not directly benefiting from the research (i.e., not personally healed of an ailment); 2) genuine disinterest; and 3) failure to see the positive value of past research outcomes.

Across the groups there was agreement that studies of African Americans only were sometimes necessary and appropriate (for example, to study sickle cell disease), but the key is to ensure that participants are well informed regarding why the research is being done on African Americans only, and why the research does not include people of other races and ethnic groups.

DISCUSSION

We observed differences in attitudes toward schizophrenia and medical research between the two participant age groups. Our study findings concur with previous investigators who noted that the Tuskegee syphilis study has contributed significantly to African Americans' distrust of biomedical research[4,15,16] but differ from previous studies in that this perceived "Tuskegee effect" applied mainly to older participants. Younger participants seem to have little knowledge of the Tuskegee study, while for older participants, Tuskegee still seems to influence their doubts about medical researchers' intentions. This finding suggests that the perceived Tuskegee effect on medical research participation among African Americans may be diminishing across generations. Bates and Harris[11] noted that the Tuskegee study was not likely to be mentioned by non-African Americans as a factor influencing their decision to participate in biomedical research. It appears this may now also be the case with younger generations of African Americans, who have been raised in an environment where public knowledge of that event is fading.

Earlier, we reported a comment by older participants that although young African Americans may not be directly aware of what happened at Tuskegee Institute, by overhearing the comments of adults they have learned not to entirely trust medical researchers. This remark is supported by the observation that young African Americans in this study did harbor some reservations about participating in medical research.

Cultural conceptions of mental illness have important effects on when and how an individual in a community seeks clinical care, possible stigmatization and the treatment options provided to persons with mental illness.[17] The diverse views expressed by participants with regard to the causes of mental illness reflect the broader public's beliefs about mental illness.[17,18] For instance, a nationwide survey of causes of mental illness found that stressful circumstances were the most commonly endorsed cause of mental illness, with more than 90% of respondents believing that stress was very or somewhat likely to be the cause of schizophrenia, major depressive disorder and alcohol dependence.[17] A chemical imbalance in the brain was the second most commonly endorsed cause for schizophrenia and major depression in that study, mirroring some of our findings.

In our study, there was confusion about the meaning of schizophrenia, with participants defining the disease in terms of positive symptoms only. An important observation was that the majority of participants believed symptoms associated with the disease can make affected individuals inherently dan-

gerous and prone to violence. This view may be responsible for the expressed desire by some of our younger participants for social distance from those afflicted with these disorders. Several investigators have identified dangerousness as a central aspect of the stereotype of mental illness,[19-21] and earlier studies have shown that blaming the afflicted individuals themselves increases social distance.[22,23] It was therefore not unexpected that a desire for social distance was described by the participants who supported the opinion that affected individuals possessed some level of control over expressed symptoms.

Previous research on racial attitudes reported that Americans who attribute mental health problems to structural causes (e.g., stress or genetics/biology) are more willing to interact with the mentally ill person than those who see individual causes (e.g., "bad character" or the "way the person was raised") as the root of the problem.[24] However, we were not able to verify this finding in our study, as this was not part of the themes discussed.

It was not surprising that genetic research continues to raise concerns for many potential research participants, including African Americans. However, rapid advances in the field of genetic research make it increasingly important to explore community members' knowledge, attitudes and perceptions regarding genetic research. Although genetic research involving schizophrenia has yet to have clinical application, genetic studies involving African Americans, such as PAARTNERS, will continue to emerge, with the attendant need for improved minority partnership and recruitment. We found that the present study's participants expressed little knowledge of genetics and genetic research. These findings highlight the need for a concerted effort to educate the African-American community about what genetic research is and why it is important for the community to participate in order to experience potential benefits that may arise from such research.

The recommendation that African Americans should be involved as medical researchers supports previously published evidence that such involvement is critical to the establishment of trust.[2,3] Gil and Bob[25] noted that the inclusion of minorities as researchers will decrease the likelihood of a perpetuation of stereotyped views and distorted perception of ethical issues by investigators. Besides, the relative scarcity of minority faculty and staff in universities and research settings can be surmounted by enrolling minority undergraduate and graduate students as coresearchers and research assistants.[26] This involvement of African Americans as investigators and research staff at all levels in genetic and medical research protocols will ensure that the research agendas correlate with the priorities of the African-

American community, thereby increasing the expectations of possible benefits and reduced risk of harm to this population.[11]

It is not unexpected that participants included oversight by a prominent authority as one of the important factors influencing participation in medical research. The awareness that such an oversight agency exists will help instill trust among participants, seeing that there is an organization that will protect their interest and ensure that investigators comply with ethical rules and regulations guiding the research process.

Limitations of the present study include the small sample size, a lack of diversity outside of a geographically restricted sampling area and a focus on schizophrenia in the context of mental illness. Additionally, the present preliminary study could not assess the diversity among different African-American communities and did not include middle-aged adults. However, many of the expressed attitudes and concerns related to general aspects of medical research. Also, within-group diversity in participants' ages, occupational status and gender assured that the results can be generalized to the broader African-American population.

CONCLUSION & RECOMMENDATIONS

Barriers and distrust exist between local African-American communities and the medical research community. However, when information is provided about a clearly established need for study, barriers to research participation among African Americans can be surmounted.

Trust and education were identified as primary to improving perceptions toward, and participation with, medical research. These factors can be facilitated by individuals who are respected and recognized within the society. Without the support of these individuals, significant inroads into these communities by researchers from outside these communities will probably not be as successful. Information from trusted sources and open dialogue with researchers tend to dispel myths, correct faulty assumptions and misinformation, and move individuals and communities beyond old barriers toward better communication and stronger relationships.

Knowledge about the benefits of research studies among lay persons can be improved through early education (e.g., beginning at high school) as well as community education programs targeting African-American communities through the local media. In addition, strong community partnerships can be formed by encouraging the participation of lay persons in local community advisory boards. Such involvement by members of the community in the design of research protocols and recruitment strate-

gies will engender a sense of ownership and partnership as well as improve community knowledge of the benefits of medical research. Our preliminary findings can be used to design specific medical research education and recruitment programs that will contribute to narrowing prevailing ethnic disparities in medical (and mental health) research participation among African Americans.

In conclusion, findings from this focus group study suggest that the following measures would help build trust and foster participation in mental illness research:

- Provide information about the program/study by trusted and committed sources.
- In research programs directed to African Americans, include qualified African Americans at all levels of the research team.
- Include information from trusted individuals who share personal positive experiences from recent research participation.
- Transfer one-on-one information with members of the community.
- Establish clear inclusion criteria (i.e., identifying exactly who is needed).
- Where only an African-American sample is required, provide detailed information about the seriousness of the condition and need for the study.
- Do not label a study as "blacks only" without adequate education and information being provided to potential participants as to why only African Americans are being recruited.
- Give information stating specific incentives, including a monetary component.
- Give information about the specific methods employed in the study, including detailed time and travel requirements as well as any required procedures.
- Hand out simplified research brochures that visually include African Americans and participant "testimonials" from recent studies, and prominently list the oversight (ethical review) agency.

Future Research

More research is needed to investigate the attitudes and perceptions among African Americans regarding mental illness, biomedical research and genetics. The focus group format has been demonstrated to be a valuable approach for gathering such sensitive information.[10] Future research may surround the attitudes of individuals in various age groups, particularly those aged 30–50 as well as males across all ages and socioeconomic demographics, as these groups were underrepresented in the current study. An interesting question is the

effect of medical research participation on attitudes and access to healthcare. Would research interventions designed to educate participants about disease manifestation, inheritance and treatment reduce barriers in seeking and complying with clinical treatment plans? Future studies can also investigate whether previous experience with mental health professionals or knowledge of treatment options by participants makes a difference in attitudes and perceptions toward schizophrenia research.

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