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An Exploration of Attitudes Among Black Americans Towards Psychiatric Genetic Research

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Abstract

With increasing emphasis on understanding genetic contribution to disease, inclusion of all racial and ethnic groups in molecular genetic research is necessary to ensure parity in distribution of research benefits. Blacks are underrepresented in large-scale genetic studies of psychiatric disorders. In an effort to understand the reasons for the underrepresentation, this study explored black participants' attitudes towards genetic research of psychiatric disorders. Twenty-six adults, the majority of whom were black ($n = 18$) were recruited from a New York City community to participate in six 90-minute focus groups. This paper reports findings about respondents' understanding of genetics and genetic research, and opinions about psychiatric genetic research. Primary themes revealed participants' perceived lack of knowledge about genetics, concerns about potentially harmful study procedures, and confidentiality surrounding mental illness in families. Participation incentives included provision of treatment or related service, monetary compensation, and reporting of results to participants. These findings suggest that recruitment of subjects into genetic studies should directly address procedures, privacy, benefits and follow-up with results. Further, there is critical need to engage communities with education about genetics and mental illness, and provide opportunities for continued discussion about concerns related to genetic research.

INTRODUCTION

With a few exceptions, Blacks or African Americans are underrepresented in genetic studies of psychiatric disorders. Non-Hispanic Whites have typically comprised 90% or more of samples in U.S.-based family history studies (Gershon et al., 1982; Sullivan, Neale, & Kendler, 2000; Tsuang, Winokur, & Crowe, 1980; Weissman, Gershon et al., 1984; Weissman et al., 1986), adoption and/ or twin studies (Cadoret, O'Gorman, Heywood, & Troughton, 1985; Kendler, 2001; Kendler & Prescott, 1999; 2000; Lyons et al., 1998; Wender et al., 1986), and genetic linkage studies (Camp et al., 2005; Holmans et al., 2007; Levinson et al., 2007; McGuffin et al., 2005; Zubenko et al., 2003). On the other hand, non-Hispanic Blacks, who approximated 11–13% of the U.S. population between 1980 and 2006 (U.S. Census Bureau, 1980; 1990; 2006), have made up 0% to less than 5% of the sample in such studies. Furthermore, among Blacks, there are no within-group formal family history studies of major depression.

Previous research has examined African-American attitudes towards participation in biomedical research in general, and has found that the reasons for unwillingness to participate typically include stigma, and cultural or racial mistrust (Braunstein, Sherber, Schulman, Ding, & Powe, 2008; Furr, 2002; McQuillan, Porter, Agelli, & Kington, 2003; Shavers, Lynch, & Burmeister, 2002; Sterling, Henderson, & Corbie-Smith, 2006). Blacks as compared to Whites have been shown to have a greater mistrust of scientific research, independent of socio-economic status (SES) and education. (Furr, 2002; Laskey et al., 2003; McQuillan, Porter, Agelli, & Kington, 2003). Wariness associated with knowledge of the Tuskegee Syphilis Study, as well as concerns about the reporting and uses of research findings, are thought to drive much of the Blacks' suspicion of biomedical and genetic research (Bates & Harris, 2004; Jackson, 1999; McQuillan, Pan, & Porter, 2006; Schulz, Caldwell, & Foster, 2003). In addition, research has highlighted the perception in some Black communities, that their participation in scientific research often provides no meaningful or long-standing benefits, outside of cash incentives to individual subjects (Audrain, Tercyak, Goldman, & Bush, 2002; Cromwell, Vaughan, & Mindel, 1975; Royal et al., 2000). In a similar vein, arguments have been made that these communities are typically exploited by researchers who derive benefit in the form of career or corporate advancement from their research, but do not "give back" to the communities (Schulz et al., 2003).

Despite many theoretical and empirical references to stigma, mistrust, and other negative attitudes among Blacks towards research, a few recent studies have suggested that the role of attitudes in determining ethnic minority participation in research is miniscule (Armstrong et al., 1999; Clay, Ellis, Amodeo, Fassler, & Griffin, 2003; Wendler et al., 2006). These studies have emphasized the practical impediments to research participation that disproportionately plague minority and poorer communities (Shavers-Hornaday, Lynch, Burmeister, & Torner, 1997), such as time constraints, lack of health insurance, not having access to media through which research studies are advertised, and difficulty traveling to and from research sites (Hussain-Gambles, Atkin, & Leese, 2004).

Although it may be reasonable to assume that some of the factors responsible for low Black participation in clinical trials and other biomedical research are the same for psychiatric research, there has been little systemic study of the elements associated with participation in genetic research of psychiatric disorders. Much of the mental illness "attitudes" research among Blacks, or comparing Blacks with other ethnic groups, has dealt with perceptions of different kinds of psychiatric disorders, stigma surrounding mental illness, and attitudes towards treatment of psychiatric disorders (Crogan et al., 2003; Schnittker, 2003).

With regard to genetics, some research has examined attitudes among Blacks and other minorities towards genetic testing (Laskey et al., 2003; Singer, Antonucci, & Van Hoewyk, 2004). More recently, there have been published accounts of attitudes among Blacks towards genetic research focusing on physical disorders disproportionately affecting African Americans (Royal et al., 2001). However there has been an absence of comparable studies on attitudes towards nonintervention genetic research of psychiatric disorders.

Studies examining Black-White differences in beliefs about causes of psychiatric disorders have shown that Blacks are less likely than Whites to using genetic or familial explanations as causative factors in mental illness, even when they accept other biological explanations, such as chemical imbalance (Schnittker, Freese, & Powell, 2000). Based on this finding, it has been postulated that different cognitive interpretations of the term "genetic" may yield different attitudes for Blacks and Whites, some of which stem from the different historical, racial, and cultural experiences that these groups have experienced (Schnittker et al., 2000). Consequently, the differences in beliefs about causes of mental illness may partly explain the differences between Blacks and Whites in treatment-seeking patterns for mental illness

(Schnittker et al., 2000). It might be tempting to speculate that such attitudes among Blacks also might be related to their disposition towards genetic research of psychiatric disorders, but it is unknown if this link exists, or the extent to which it does, due to lack of empirical investigation directly addressing this issue.

As part of a collaborative effort to increase Black participation in a genetic study of major depression, we initiated a series of studies to understand possible reasons for underrepresentation. The rationale for this overall effort is based on the observation that Blacks are underrepresented compared to whites, in recent molecular genetic studies of major depression (Levinson et al., 2007; Lotrich et al., 2003). Major depression is a widespread psychiatric disorder which, in the year 1990, was estimated to be the fourth leading worldwide cause of disability (Murray & Lopez, 1996). Depression is also shown to be genetically influenced (Sullivan, Neale, & Kendler, 2000), and by the year 2020, it is expected to be the second leading worldwide cause of disability, after ischemic heart disease (Murray & Lopez, 1996). The need for inclusion of participants of all racial and ethnic groups into research, so all can benefit, makes the examination of the barriers to recruitment of Blacks into psychiatric genetic research an important objective.

Accordingly, this study's purpose was to explore themes related to people's attitudes towards psychiatric genetic research, using a majority Black sample, and to determine their willingness to participate in genetic studies of psychiatric disorders, if given the opportunity to do so. We used focus groups to yield qualitative data for generating hypotheses, which could be systematically tested in future studies. This paper reports the main findings from the emergent themes.

METHOD

Recruitment Procedure

The study was approved through the New York State Psychiatric Institute Institutional Review Board. Recruitment flyers were posted in various locales, such as university campus lobbies, waiting areas and lobbies of clinical institutions affiliated with university medical centers, and in community services such as barbershops, laundromats, and hairdressers. Over three months, 74 people responded to the flyers. Fourteen of these individuals were unable to be subsequently reached by telephone after multiple attempts, resulting in 60 people being contacted by telephone to be given further details about the study and to determine their eligibility to participate. Potential participants were informed that the focus groups were being audiotaped and that written consent to participate in the groups would also imply consent for the use of their audiotaped responses. Once the study objective and procedures were explained, participants' verbal consent was required so they could be screened to determine their eligibility.

Selection Criteria and Screening Procedure

The general criteria for study inclusion required that participants be English-speaking adults 18 years or older via self-report. Specific criteria focused on three elements: 1) race/ethnicity, 2) lifetime history of depression or anxiety, and 3) healthy without history of major psychiatric illness. Ethnicity criteria were established because we wanted to focus primarily on non-Hispanic Blacks, with the initial intent of recruiting a smaller group of Whites for comparison purposes only. Therefore, anyone who did not self-identify as non-Hispanic Black/African American or non-Hispanic White/Caucasian was excluded. The

general and ethnicity criteria were assessed using the Focus Group Screening Instrument¹ that was developed for this study.

Lifetime history of depression/anxiety criteria were established because we wanted to track people's willingness to participate in two genetic studies, which were being conducted at our research site and which investigated the genetic bases of panic disorder and/ or social phobia, and of major depression. Because one of the studies required healthy controls, we also screened for people who reported no personal history of any major psychiatric disorder. Anyone who reported a history of mania or psychotic symptoms, such as hallucinations and delusions, outside of major depression, was excluded. Participants' eligibility for clinical criteria was assessed using a clinical screening instrument² which asked a series of questions regarding history of anxiety and mood symptoms, mania, substance abuse, and mental health treatment. The questions were adapted from a pre-existing clinical screening instrument developed by research staff members in the genetic study of panic disorder and social phobia.

Volunteers were typically screened within 24 hours to one week from their initial contact. The days and times of the focus groups were predetermined with the goal of having about six groups of 4–8 individuals, over a period of six to eight weeks. By the time screening was complete and the groups were formed, 27 people had been eliminated. Thirteen were found to be ineligible on the basis of ethnicity, and 5 reported having had a history of psychosis outside of depression. Eight people had schedules that could not be accommodated by research staff.

Focus Groups

Out of 33 confirmed participants, 26 came to the research site as scheduled and comprised five focus groups (held on separate days), with an average of 3–6 participants in each group. There were significantly fewer Whites than Blacks, with three of the five groups consisting of both Black and White respondents. The remaining two groups had only Black participants.

The focus groups were held in a conference room with about a 15- to 20-person capacity. The room was furnished with a large oval table and chairs. Snacks and beverages were provided for the participants. Research staff consisted of a group moderator and a note-taker. The moderator and note-taker were both of African descent and were at least master's level researchers in the health sciences, with experience conducting focus groups. Upon arrival to the group session, participants read and signed consent forms and completed a brief demographic questionnaire.³ They were encouraged to clarify any ambiguities on the consent forms, which explained the study's purpose, procedures, confidentiality, compensation, risks and benefits, participant rights, and the contact information of the Institutional Review Board, principal investigators, and research staff. The moderator oriented group members as to the purpose of the study. Participants were instructed to raise their hands if they wanted to speak. All participants were given an opportunity to speak through a pocket-sized digital microphone recorder that was passed around the table. Less outspoken participants were gently encouraged by the moderators to speak, and by the end of each group, everyone had given at least one response to each question. Each focus group lasted approximately 90 minutes, and each participant was compensated with a \$40.00 U.S. postal money order at the end of the session. The focus groups were professionally transcribed from the audiotaped recordings.

1. Furnished upon request

2. Sample clinical screen will be furnished upon request.

3. Furnished upon request

Data analytic procedure. Seven primary topic areas were addressed in the focus groups, which were anchored by specific questions asked in the focus group.⁴ The areas were: 1) beliefs about causes of psychiatric disorders, 2) understanding of genetics/ genetic research, 3) perceived drawbacks of genetic research, 4) personal concerns people might have about genetic research, 5) practical barriers to participating in genetic research, 6) perceived benefits to genetic research, and 7) possible incentives to participating in genetic research. Because there was considerable overlap in the responses to domains 3, 4, and 5, they were collapsed to form a single domain “Perceived Drawbacks and Barriers to Participating.”

We adapted our analytic strategies based on guidelines for coding open-ended data reliably, as outlined in Hruschka and colleagues (2004). First, by identifying key words and phrases in the responses, an initial master list of theme codes was generated for each domain by going through the entire set of focus group transcripts. Transcripts were used along with written notes to further extrapolate meaning from the responses. Second, a training session was held in which two raters independently coded a small part of each transcript (e.g., one group in each topic area), using the theme code master list, and then compared ratings, discussing any areas of disagreement, and coming to consensus on the specific meanings of various responses. The codes were then modified and refined to reflect newer guidelines established from the training session. Using the newly established codes, raters independently coded the full set of transcripts. An initial computation of inter-rater agreement warranted the necessity for a second session of code modification and refinement.

After we completed the second round of coding, we obtained modest inter-rater agreement on the first three domains, with 68% inter-rater agreement for beliefs about causes of psychiatric disorders, 85% agreement for understanding of genetics, and 64% agreement for understanding of genetics research. Because of time constraints, no further coding sessions were held, and therefore, in computing the aggregate and relative distribution of codes for these domains, we selected only responses for which raters showed complete agreement. This resulted in a total of 63 coded responses for “Causes of Psychiatric Disorders,” 28 coded responses for “Understanding of Genetics,” and 32 coded responses for “Understanding of Genetic Research.”

Because the final three topic areas, respectively addressing perceived benefits, drawbacks, and incentives to participating in genetic research, were considered to be of greater importance for the purpose of this study, we went through an additional iteration of coding for these three areas. Once we obtained adequate inter-rater agreement (at least 80%), the two raters (with an option to include a third rater, if necessary) conducted consensus ratings to be able to calculate compare the relative distribution of thematic responses within the topic areas.

RESULTS

Demographic Characteristics of Participants

The 26 focus group participants ranged in age from 22 to 65 years, with a median age of 42. The average household income range was \$20,000 to \$29,000, with 69% of the sample reporting annual household incomes of under \$30,000. Eight of the participants were non-Hispanic White (four males and four females); 18 of them were non-Hispanic Black (four females, fourteen males). Participants’ level of education ranged from eighth grade to post-bachelor’s graduate-level work, with 15 individuals having at least some college education

⁴Furnished upon request

or higher, and 2 individuals having less than a 12th grade education. Most of the participants were single/never married (n = 19).

Response themes—The total number of coded responses within a topic area, along with the proportion of response themes for that area is provided in tables 1 and 2. Table 2 also includes the inter-rater reliabilities (kappas and percent agreement) before consensus, and the frequencies of response themes after consensus for the topic areas described.

Beliefs about the causes of psychiatric disorders—When asked about their beliefs about causes of psychiatric disorders, participants provided a wide range of responses, and endorsed mostly environmental causes, the most frequent of which was “general stressful life events,” which accounted for 27% of the responses.

“I feel that many people get stressed out, whether from work, working long hours or people have many things to take care of— take care of the kids or balancing work and family. Also, dealing with things that are beyond their control ... Stress from money problems, relationships, the environment, health issues, all of those seems like they play a role.”

The next common theme was family/ childhood upbringing, such as learned behavior, relationships during childhood with family members, family/community environment, and early socialization, this accounted for 19% of the responses in this topic area.

“... I think it’s the environment ... We watch and imitate what our fathers and mothers do. If they’re abusive, and we saw it, then maybe when we get older we might wind up doing the same thing ...”

Lifestyle-related personal habits, such as exercise, diet, and substance use, accounted for 13% of total responses on the causes of psychiatric disorders. Many responses across various groups expressed the idea that substance abuse and mental illness were heavily associated. Most of the participants believed that drug and/or alcohol abuse brought on depression, while others seemed to be aware of an interactive relationship between substance use and depression, with many stating that depression often preceded alcohol or drug use, which in turn exacerbated the tendency to depression.

“For myself a lot of my depression was worsening by my self-medicating with the use of alcohol and drugs. It played a big part in my depression.”

“I was depressed before I even started using drugs. So I was depressed first. Then as I began to use drugs I became even worse. Then I had to get on medication. When I stopped drugs, that’s when I started to feel much better.”

“I’m self-medicating all the time, but I was depressed before.”

Understanding of genetics—Respondents most commonly described their substantive interpretation of the term “genetics” by talking about hereditary in terms of traits that are passed down from parents to children (39%). For instance, this individual tried to articulate his understanding of genetics.

“I just started getting to know really what it really means. It’s got to do with genetic research with your family. You know, you and your brother got the same type of attitude or you know, your mom is—to me it’s like the environment of your family. If all of y’all got the same—how do I put it?—the same ... I can’t explain it right. I know it’s got to do with the family environment, that’s what I know about it. The genetics in your body, in your family ... me and my brother have the same type of blood or whatever.”

The next common response was having a superficial knowledge of some of the terminology associated with genetics, such as DNA, RNA, Helix, mutations, and so forth (36%). Interestingly, about 25% of the responses noted a lack of knowledge or understanding of genetics. For example, one respondent stated:

“I have not a clue ... That’s like asking me about rocket science.”

Another respondent felt that minority communities, in particular, were uneducated about genetics.

“I don’t think people know enough about it— minorities anyway. It’s not an issue in our community—genetics. It’s really not a big issue. I mean it might be a general issue where we know general things about DNA, RNA—that my child has my genes. In general, we all know that. But when we get into—genetics can cause mental illness. Well, it can come from genetics. I wouldn’t know anything about it if I didn’t read or watch television the way I do.”

She further went on to state that the subject of genetics is only taught after secondary school. She cited this as a reason for the relative lack of knowledge in the general population, not just in minority communities.

“It’s not something that we learn unless we go into biology or one of the sciences. We’re not taught that in school as one of the basic courses. I mean they do tell you about reproduction and they touch on the DNA, and they tell the kids about genes. My son comes home he tells me, ‘yeah, I know what a gene is. I have your genes.’ Okay, but in the big picture nobody really knows enough. They don’t teach us enough.”

Understanding of genetic research—When asked about genetic research specifically, participants spoke of experimental procedures like cloning, and transgenic mice (28%), and biomedical research with the purpose of trying to find out about the origins of specific diseases/conditions (22%). As with genetics, a significant proportion of respondents also articulated incomplete understanding of genetic research (25%). Some participants voiced the opinion that genetic research is inaccurately represented or sensationalized by the media, which may be partly responsible for the current public misunderstanding about genetics.

“Well, I think people know about what gets a lot of media attention, like—or advertising. So people know about Dolly the sheep and people know about drugs that are advertised on TV. But other kinds of research I don’t think very many people know really.”

Another respondent, like many others, highlighted the conflict she faced, in trying to balance her fears with her desire to know and understand more about genetic research.

“Genetic research—I’m a little leery with that word research. You know, after reading about certain things—they use people for research and they’re like really messed up. I know that somebody has to step up, you know, so you get testings or see how things are going to work. Genetics—I think it has to do with the DNA or your genes or something like that. As far as like splicing animals with different animals and stuff like that, I think that’s kind of like playing with fire. I’m a little afraid and then I’m curious. I don’t want to see nobody grow an extra head or an extra toe or something like that. But if you don’t explore you won’t know.”

Similarly one respondent expressed the opinion that fear of the unknown can deter people from participating in genetic research.

“A lot of people’s concerns about genetic research is probably more from ignorance than anything else. ‘Cause a lot of genetic research is not even so much about taking medication, it’s just basically them taking some genetic material and running tests on it to see if you’re predisposed to anything.”

Perceived advantages/benefits of genetic research—Despite a perception of being relatively uninformed about genetic research, most people were able to identify what they perceived to be some advantages of genetic research. The top themes were identifying and understanding the origins of diseases and conditions (48%), and preventing and/ or curing diseases through more timely, efficient, and targeted treatment (35%).

In addition to thinking that genetic research was good for keeping society better informed in general, some respondents felt that genetic research could be helpful to individuals and society by de-stigmatizing certain disorders through the removal of personal blame or responsibility, and by disassociating those conditions with character flaws or failures.

“I think it can also lead to better understanding of cause, which may be a benefit. Sometimes there’s this blaming of parents or other people.”

Certain group participants highlighted the idea that some of the purported benefits of genetic research could also be drawbacks, depending on how they were contextualized.

“If someone has been convicted of violence or is prone to violence, sexual aggression or whatever, it would give you a chance to look for that in an offspring or the next generation of violent behavior. It would give you a warning sign.”

When asked by the moderator whether this issue was a drawback or an advantage, the same respondent went on to state further that:

“This is all hypothetical. If my father was a violent felon who was tried for murder, and if they did the research that would be necessary to find that if I carried this, ‘violent gene,’ even if I didn’t I could be ostracized the rest of my life. So that’s one of the drawbacks.”

Another respondent in different group voiced a similar concern—that knowing about someone’s genetic predispositions in advance, although not necessarily a bad idea, could be problematic when viewed in a different context.

“But the same thing that could be beneficial could also be a flaw, because once again if you’re judging people you could also overdo it. And say, this kid has ADD, and then put him on Ritalin before he’s gotten a chance to prove himself otherwise, ‘cause he’s predisposed— because the other kids had it or ‘cause the household’s nutty. So the drawback is the same as the benefit. I mean it’s good to know, and to learn, and to be forewarned about certain dispositions, but at the same time to characterize and label somebody and not give them a chance to prove otherwise...”

Perceived drawbacks and barriers to participating in genetic research—The two most prevalent response themes in this area involved unpleasant study procedures—drawing blood, and unintended adverse effects resulting from participating in genetic research. For example, some people described extreme situations:

“There’s a possibility that you can be lobotomized. You just lose it all. These are experimental so they don’t know the effects that they’re going to have. So I would be concerned that something could go wrong and you’d be a vegetable.”

“I watch a lot of TV, but still lots of shows reflect that’s really happening. And they had a number of college students on one show participate in a study and the

medication—they found out from what they were taking, in the end a couple of them committed suicide. Anyway, the law eventually was able to make a case on the doctor who headed up the research study that he allowed that medication to be used for his research of whatever kind he was doing. These were supposedly normal people, but they went in—the medication made them depressed and a couple of them committed suicide.”

Other people described less extreme, but more probable situations. For instance, a woman recounted an actual experience that she had while participating in a research study. She indicated that this experience had led to her subsequent fear of certain types of research.

“You know, being afraid to do it ‘cause of things that happened to other people participating in ... I actually did take a drug. It didn’t even have a name; it had a number. I had to take six pills like three times a day. And I’ve never been more scared. I wanted to do it, and I wasn’t even getting paid for doing this. I’m helping with research; I might be the breakthrough. After I took my first couple of pills, I started getting all paranoid and I didn’t take any more of them.”

Many respondents emphasized the idea that psychiatric disorders, compared to physical illnesses, were more likely to trigger feelings of stigmatization and concerns about confidentiality.

“I think there’s a stigma attached to psychiatric disorders. I think some of my family might be more willing to have a blood test to see if certain people are predisposed to cancer or something [other] than this mental illness.”

“I have no medical illnesses I’m ashamed of. But when it comes to my mental health issues, what I share with my doctor and those professionals is my own personal information. So I think confidentiality is probably one of the foremost important things.”

“It’s something to watch out for—that people’s privacy is respected. People could be stigmatized. Other people will look down on them perhaps, knowing—they wouldn’t want to marry them ... And sometimes, they’d just be branded as flawed, unfairly perhaps.”

Many respondents also raised concerns about family members who are often required to participate in genetic studies, or whose health history is required as part of those studies. For example, someone expressed the idea that while he understood that certain illnesses may run in his family, it would be extremely difficult to convince family members to participate in the studies that he has participated in.

“If it involves getting other family members involved also, it could be very awkward sort of. Something that’s kind of very private, psychiatric disorders, and there’s a lot of shame in society about it. So when you want to involve other family members it becomes a very touchy issue. A lot of families, I don’t think they’re up for all this. I think it could cause great disturbance and friction. As for as me, I don’t have any problem with it ‘cause I’m fascinated by human behavior. But I could never imagine my family being in this room doing this survey in a million years. And they would not want to hear anything about their predispositions.”

The personal and institutional treatment of research participants was an additional area of great concern. Respondents voiced objections to unethical experimentation, and concerns about the ultimate purpose of the research were articulated as well.

“I would feel they would be using me as a guinea pig—through genetic research they might try to help other people, but I would feel like I’m not going to be no guinea pig for nobody else. That would be my barrier.”

“I was just thinking in terms of people who become part of the genetic research program. I wouldn’t want to be getting foreign drugs to me or things of that nature that have to be ingested in one way or the other, create another problem in the guise of trying to help me—to help with the research and help me get better. But something else might happen.”

“I think that there is a fear of the unknown. There are always ethical considerations about how the research is done, and what it is, and what are the goals of the research. And, of course, the ethics of the people who are conducting the research.”

“... if you’re talking about doing genetic engineering, most people have problems with it—in developing the perfect human. That’s where a lot of the problems come in. It’s ethics issues that come into play when you’re talking about genetic engineering of human beings. So that could definitely create problems down the road.”

In discussing drawbacks, there were two separate references made to race made by participants in different groups. One of the responses expressed doubt that information garnered from research findings would necessarily be beneficial to Blacks in all cases.

“I’ve seen so many studies where people get the information and it really doesn’t faze them. African Americans have like this high number of people that have heart disease. It’s like, you know, they still won’t change their habits. They won’t give up eating these greasy, fatty foods and exercising, and everything like that.”

The same respondent further questioned the results of a recently published study he had read about. This is a portion of the interchange between the moderator and this participant.

“They actually had one study I saw in the paper today that said African Americans are—cigarette smoking affects them more than other racial groups. And I was like [laughs]—I thought that was kind of funny. I wonder how many different groups did they test? If they went across the whole board? Because they didn’t give any other numbers, they just came out with that. That was the blurb line, that we’re more susceptible to cigarettes—smoking cigarettes than other racial groups.”

Moderator: Do you think they were saying that African Americans are more genetically predisposed to having negative effects of smoking?

“Well, see, the thing about it was it would have to lead to the fact that somebody engineered cigarettes to affect African Americans that way. I mean it’s like—I mean tobacco is a naturally occurring substance until you add all the other stuff in like nicotine and all the other things.”

There was no dissent from other group members about this opinion, although another participant stated that she had also heard about the study and recalled some of the specific findings. However, she did not comment about the further implications of the study, nor did she agree or disagree with the former respondent.

Another response featured issues of both race and class, in which the participant demonstrated awareness of his racial group membership and social class status as a research participant. But as the conversation went on, the same respondent appeared to downplay the issue of race.

“I have to admit I feel more comfortable if there are Black people in the room. I try not to, but I’m always in the throws of us and them.”

Moderator: You’re talking about people of other races?

“People, classes, races, whatever. I’ll give you an example. My meeting’s in Town X and it’s evidently clear that these people’s problems in White Town X are not the same as our problems in Town Y. I’m trying not to be partial, but it’s a reality. We’re talking about living on the streets in Town Y, there’s a big difference.”

Moderator: Well, what about as far as participating in research? What if there were White researchers here doing this, would you feel as comfortable as if there were Black researchers?

“I’m comfortable by the way it’s presented to me. If you tell me I don’t know enough about something and can explain it to me, I respect that 100 percent. But if you come at me like I know what you’re going through and you don’t have a clue, I’m very offended by that.”

Incentives to participating—Receiving direct benefit, such as treatment, education, assessment or some other form of research-related intervention, emerged as a top incentive for participating (19%).

“And then offer some relevant intervention for free.”

“If you had some kind of outreach, a van or something like that, and go to neighborhoods you’d get a lot of response.”

Closely following were monetary compensation and follow-up with participants. Monetary compensation was mentioned in all the groups, with no dissent from group members. Many participants spoke of the desirability of following up with them as a way of making their participation more meaningful. For example, these responses expressed the sentiment that most participants preferred some form of follow-up contact, active engagement during the study, or information regarding outcome of the research study in which they participated.

“I think that an awful lot of these research focus groups and studies and stuff, they don’t keep track of you and they don’t tell you what happened later. I think if people found out more information, if there was a follow-up ... They know they’re participating in this but—you know, then you got an email six months later or a year later, they’re having another group and they came up with this theory, this research—something which makes your participation have more significance in some sort of a context.”

“Well, for example, let’s say you draw some blood from someone. Okay, this week—next week you sit down and go over with them the lab results; your objective in drawing the blood, or what you saw, and how this can be used. I mean I think people want to know ‘what are you doing with my body parts? What have you learned from me?’ So I think some people would be concerned about that. Because then that may inform you a little bit more about yourself.”

In addition to research-related treatment, money, and follow-up, respondents also mentioned desiring hospitable accommodations at the research sites (e.g., food, beverages, activities while waiting, etc.), having a personal or family history of the disorder being investigated, and the desire to contribute to society and fellow humans.

Willingness to participate in genetic research. After informing participants of ongoing genetic studies of anxiety disorders and/or major depression at the research site, the group moderators explicitly asked group members whether they would be willing to volunteer to participate in such studies. All of the participants indicated their willingness by allowing focus group research staff to give their phone numbers to the administrative staff (of the genetic studies) who would then contact them and have them go through a separate consenting process for the studies. Most participants indicated that they had never

participated in genetic studies because they were not aware that these studies were going on. When asked about the preferred method of getting to know about the studies, the primary response was through word of mouth.

DISCUSSION

This study aimed to explore perceptions and attitudes towards genetic research of psychiatric disorders, using focus groups consisting primarily of Black participants. We observed that, despite a perception of having inadequate knowledge of genetics, respondents were able to voice a variety of opinions about genetic research, and they also were able to weigh the perceived merits and disadvantages. On one hand, participants believed that genetic research could generate new and important knowledge relevant to preventing and treating certain disorders more effectively. On the other hand, they expressed concerns about study procedures and safety as well as concerns about privacy and confidentiality with respect to psychiatric illness.

In general, we found that the participants believed that psychiatric disorders are caused primarily by environmental factors, which include mostly stressful life events and circumstances and, to a lesser extent, family upbringing. Still, all the participants acknowledged some genetic contribution to mental illness and felt that genetic research was relevant for psychiatric disorders. Many of the respondents either had a history of being treated for depression and/or substance abuse, or knew someone who did, which may have influenced their ideas of mental illness origins. The medical or disease model, which is typically that endorsed by mental health professionals, does not reject, and in fact may emphasize, the genetic underpinnings of psychiatric disorders (Schneider & Conrad, 1980).

The top two perceived drawbacks to genetic research were unwanted adverse effects and unpleasant study procedures. Many expressed concerns about being injected with or ingesting unknown substances that may lead to unpleasant or harmful side effects. Similar fears have been cited as deterrents to participating in clinical trials of cancer and other serious medical illnesses (Outlaw, Bourjolly, & Barg, 2000). Some research has suggested that despite a lack of technical knowledge associated with advanced course-work in genetics, most people have enough knowledge of genetics that their concerns about genetic research ought to be taken seriously (Bates, Lynch, Bevan, & Condit, 2005).

Although participants were not directly asked about race-related issues in research participation, there were two references to race when participants spoke of drawbacks or concerns about genetic research. The infamous Tuskegee Syphilis Study, which involved research negligence with Black participants that caused long-lasting deleterious effects, has been frequently referenced as a reason for the distrust of biomedical research among African Americans. Even though at least one response demonstrated elements of racial distrust, contrary to our expectations, racial themes were not frequently brought up—even among groups in which all the respondents were Black.

It was observed that respondents frequently grouped together themes of privacy, confidentiality, stigma, and family involvement in research. Because genetic research usually involves family members either indirectly through proband reports or directly through their participation, the potential for stigma and shame associated with “mental illness in the family” may be exaggerated in genetic studies compared to other forms of health research (Biesecker & Peay, 2003). This is consistent with Schnittker and colleagues’ finding (2000) that among Blacks, “family upbringing” correlated more strongly with “genetic factors,” than with other environmental factors as a cause of mental illness.

Our study results suggest that the participants generally had a positive orientation towards genetic research of psychiatric disorders. However, the findings need to be interpreted cautiously in light of the fact that more than half of the sample had had previous experience participating in health research studies. This could have created a biased sample in terms of the participants' general attitudes towards medical research. The study selection rate was 36%, due to our specific selection criteria. While this enabled us to track people's willingness to enter into ongoing genetic studies, the limited sample size did not permit us to make comparisons between Blacks and Whites, and those with and without a history of mental illness. However, we observed that the top two to three themes in the topic areas were all expressed by both Black and White participants, as well as those with and without a reported history of mental illness. As can be the case in focus group settings, it is possible that certain participants felt less sure of their opinions and thus did not voice them, or perhaps they suppressed their dissenting views about others' opinions. Nonetheless, this study has brought up a few issues that potential participants of genetic research may grapple with, and so we highlight the following points to consider.

1. *Education about genetics.*

Although educating people about genetics may help to erase some fears, it may also open up a different set of concerns, which will inevitably arise as people learn more about the scope and implications of genetic research. The demystification of genetics, along with provision of platforms where concerns can be articulated via public health and community forums and organizations, may be necessary to encourage active cooperation in such types of research from community residents. Genetics education also should be directed at mental health professionals and primary care practitioners who come into regular contact with a range of consumers and who may be seen as less intimidating or distant than researchers in university settings.

2. *Family involvement.*

In publications addressing the ethics of psychiatric genetic research, there is a dearth of information from the participants' perspective on the impact of family involvement in their willingness to participate in genetic research. Among Blacks, there may be even greater stigma surrounding mental illness, and therefore getting family members to participate in genetic research may present a challenge. More research is needed to examine the ways in which family involvement affects potential participants' willingness to participate in genetic studies of mental illness.

3. *Follow-up with participants.*

Many publications are written stylistically for scientific journals, making them inaccessible to the layperson. Following up participants with a brief summary of findings, written in jargon-free language, might not only validate their present contribution to research, but also make them more willing to participate in future studies. In addition, subjects need to be informed that while results may not contain any information that will be personally useful to them, the research findings are often used to generate knowledge that will inform future efforts in preventive and therapeutic developments.

4. *Racial mistrust.*

Elements of racial mistrust may continue to feature in the recruitment of Blacks into genetic research due to current perceptions of differential

research experiences and reporting of study results, based on race. Racial stereotypes of supposed genetic inferiority of Blacks, propagated through publications such as *The Bell Curve* (Hernstein & Murray, 1996), It is important that investigators direct attention to the ways in which the results of recent studies have been interpreted and reported (Ossorio & Duster, 2005)—via scientific publications, and non-scientific forums such as popular magazines, televised shows, and how various racial groups might be portrayed by these reports.

5. *Benefits.*

Unlike clinical trials or other studies investigating psychotherapeutic or pharmacologic effectiveness, non-intervention psychiatric genetic research does not involve the provision of research-related treatment or similar services. Genetic research of psychiatric disorders is still exploratory and is not likely to yield any information that would be clinically meaningful to a participant. Besides monetary compensation, other forms of compensation can be provided, such as referrals to healthcare resources or free educational seminars at community agencies and forums.

It is likely that psychiatric genetic research will increase exponentially in future decades, as more sophisticated molecular research techniques are used to discover the underlying pathways to common mental illnesses, such as major depression (Appelbaum, 2004). Engaging potential research participants of underrepresented groups in meaningful discourse about their concerns as research subjects is essential in eliciting their trust and collaboration. This effort represents a preliminary step towards ensuring that benefits derived from genetic research are proportionally realized across various racial and ethnic groups. Additional research with larger, more representative samples is necessary to systematically investigate the specific ways in which attitudes predict willingness and actual participation in genetic studies of psychiatric disorders.

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TABLE 1

Proportion of Response Themes for Topic Areas 1–3

Topic Area	Coded Response Themes	Proportion of Responses*
Causes of Psychiatric Disorders n ^{**} = 63	General stress (e.g., work, relationships, financial problems)	27%
	Childhood & family upbringing; learned behavior from family, and community in which one was raised	19%
	Genetic; what is inherited biologically from parents	17%
	Personal lifestyle (diet, exercise, substance use, hobbies)	13%
	Combination of genetic and environmental factors	6%
	Personal strength and resilience	6%
	External events (e.g., natural and man-made disasters, recession, etc.)	5%
	Medical/organic factors (e.g., stroke, brain damage, post-partum)	5%
Understanding of Genetics n = 28	Hereditary (what is passed down biologically from parents to children)	39%
	Molecular terminology (DNA, RNA, chromosomes, helix)	36%
	Lack of knowledge or understanding of genetics.	25%
Understanding of Genetic Research n = 32	Experimental research (e.g., cloning, etc)	28%
	Lack of knowledge or understanding of genetic research	25%
	Biomedical research (specific disorders, assessing people and their family history)	22%
	Curiosity and apprehension	13%

Note

* Percentages computed using only themes agreed upon by both raters.

** Number of coded responses

TABLE 2

Proportion of Response Themes for Topic Areas 4 – 6.

Topic Area	Inter-rater Percent Agreement(Kappa)*	Coded Response Themes	Proportion of Responses**		
Perceived Benefits n = 31	88%(0.74)	Increase understanding about health, behavior and origins of disease	48%		
		Prevent/cure diseases & conditions	35%		
		To be better informed in general	10%		
		De-stigmatizes (removes personal blame)	3%		
Perceived Drawbacks/ Barriers & Concerns n = 97	81%(0.48)	Unpleasant study procedures	15%		
		Unintended harmful research outcomes	14%		
		Violation of privacy and confidentiality	12%		
		Fear of what the results will reveal about you	11%		
		Stigma (embarrassment about mental illness in family)	11%		
		Improper treatment of research participants	10%		
		Questionable ethical practices (e.g. cloning)	8%		
		Mistrust (e.g., suspicion about researchers' motives)	7%		
		Time commitment	4%		
		Discrimination from insurance companies	2%		
		Costs of participation	2%		
		Incentives to Participating n = 47	84%(0.27)	Medical compensation (e.g., treatment, assessment)	19%
				Cash/monetary incentives	15%
Following up with participants	15%				
Hospitable research site	11%				
Personal/family history of disorder investigated	11%				
Wanting to contribute to society	11%				
Assurance of safety/appropriateness of study	9%				
Study is advertised through appropriate channels	4%				

Note

* Figures computed before consensus was obtained.

** Percentages obtained after consensus was obtained.