

Community Perceptions of Genomic Research: Implications for Addressing Health Disparities

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BACKGROUND Increasing the engagement of racial and ethnic minorities in genomic research may help alleviate health disparities. This paper examines community perceptions of the relationships between race, genes, environment, and health disparities, and it discusses how such perceptions may influence participation in genomic research.

METHODS We conducted semi-structured interviews with 91 African American, Latino, and white lay community members and community leaders in North Carolina. Using constant comparison methods, we identified, compared, and developed linkages between conceptual categories and respondent groups.

RESULTS Participants described gene-environment interactions as contributing to group differences in health outcomes, expressed the belief that genetic predisposition to disease differs across groups, and said that social conditions trigger group-level genetic differences and create poorer health outcomes among African Americans.

LIMITATIONS Given the regional presence of major research institutions and the relatively high education level of many participants, this sample may not reflect the perspectives of those most disparately affected by health disparities.

CONCLUSIONS Members from multiple community sectors share perceptions and may respond to similar approaches when attempts are made to increase participation in genomic research. Researchers may inadvertently fuel the perception that health disparities experienced by minorities are rooted in the shared genomes of a particular group as distinct from those of other groups. The way researchers use race and ethnicity in recruitment, analysis, and communication of research findings inaccurately implies that there are genetic differences between races, when categories of social experience or ancestry may more accurately characterize health differences. Understanding these issues is crucial to designing effective community engagement strategies, recruitment plans, and messages about genomic research, which could ultimately help to lessen health disparities.

Technological advances have improved our ability to prevent, diagnose, and treat disease. Despite these advances, significant health disparities persist among racial and ethnic minorities [1]. These disparities have been linked to a variety of factors, including social and environmental inequalities and race-specific genetic variations [1-4]. Advances in genomics may allow us to disentangle and fully evaluate how genes and gene-environment interactions contribute to health [4]. In turn, this knowledge may provide strategies for addressing health disparities from a comprehensive perspective [3].

Progress in genomic sciences as a strategy to ameliorate health disparities is contingent upon members of diverse racial and ethnic groups engaging in the research process. Historically, however, research study populations have not reflected the diversity of those experiencing the diseases or conditions of interest [2, 3]. It is crucial that communities of color be engaged in genomic research in order for further advances to be made in personalized drug development, diagnostic and prognostic tools, and research into the effect of gene-environment interactions on health [2, 3]. Other advantages of community engagement in genomic research are that it facilitates an ethical and practical shift toward more participant-centered research practices and processes, and it allows us to consider the factors that influence people's willingness to engage in genomic research.

Previous studies have examined potential barriers to par-

ticipation in genomic research. Although some studies have found that members of certain minority groups are hesitant to participate in population-based genetic research [5, 6], other studies have supported the contention that willingness to participate in research is the same across racial and ethnic groups, regardless of social class and knowledge [7-9]. Prior research with African Americans has examined how lack of familiarity with genetic concepts acts as a potential barrier to use of genetic services [10]. Although researchers have explored community perceptions of race and genetics [11, 12] and have looked for associations among race, genetics, and health outcomes [13], we know of no studies that have explored the public conceptualization of race (whether as a social or biological construct) and how it might shape understanding of and interest in genomic research.

Improving minority participation in genomic research requires a better understanding of how communities collectively view the social and genetic components of race and ethnicity, how those components interact to create

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differences in health outcomes, and how individuals weigh these issues when faced with opportunities to participate in race- and ethnicity-based genomic research. In this article, we report on findings from a qualitative study that examined individuals' perceptions of the causes of health disparities, and we consider the implications of those perceptions for genomic research.

Methods

We conducted in-depth semi-structured interviews with 91 lay community members and community leaders. Within minority groups, community leaders are central to information dissemination and health-related decision making [14]. Their voices are thus an important factor when members of these groups are evaluating opportunities to engage in genomic research that aims to address health disparities.

The interviews took place across a 22-county region in central North Carolina. Participants were recruited using purposive sampling based on self-identified race or ethnicity (African American, white, Latino), age (18–35 years, 36–65 years) and community status (lay, leader). Leaders included individuals working in or holding formal leadership positions across a range of community segments (clinics, grassroots organizations, media, education, etc) [15] and those in informal positions, such as neighborhood block captains or community activists. This study was approved by the institutional review board at the University of North Carolina at Chapel Hill (UNC-CH).

Recruitment. Recruitment was facilitated by regionally based community outreach coordinators who are part of the community research infrastructure of the North Carolina Translational and Clinical Sciences (NC TraCS) Institute, which is the administrative home of the Clinical and Translational Sciences Award (CTSA) at UNC-CH. To facilitate research linkages, each community site in the NC TraCS Institute maintains collaborative relationships with regional community-based organizations and clinical practices. Coordinators at each site contacted local agencies and clinics, regional community advisory boards, and a pool of community experts as recruitment sources. The coordinators then identified potential participants who met the inclusion criteria (age, sex, racial/ethnic category, community segment, and geographic location) and who agreed to be contacted by the study coordinator about possible participation. Latino interview participants were recruited by a community-based bilingual and bicultural research assistant, who made contact with organizations that serve the Latino community and asked for their aid in recruiting participants.

Interviews. Interviews were conducted by 3 trained research assistants who resided within the local communities. Interviews were held at community locations such as local libraries, community centers, and private offices. Latino participants had the option of completing their interview in English or in Spanish. For interviews conducted in Spanish,

all study instruments were translated into Spanish using standard forward-and-back translation techniques [16] to ensure that materials were linguistically and culturally comparable to the original [17]. Interviews were audio-recorded and lasted 48 minutes on average (range, 35–75 minutes). Areas of inquiry included knowledge, beliefs, and experiences related to several topics: race and ethnicity, genomics and genomic research, the role of genomics in health disparities among diverse population groups, and beliefs about the benefits and harms of genomic research. As part of the interview, the terms *genetics* and *genomics* were defined for participants. For the purposes of this study, *genetics* is defined as the study of inheritance, or the way traits (like hair color or eye color) are passed down from one generation to the next. *Genomics* is a newer field that includes the study of all the genes in a person, as well as how those genes interact with each other and with a person's environment. After each interview, participants completed a brief demographic survey and received a \$30 Visa gift card.

Data management and analysis. The audio files were professionally transcribed verbatim, and all identifying information was redacted. Transcriptions were imported into ATLAS-ti.v6.2, a computer program for managing text data. A 5-person team developed codes for conceptual categories by organizing the research questions into broad categories. Each code was assigned example text from the transcripts and rules for use to ensure appropriate and consistent application of the codes. Once the codebook was finalized, the research team coded transcripts in 2-person teams. Each team reconciled their application of the codes for each transcript and presented any challenges, with reconciliation, for review by the full team. Coding meetings were held on a weekly basis to ensure that the codes were being used appropriately across teams and to discuss any modifications to the codebook. A primary and secondary analyst then constructed matrices to identify, compare, and develop linkages between conceptual categories and respondent groups. Using constant comparison methods, thematic domains were delineated as the analysis of text data continued [18]. Demographic survey data was managed using Excel.

Results

Most lay participants (61%) were employed, 30% had a high school education or less, 76% had no history of clinical research participation, and approximately half (51%) were women. Among community leaders, 48% were African American, 55% were women, 73% had at least a college degree, and 34% had a history of clinical research participation (see Table 1). There was little variation in themes between responses from lay participants and responses from community leaders. Findings are presented across categories of race or ethnicity unless otherwise indicated.

The current study presents findings on 3 interrelated themes. First, we discuss participants' perceptions of the relationships between race or ethnicity, genetics and

genomics, and health outcomes. Second, we detail participants' understanding of gene-environment interactions by examining how they discuss racial and ethnic differences in socioeconomic and social contexts and by looking at what they say about the relationship of such differences to genetic predisposition. Finally, we consider how these perceptions can inform minority participation in genomics research that aims to improve health equity.

Race, ethnicity, genes, and health inequities. Respondents often used physical characteristics, such as differences in body type and hair texture, as evidence of genetic variation. Participants understood genetics as being related to traits that are passed down through families and that contribute to physical characteristics, frequency of disease, and predisposition to disease. Genetics is viewed as being largely unchangeable and leading to inevitable health outcomes, and it is credited with being the reason why family members often experience the same health condition. One Latino male leader described genetics as follows:

Genetics is an inheritance from your family. For example, you have children and they can have your same eyes. . . . And diseases too, because they say "my grandmother had heart disease, my grandfather had diabetes," and you end up getting it until the third or fourth generation.

Genetics was seen as a key factor contributing not only to health outcomes but also to differences in predisposition across racial and ethnic groups. One African American male leader described this contribution by saying, "Genetics plays a large part in it. . . . Certain populations seem to be more susceptible to certain diseases." Similarly, a Latino male leader said, "I heard that the African race is more prone to disease, because of their genetic form." Genetic profiles that place an individual at risk for poor health outcomes were discussed as a tiered system; African Americans were seen as having the worst genetic predisposition to poor health, followed by Latinos, and then whites. Participants acknowledged that there are variations in disease outcome by racial or ethnic group; however, respondents only discussed disease differences that exist for racial and ethnic minorities, and all but one of the examples given were for disparities experienced by African Americans. Although this perception was present for all 3 respondent groups, the proportion of respondents indicating that genetic differences are an underlying cause for differences in disease outcomes was nearly twice as great among white respondents as among African American or Latino respondents.

Race, ethnicity, and gene-environment interactions. Participants were familiar with the concept of genetics; however, there was an overwhelming lack of familiarity with the term *genomics*. Most participants (84% of African American respondents, 81% of white respondents, and 76% of Latino respondents) had not heard of the term.

Although some of the terminology was unfamiliar, par-

ticipants had clear concepts of how race and ethnicity drive and interact with differential social conditions. Race and ethnicity were described as being associated with differing cultural norms and behaviors and with the creation of differential conditions under which genetic expression occurs. Racial and ethnic groups were often described as differing in diet and levels of physical activity, both of which were said to contribute to differences in disease outcomes. Diet included the type and amount of food consumed and how food is prepared; African Americans and Latinos were perceived as choosing less healthy food items and preparation techniques. A white lay female participant offered her perception of how dietary differences contribute to differential health outcomes:

I think we are all predisposed to certain diseases based on your race. . . . If you lived differently, then it doesn't have to affect your life. . . . Black people have [high] blood pressure, cut out fast food, cut out the chitterlings or whatever that's ethnically part of their diet, things that they have had in their history for years.

Although participants described differential health outcomes as largely attributable to social and cultural differences between racial or ethnic groups, participants also offered in-depth discussions of how each group's phenotypic expression (that is, what they look like) mediates the social conditions under which differential health outcomes occur. These social determinants included differential access to health care, education, fiscal resources, and even healthy food options. Latino respondents also cited language as a cause for differences, specifically in health outcomes, due to the inability of non-English speakers to access adequate or appropriate health care and challenges in communicating with health care providers. One African American male leader described the situation as follows:

I think that by way of people not being in the same economic playing field as a lot of other ethnic groups, by them not having access because of economics, it leads people not to get early treatments, which leads to the progression of certain diseases, or getting a further developed disease that someone with insurance was able to get early treatment and be treated for certain things.

Interactions between genes and the environment were also described as creating racial and ethnic differences in gene expression based on where groups live, including both the physical living conditions and how "place" affects accessibility to health-promoting services. An African American lay female participant described this by saying:

. . . on this side of the track has better stuff than on the other side of tracks. The one is getting better water, better meat, better vegetables. Their health is going to be better, their health is not going to decline as fast as the ones who is not getting those same things.

TABLE 1.
Demographic Characteristics of Study Participants

Demographic characteristic	Laypersons n = 47 No. (%)	Community leaders n = 44 No. (%)	Total N = 91 No. (%)
Self-identified race/ethnicity			
White	15 (32)	11 (25)	26 (29)
African American	16 (34)	21 (48)	37 (41)
Hispanic/Latino	16 (34)	12 (27)	28 (31)
Sex			
Male	23 (49)	20 (45)	43 (47)
Female	24 (51)	24 (55)	48 (53)
Mean age in years	37	44	40
Employment status			
Employed	27 (61)	36 (82)	63 (72)
Unemployed	9 (20)	3 (7)	12 (14)
Retired	3 (7)	3 (7)	6 (7)
Other	5 (11)	2 (5)	7 (8)
Level of education			
Some high school or less	8 (19)	2 (5)	10 (11)
High school graduate/GED ^a	5 (12)	3 (7)	8 (9)
Technical school	4 (9)	3 (7)	7 (8)
Some college	8 (19)	4 (9)	12 (14)
Completed college	10 (23)	14 (32)	24 (28)
Some graduate school	3 (7)	5 (11)	8 (9)
Graduate degree	5 (12)	13 (30)	18 (21)
Marital status			
Married	25 (56)	23 (52)	48 (54)
Separated	2 (4)	1 (2)	3 (3)
Divorced	4 (9)	8 (18)	12 (13)
Widowed	1 (2)	0 (0)	1 (1)
Never married	13 (29)	12 (27)	25 (28)
Income			
Less than \$5,000	8 (19)	1 (2)	9 (10)
\$5,000–\$20,000	10 (23)	6 (14)	16 (19)
\$20,000–\$40,000	9 (21)	10 (23)	19 (22)
\$40,000–\$60,000	9 (21)	13 (30)	22 (26)
\$60,000–\$80,000	2 (5)	4 (9)	6 (7)
\$80,000 or more	5 (12)	9 (21)	14 (16)
History of participation in clinical research			
Yes	7 (16)	15 (34)	22 (25)
No	34 (76)	28 (64)	62 (70)
Not sure	4 (9)	1 (2)	5 (6)
History of participation in genomic research			
Yes	2 (4)	5 (11)	7 (8)
No	43 (96)	37 (84)	80 (90)
Not sure	0	2 (5)	2 (2)
History of tissue or sample donation			
Yes	5 (11)	2 (5)	7 (8)
No	38 (84)	40 (91)	78 (88)
Not sure	2 (4)	2 (5)	4 (4)

Note. Some percentages may not add up to 100% due to rounding or to missing data.

^aHas passed the General Educational Development test and received a Certificate of High School Equivalency.

African Americans were described as experiencing the poorest living conditions, Latinos were described as having somewhat better living conditions, and whites were described as living under the best conditions. African Americans were viewed as being more likely to live in conditions that exacerbate the expression of existing genetic predispositions to poor health outcomes. These living conditions were said to include the presence of toxins, insects, and proximity to industrial waste. A white male leader offered this explanation:

A certain racial group maybe have a higher propensity for a certain disease, but if they have a healthier environment where they're eating healthier, it could lower the risk of heart disease or whatever. . . . On the other hand, if they genetically are prone to one certain disease, and there's nothing done to help that, and their environment is a poor environment where they may be putting toxins in their body, breathing toxins, drinking polluted water, I think that's definitely going to not only not help, but it's going to hurt. It may even bring that disease on earlier, and I think there's a difference in where racial groups tend to live. I would think that would have an effect on diseases and whether they may carry a genetic trait, but because of some of those disparities they may not be able to prevent them as best they could if they were in a more healthy environment.

Weighing engagement in genomics research and health equity. Given the cross-cutting belief that racial and ethnic groups are genetically and often socially distinct from one another, there are close ties between the factors that influence respondents' evaluation of genomic research and further perpetuation of the hierarchical structure respondents described. Not surprisingly, most African American and Latino respondents indicated concerns about research that aims to address health disparities (88% and 86%, respectively); however, most white respondents (81%) also cited concerns. Among those with concerns, the proportion of respondents whose concerns were directly tied to race was nearly twice as great among African American and Latino respondents as among white respondents. African Americans and Latinos spoke of mistrusting researchers and the government; these individuals also spoke of fearing medical abuses, the use of research to "promote" one race over another, genocide, and mistreatment or targeting of a particular race. Among one-third of Latinos, mistrust was closely tied to fears of deportation for family members who are undocumented immigrants. One African American female leader described historical and current concerns regarding this type of research:

I think the fear is misusing the information; again, in our society we value different populations; the fear is that they could say, we only want 10% of this race to be born in a particular year because that is all we need or something. . . . The people that are doing the research, it is incumbent upon them to have the values that it's going to be done for good and not for abuse and for mistreatment of any race, one race versus another.

Similarly, a white female leader said:

There's a long history of really bad practices . . . the history of Nazi Germany and the history of the Tuskegee experiments and the ways in which minority groups or people who are different . . . has the potential to reinforce stereotypes, to damage those people, to put them in situations where they're being exploited.

White respondents discussed race-related concerns regarding the use of genomics research to “mark” or to racially profile minorities. Instead of using research findings to address health disparities, this type of profiling could be used to reinforce stereotypes or to deny access to health insurance. A few white respondents also raised concerns that genomic research that aims to address health disparities may provoke race-related sensitivities, including elevated racial tensions, or may even result in a racial or ethnic group being blamed for certain health outcomes. One white male leader offered this perspective on concerns about genomic research that addresses differences in disease outcomes between racial or ethnic groups:

The only thing I can think of is maybe identifying some inequities that are present, and that may cause maybe some racial tension—you know, for instance, if African Americans have a higher rate of heart disease, and if you're looking at genomics in that, that may be higher also because in general African Americans don't get promoted as quickly, live in poorer conditions, and a lot of that stuff I think we know already, but what I'm thinking in my head is there may be some tensions created when things like that are brought to light, and the more it's brought to light, I think the more we can help it, but it also may cause some tension.

Despite such concerns and the potential for harm, participants also identified potential benefits of genomic research. Each racial or ethnic group described the value of the anticipated knowledge to be gained through such research. New knowledge could provide a better understanding of the role of the environment in health, how diseases manifest, and prevention strategies, and this improved understanding could provide a basis for better medical care. Both African American and white respondents discussed the value of “helping certain races” or helping those most affected by health inequities. One lay white female respondent also discussed the value and the potential implications of genomic research that attributes disparities to social ills rather than to genetic differences:

What would be really awesome is if they did research on everyone's genetics and found that we're much more alike than we are different inside our bodies. And so maybe people will have to face up to the fact that it's class and poverty that's causing higher rates of obesity, diabetes, heart disease, and almost any other disease you can mention in African Americans instead of the inverse, which I think is the scary side. I think finding differences could lead to race blame. I'm afraid of that.

Discussion

In this study, we explored community members' understanding of genomics and genetics, as well as their understanding of how these concepts relate to disparate health outcomes. Genetic researchers and social scientists have traditionally found it difficult to synergize biological and environmental explanations for health outcomes and health disparities. Interestingly, when considering determinants of health outcomes, community participants readily acknowledged the contributions of both biology and the environment, as well as the necessary interconnectedness between the two. Almost all participants had a clear and largely accurate understanding of genetics. Only a few respondents had ever heard the term *genomics*, but they largely endorsed the concept that interactions between genes and the social and physical environment contribute to group differences in health outcomes. They offered in-depth discussions of various social determinants of health, and they addressed the ability of those social determinants to create conditions that could affect gene expression and subsequently lead to health disparities. Given the prevailing use of labels to describe scientific work, researchers may sometimes be misled about community understandings of science and may fail to recognize that many scientific concepts are well understood by communities even though certain terminology may be unfamiliar.

Two main findings offer important insight for effectively engaging communities in genomic research in order to improve health equity. First, participants think that racial differences in physical appearance are evidence of genetic variation between racial groups, and this concept of race is part of their rationale for believing that racial and ethnic groups are genetically distinct. This belief prevails despite the fact that research has determined that there is significant genetic similarity between racial groups [19]. In fact, advances in research indicate that genetic differences in health have less to do with shared genomes among people with similar phenotypes, and more to do with shared geographic ancestry, which presents in a wide range of physical manifestations [20]. These findings are evidence that significant opportunities remain in translating clinical discovery to community understanding.

Second, individuals across racial and ethnic groups in our sample described a hierarchy of genetic predisposition (which mirrors social hierarchy) to explain poor health outcomes, primarily among African Americans. White respondents more frequently cited genetic differences as the basis for disparate health outcomes. Respondents viewed this greater genetic predisposition to disease as being triggered and magnified by exposure to worse social conditions, resulting in poorer health outcomes in African American communities. The idea of hierarchy along racial lines is not new, and historically it was used to justify the structure and enforcement of social inequalities [1, 21]. Although respondents did

not justify social inequality based on genetic inequality, participants did describe health disparities as being the result of genetic differences made manifest by social racialization. Although the perception of genetic differentiation by race is misconceived, interesting considerations are raised by the prevalence of this perception—particularly among those most often positioned at the top of the social hierarchy. In both the community and the clinical research enterprise, underlying assumptions of genetic predisposition may further perpetuate social inequality, undermine the need for genomics-based health disparities research, and hinder engagement by a broad spectrum of necessary community participants [3, 22]. The research enterprise also fuels the community perception that the gross health disparities experienced by communities of color are rooted in shared genomes that are distinct from the genomes of other racial and ethnic groups. Through their use of race and ethnicity in recruitment, analysis, and communication of findings, researchers often inaccurately imply genetic differences by race, when categories of social experience or ancestry may more accurately characterize differences in health.

Community participants expressed concerns and ideas about potential harms from genomic research that aims to address health disparities, including exacerbation of racial inequalities and misuse of information; these concerns and ideas are similar to those found in other studies [23-25]. Research that includes a racial component inevitably raises concerns regarding medical abuse or misuse of information, and such concerns are particularly salient for members of underrepresented and historically disenfranchised communities [7, 24, 26]. As the field advances, genomic researchers must recognize and attend to these concerns both in terms of how they conceptualize race and ethnicity and in how they discuss and operationalize individual and community-level protections [23]. Evidence supports significant genetic similarity between racial and ethnic groups, but prevailing social notions of race do not reflect this evidence; this suggests that communities and researchers may need to fully consider and interpret the individual and social harms of engaging in this type of research [27]. The differences in how groups in this study conceptualized harms and benefits suggest that Latinos may be more motivated than whites or African Americans to engage in research that is directly relevant to their immediate families as opposed to research that is designed to benefit the larger society. Researchers should consider different racial and ethnic groups' motivations for research participation, particularly how they evaluate benefits and harms. These issues are critical to the design of community engagement strategies, recruitment plans, and messages about research. Additionally, we found that, as in other studies, language barriers and fears of deportation remain a relevant concern in Latino communities [28].

These findings should be considered in the context of the study's limitations. We interviewed individuals within the central region of North Carolina, which is home to several

major academic and private research institutions and organizations. Therefore the views expressed by participants in this study may differ from those of individuals in communities with less research saturation. As evidence of the ecologic context of research and higher education, many of our participants had at least some college education, even though we recruited across a variety of community networks. This population may not reflect the perspectives of those most disparately affected by factors that contribute to differences in health.

As the field of genomics evolves, scientists will better understand the potential uses of genomics to improve preventive, diagnostic, and therapeutic technologies. The challenge remains that racial and ethnic minorities experience disparate health outcomes yet are underrepresented in genetic and genomic research [2, 3]. To overcome this challenge and further minority engagement in genomic research, we will need to gain a better understanding of how community members conceptualize genetics, genomics, race, and ethnicity; what factors contribute to differences in disease experience; and what are their considerations when engaging in this type of research.

Initially, we recruited both lay community members and community leaders, and we expected some differences between these 2 groups in their level of familiarity with and perceptions of genomics. Despite stark differences in education and in history of clinical research participation, the lack of variation in responses between these 2 groups indicates that members from multiple sectors of the community share perceptions in this emerging field, and they may respond to similar approaches when attempts are made to increase participation in genomic research. Additionally, genetic and genomic researchers have the opportunity to more clearly consider the function of race and ethnicity in gene-based research, particularly when addressing health disparities. NCMJ

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