Understanding Diverse Perspectives on Genetic Research Through Focus Group Talk

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Abstract
While genetic research (GR) is fueling discoveries in fields like precision medicine, there is a growing concern that under-representation of racial and ethnic populations in GR will limit access to its benefits and subsequently worsen health disparities. This study aimed to understand GR perceptions among members from underrepresented communities by studying discourse and language use in focus group discussions. Nine focus groups were conducted with adults from three populations: African American, Hispanic/Latino, and Native American; 53 women and 15 men participated. Data were analyzed using methods of discourse and content analysis. Discourse analysis highlighted how conceptualization of science and family—rooted in historical experiences—can influence views on GR risks and benefits to self and others. The use of focus group discourse in particular provided an opportunity for group sense making around the science and ethics of GR. Content analysis highlighted differences between the language use of focus group moderators, who spoke about scientific discovery and research oversight, and that of participants, whose talk highlighted ancestral bloodline, personal risk, and ethical concerns. The findings can inform efforts to bolster GR participation, including recruitment and educational campaigns. However, they also challenge researchers to consider areas of discordance between their own and community members’ conceptualization of the risks and benefits of GR participation, including the notion of future and family benefit.

Keywords
genetic research, biobank, research participation, racial/ethnic minority

Increasing the participation of underrepresented groups in genetic research (GR) is critical to ensuring its benefits apply to diverse subgroups of the population (Landry, Ali, Williams, Rehm, & Bonham, 2018). Failure to increase diversity in GR may in fact exacerbate existing health disparities by limiting benefits from scientific advances, including development of genetically targeted cancer treatments and diagnostic tools (Hindorff, Bonham, & Ohno-Machado, 2018; Huey, Hawk, & Offodile, 2019).

Underrepresented populations face a range of personal and systemic barriers to participation in clinical research generally and GR specifically, including ineffective research communication strategies, distrust of medical research or care, lack of access, limited health literacy or genetics knowledge, and perceptions of benefits and harms (Echeverri et al., 2018; Furr, 2002; George, Duran, & Norris, 2014; Rogers et al., 2018). In the United States, strategies to increase enrollment in GR among underrepresented populations include targeted recruitment, education campaigns, and community engagement (Buseh, Stevens, Million-Underwood, Kelber, & Townsend, 2017; Culhanne-Pera et al., 2017; Johnson, Powell-Young, Torres, & Spruill, 2011; Trinidad et al., 2015). Efforts to understand perceptions of GR and motivations for participating in it are necessary to inform appropriate strategies. Existing research suggests that members of populations currently underrepresented in GR may be motivated to participate by a wide...
range of reasons from personal benefit to altruism (Buseh, Stevens, Milon-Underwood, Townsend, & Kelber, 2013; Heredia et al., 2017; Sanderson et al., 2013; Streicher et al., 2011; Trinidad et al., 2015). There is only limited research, however, that further explores how individuals from diverse communities may conceptualize constructs like altruism (Davis, Arnold, Mills, & Miele, 2019) and risk (Dixon-Woods et al., 2007; Viberg Johansson, Segerdahl, Ugander, Hansson, & Längenskiold, 2018), especially in the context of GR, which often involves indefinite storage of genetic samples for unspecified future use (McGuire & Beskow, 2010).

Conceptualization may be especially difficult in the realm of genetics and GR, which are biologically and scientifically complex topics. Knowledge of them is limited among the general population, including those with higher levels of education (Chapman et al., 2019; Hann et al., 2017; Kaphingst et al., 2016; Krakow, Ratcliff, Hesse, & Greenberg-Worisek, 2017; Lanie et al., 2004; Peterson et al., 2018). Focus group discussions—which involve group interactions—may provide a platform for individuals to share information and opinions, especially on topics with limited familiarity. They also privilege participant interactions; while the moderator poses questions and facilitates the flow of conversation, focus group participants can also ask and answer questions among themselves. As such, group discourse may be able to elicit information about how participants conceptualize complex concepts in GR.

This study aimed to understand GR perceptions among members from underrepresented communities (African Americans, Hispanics/Latinos, and Native Americans) by studying discourse and language use in focus group discussions. Understanding how individuals talk about GR may offer insights into attitudes, beliefs, and knowledge, which subsequently may help researchers develop more effective and appropriate approaches to involving diverse populations in GR.

Method

Research Strategy

Focus group methods are used in qualitative inquiry when there are perceived benefits to group interaction (Krueger & Casey, 2009). Focus group talk differs from natural conversations that take place in everyday discourse, but it can provide a platform for individuals to produce joint accounts (Smithson, 2000), which may serve as a way for individuals from similar communities or backgrounds to consider a range of views on a topic. Focus group methods may allow individuals to discuss a less familiar topic like GR by sharing their perspectives and raising questions among each other. Composing groups of individuals homogeneous on a characteristic such as race, ethnicity, gender, or occupation is a common strategy for creating an environment where participants feel more comfortable sharing their perspectives (Krueger & Casey, 2009). In this study, focus groups included individuals from racial and ethnic minority populations that were geographically proximal.

The aim of the focus groups was to elicit views on GR from individuals underrepresented in GR. This included assessment of language use (e.g., vocabulary) within or across groups. To accomplish this, the analytic approach was 2-fold: (1) methods of discourse analysis were used to explore how members of the groups spoke about GR, including the manner in which they described topics and made connections between issues within the larger context of the discussion and (2) methods of content analysis subsequently provided a systematic way to identify key vocabulary use in the discourse categories to assess whether they were expressed similarly or differently across groups.

Setting and Recruitment

Three focus groups were held with Hispanic/Latino men and women and three with African American men and women in Jacksonville, FL. Focus groups with Hispanic/Latino individuals were conducted primarily or exclusively in Spanish. Participants were recruited through flyers in local churches and word of mouth. Three focus groups were held with Native American men and women from a Federally Recognized Indian Tribe in the State of Minnesota. Participants were recruited through flyers in the tribal health center and word of mouth. All nine focus groups were held in community settings unaffiliated with the research sponsor (Mayo Clinic). Participants received a US$50 gift card as incentive and refreshments were served during the focus group sessions.

Data Collection

The focus groups employed a semistructured moderator guide with questions related to initial reactions or impressions of the term “genetic research,” questions about what participants had heard about GR or would want to know about it, and questions related to why someone might or might not participate in GR. A brief survey containing demographic items and questions on GR experience was administered prior to the group discussion. Members of the Community Research Advisory Board and the affiliated tribal council reviewed the study materials (e.g., moderator guide, survey, recruitment flyers) and provided suggestions for modifications. This study was approved by the Mayo Clinic Institutional Review Board (#16-009788) and the tribal council. Participants provided written authorization to use health information shared during the session and oral consent to participate at the beginning of each focus group session. Focus groups were audio recorded and transcribed verbatim by trained medical transcriptionists. Spanish-language audio files were transcribed in Spanish, translated into English, and subsequently reviewed and annotated by two bilingual study staff to ensure accuracy of meaning.

Data Analysis

Focus group transcripts were first analyzed using methods of discourse analysis. More specifically, this study employed the
discourse tools outlined by Gee (2014), which serve as questions to ask of the data, for example, what meaning do speakers attribute to the words used, how do speakers link together topics, and what issues or debates does the speaker assume the listener knows in order to understand the wider historical context. While there are many approaches to discourse analysis (e.g., conversation analysis, discursive psychology; Bischofing & Gazso, 2016; Powers, 2001), we elected to use this particular approach because it had the potential to be most easily applied by members of our multidisciplinary study team, including community members, who varied in their prior qualitative research experience and training. The analysis began with study team members reviewing transcripts for instances of language that portrayed perceptions of genetics or GR, as well as descriptions related to benefits or risks to participating in GR. Audio transcription features in qualitative software (NVivo 12 Plus, QSR International) were then used to code sections of the audio to the discourse tools, including the connections tool (what sort of connections is the speaker building?) and the Big C conversation tool (what issues or sides are assumed to be known, and can this be seen as carrying out a widely known debate?). The audio transcription feature in NVivo Plus was also used to tie the audio data to excerpts from the written transcript and reflections of the investigators. This served the purpose of analytic memoing and allowed for review of audio segments for intonation or other linguistics cues. The study team then organized the data into categories that represent primary findings.

Methods of summative content analysis were employed after the initial discourse analysis was complete. Summative content analysis is used to identify the use of words in context (Hsieh & Shannon, 2005). While some summative content analyses further quantify word use, the aim in this study was simply to identify word use and see if there were preliminary differences between the communities participating in focus groups. Content analysis began with study team members reviewing transcript excerpts coded to the discourse categories using NVivo Plus. Keyword searching was also employed to identify any cases where similar words were used in the same or different context. Multidisciplinary team members were involved in discussing comparison of word use across groups, and analytic memos were written to capture impressions. Word use was displayed in table format to facilitate comparison across groups. During this step of analysis, the study team further noted difference in language use between participants and moderators in particular, so an additional category was added for moderators as a group and data were queried for moderator talk in each discourse category.

Results

Three focus groups were conducted in each community (n = 9 focus groups) between March 18 and October 26, 2017. A total of 53 women and 15 men participated (n = 68). Twenty-four self-identified as Hispanic, Latino, or of Spanish origin and 24 self-identified as American Indian. The 24 participants who self-identified as being of Hispanic, Latino, or of Spanish origin reported origins that spanned four continents. Twenty-one reported being Black and/or African American. Twenty-four reported usually speaking Spanish at home, while three reported usually speaking Dakota at home. The mean age of participants was 50 years (range 18–88). Nine percent (n = 6) had less than a high school diploma, 29% (n = 20) had a high school diploma or General Education Development (GED) Diploma, and 41.2% (n = 28) had an Associate’s degree or higher. Twelve percent (n = 8) were uninsured. Two thirds (n = 46) were employed at least part-time. Eighty-two percent (n = 56) reported never having given a blood, tissue, or saliva sample for research. The study findings are reported below by analytic approach.

Table 1. Discourse Analysis Categories and Central Issues.

| Category                  | Central Issues                                                                 |
|---------------------------|--------------------------------------------------------------------------------|
| Family and bloodline      | 1. Genetics as bloodline and an immutable part of individuals and their families |
|                           | 2. DNA-based knowledge that differs from cultural or religious beliefs         |
|                           | 3. (Un)certainties of genetics and GR including hereditary disease and race- or |
|                           |   ethnicity-based disease risk                                                 |
|                           | 4. Personal donations as donations of family bloodline                         |
|                           | 5. Benefits to “future patients” as inclusive of benefits to future generations |
|                           | 6. References to GR participation as helping others in a “community”          |
| Science and experimentation| 7. Futuristic talk of “science fiction,” “cloning,” and “experimenting” (caution) |
|                           |   versus talk about scientific “discovery” (exciting)                          |
|                           | 8. Ethical concerns connected to past (mis)treatment and shared historical     |
|                           |   experiences of science misuse                                                |
|                           | 9. Skepticism related to researcher intentions and institutional GR oversight  |
|                           |   of futuristic science                                                       |
|                           | 10. GR as a social good versus profits, financial motives, and limited access  |
|                           |   to benefits                                                                  |

Note. GR = genetic research.

Discourse Analysis

The results of the discourse analysis are summarized below in two overarching categories, which are also summarized in Table 1: (1) family and bloodline and (2) science and experimentation. Transcript excerpts included below indicate the focus group identifier (AA = African American, HL = Hispanic/Latino, and NA = Native American) and speaker (P = Participant, M = Moderator). When text represents more than one participant, the participants are numbered.

Family and bloodline. Participants described genetics as bloodline. In this way, it was an immutable part of themselves and
also a connection to family roots. Thus, GR was described as a way of understanding themselves and their ancestry. Participants recalled experiences, especially with online ancestry research, as they spoke of GR as personal exploration. Participants in one group spoke about genetic information being helpful in cases where recordkeeping was incomplete or as a way to preserve a bloodline. In this regard, bloodline was referred to as constant or unchanging, even to the extent that it could be preserved for the future.

NA FG2

P1: Especially with Native Americans back—back with our ancestors, they didn’t sign their kids over by adopting um if you were my brother’s kid and you can’t take care of him, give me him he’s mine. Or clans where they’re I’m your mom even though you’re my sister. It just depends um that’s how we that’s how if a clinic was asking someone Native American a question and they said, “Is that your daughter?” Yeah, but it’s really your brother’s daughter and it’s not technically yours. Those confusions come into play, so I think genetic testing would definitely help...

P2: Yeah.

P1: Stop some of that stuff or be able to help you.

NA FG2

P: I fall under those nationalities cause you know being of Native American descent, some days at some time in the future there might not be Native Americans no more. And maybe they can—the bloodline now so it is kind of if we can save it somehow you know to me. Well, someday we maybe could be, so they don’t disappear completely (chuckles).

While participants talked about bloodline and family connections, talk of ancestry in some focus groups was related to the potential of DNA-based knowledge to differ from cultural or religious beliefs. This included spiritual beliefs that may not align with DNA research on ancestry and migration.

NA FG3

P: My daughter also um took that (ancestry website) thing and she also took the later test that told what kind of medications would help her and so on. Um, but I think for in an Indian community um it—it gets in to your spiritual beliefs as well because we have people seat—seated here that have traditional beliefs and people that don’t. And people who have traditional beliefs um talk about the creation story and about how we were here from the beginning. Okay, so if you look at this (ancestry website) stuff and we’ve been told through the years that the Indian people came across the Bering Strait, this comes into question.

HL FG2

P: I would say that, in knowing a little more about our development, it could be through the past, through our relatives or where we come from. But I don’t think we depend entirely on that [genes]. Maybe it is because of the my religious beliefs that I do not allow myself to believe much in that kind of...I prefer to lean a little more toward Creation such as it is.

In fact, discussion among participants in all of the focus groups included group sense making when participants debated (un)certainties of genetic knowledge and by extension GR. While diseases were often described as “hereditary,” participants also shared personal stories of situations where diseases might “skip generations.” This type of group sense making also occurred when participants discussed why bloodlines might change, how old bloodlines could be connected to new diseases, and why genetics would be linked to race- or ethnicity-related disease risk or treatment. The potential role of the environment for interacting with or further prescribing genetic disease risk was raised in three of the focus groups (AA, HL, and NA). In conversations such as this, it was common for participants to use interactional tools to coproduce the narrative, including agreeing or disagreeing with the previous assessments or making connections between or shifting topics (Pomerantz, 1984; Sidnell, 2010).

AA FG2

P1: So how is it that because I have this gene from thousands of years ago, you know because bloodlines go back very far—how is it that because I have this, I can catch something that’s new? So it makes me wonder, like, can’t they find something like the DNA of the cancer and then figure out how to stop that, like the DNA of the cancer so it can stop spreading because it’s like a new system you’ve got and your body start fighting itself, so I would think that they would be able to figure out how to, you know, stop your body from overreacting or growing because, pretty much, it’s just your tissue which is growing at a rapid stage. So I would think that they would be able to just stop that because they had all this—it’s just, I don’t know (laughs) just feel like they
should be able to stop reproduction of your tissue.

P2: But you’ve also got to realize that it’s not just your bloodline, like me and you have—when you have a child with somebody else, you’re merging your bloodline with somebody else’s, so that’s kind of like—so then your cells or your tissue then merges with somebody else’s, which could create something completely unknown, like that’s how I would think of it.

AA FG2

P1: That’s true, but I’m saying, though, as far as the women are concerned, I don’t think it’s a certain—I don’t want to say genetics. I don’t see how breasts have an ethnicity. You see what I’m saying? I mean, I know it has a color, but I’m just saying, though, how can your breasts have, you know, my breasts—

P2: The tissue—the tissue, right? (laughs)

P1: Yeah, yours may be bigger than mine, but how can you tell me that, you know, in the inside, it’s all the same (laughs). I’m just saying!

P3: Yeah, that’s true.

P1: How can your breasts—mine might be bigger than yours or yours might be smaller than mine, but in the interim of it, it’s... they’re breasts.

P2: Tissue is tissue.

P1: I guess my thing is what—what makes up tissue. Doesn’t...this may be a biology course that I may have forgot...

P3: Yeah, cell DNA.

P2: ...right, but what makes up your tissue because if tissue was made up with cells, blood cells, which then leads to your DNA, which is going to be different from me and (Participant 1), then of course that’s why the tissue...that’s why the cures or the medicine may not work for everybody because everybody’s tissue is the same.

P3: So and there’s different chemotherapies. I’m not saying...

P2: She’s saying what if they had that? What if they had the different chemo for your genetic makeup?

More specifically, participants connected talk about family/bloodline to the topic of participation in GR studies when they described personal genetic donations as donations of family bloodline. When genetics were viewed as part of the family bloodline, there was stated presumption of family benefit from GR participation. This was typically in the context of ensuring that family members received genetic information, compensation, or access to scientific/medical discoveries related to the individual’s participation.

NA FG3

P: I wouldn’t participate if my children, my mom, my aunties, grandchildren if they wouldn’t benefit from them. If they’re if something happened to one of them and it there could be a cure because of my part in this study, I would have to have somebody benefit from that.

AA FG2

P1: If they told me, once they find a cure for it, then my family for the next 10 generations would have the antidote.

P2: But why would you just want it for your family, though, if you know other people are...

P1: Because I participated. No, a free charge...not, I don’t have to go pay for it.

Discourse analysis also highlighted how participants perceived the idea of “future” patients. Specifically, focus group participants commonly spoke about future generations, including children or grandchildren not yet born. This was despite the moderators’ examples of GR in which participation was for the benefit of future patients—cancer GR and biobank research.

AA FG2

M: Research is helping us understand how the genes work, what they do, and you may not get the information that will help you necessarily now, but it is something that will help in the future...why do you think people might participate in a genetic research study?

P: To pass onto grandchildren or somewhere down their bloodlines to make sure they don’t suffer from their family history of diseases.

HL FG1

P: That is done for the future, I think, ours, our grandchildren, great-grandchildren... The hardest thing for me would be to know who has access to that, because unfortunately it is true, one does it to help our future generations, my children, grandchildren, great grandchildren...But how much security or privacy, how much they are going to do [inaudible]. That would be more my fear and would prevent me from giving something from body or my blood, knowing what they would really use it for, and not for other purposes and not the intention of
what I really want to do, OK? Because that is how money donations are now seen. They often do something else and not to the cause you donate to. So that would be my insecurity.

In some cases, talk was more generally about future benefits to people—consistent with language researchers would use in research consent documents and a broad construction of altruism—such as “helping someone else” and being for the “good of humanity.” In all three populations, though, there was language use that denoted a concept of community that was outside of a family but potentially less broad than humanity. The actual term “community” was only used in the Native American focus groups, but language denoting a sense of community, including the use of pronouns like “us” or “our,” was pervasive. Participants in the Native American focus group used the term “our children” in several discussions, which may reflect a shared connection or responsibility for children or community members who are not blood relatives.

NA FG2

P: We’re all Natives and it’s very, very family orientated...We’re Native American people, I think the community even, um within our community, if someone in our community would have a sickness or a disease or have something and that we were able to help another community member or family member, we would be doing it.

NA FG3

P: I don’t know, I just think how they treat us and make sure that it’s ethical because it wasn’t before.

These descriptions of ethical concerns that were grounded in historical experiences were likewise connected to the topic of futuristic “science fiction” talk. In the two excerpts below (NA FG1 and AA FG2), the moderator had noted that in biobank research the studies “are reviewed by an oversight board called an institutional review board that makes sure that the researcher is following rules related to things like ethics and privacy.” Participant responses to that moderator statement demonstrate skepticism related to research intentions and institutional oversight. Participants connected the notion of “making sure that the researcher is following rules” to talk about clone armies and evil villains, even though humor was often engaged during those exchanges.

Science and experimentation. GR was often described by participants—especially as first impressions in the early part of focus groups—using futuristic terms that portrayed caution such as “science fiction” and “cloning.” The following participant from HL FG1 described his impressions like this: “(Genetic research is) something that isn’t completely discovered, that is a taboo and could be a good name for a movie from the future.” Likewise, most focus group talk that referred to “experimenting” raised questions from participants about whether participating in GR involved something invasive that could make someone sick. In the following exchange, “knowing that it’s genetic” implied, for some, that GR is doing something to the participant’s genes that could harm him or her. In other groups, the participants spoke about “adding” to the DNA. Similarly, the notion of being a “healthy volunteer” was described as important because GR could make a healthy person unhealthy, and likewise unhealthy people might not be able to risk participation in GR, including giving up their blood.

AA FG1

P1: Yes, how would it affect you when you take that? Knowing that it’s genetic, you know.
M: Okay.
P2: I think you get sick.
M: Say it again?
P2: You get sick.
M: Okay if you get, if it will make you sick?
P2: Hmm.
M: Okay.
P3: Do you have many side effects from their testing?

In contrast, descriptions of GR used positive language and had positive affect when they were related to scientific “discoveries,” some yielding “wonderful” results. A participant in one of the Native American focus groups recalled an advertisement she saw on TV for a cancer treatment: “They took like 25 people and the cancer quit. The cancer disappeared and I thought ‘Oh, if I ever get cancer I want that.’” The analysis also highlighted the connections that focus group participants made between the science of GR and larger sociocultural topics, including past (mis)treatment by researchers.
I'm afraid of it too simply because I think that you’re having so many different type of DNA done—that they can do researches and tests that is not really benefitting the rest of society, you know, that you learn about some virus that will affect everybody in maybe three hours, you know. Evil villains (laughs).

And even taking information and not doing what they said they’re going to do with it and who’s going to know? Who’s going to know the difference?

The exchange below demonstrates how excitement, such as the potential of GR to help people with cancer, may still be tempered by skepticism connected to historical experiences. In this way, risk was described as both personal (physical) and as related to mistreatment of communities of people.

I think it’s a great idea. Yeah.

I mean if it can’t help the patient now that’s going through cancer, hopefully it will be able to help someone in the future.

Okay, anyone else?

I also think it’s great, but I am skeptical.

Umm-hmm (yes).

There are techniques and things that happen for testing and everything like that that happen behind closed doors that we’re not sure about and we don’t ever get to see...

Okay.

...and so I’m not really sure about how things like that are handled and, historically, things like that have not been handled very well.

Related to this skepticism was discussion portraying GR as a social good versus being motivated by profits and money. This analysis applied a broad view of politics as the distribution of social goods and the manner in which people talk about it (Gee, 2014). In these focus groups, discourse included conversations around who has access to discoveries from GR. Researchers, pharmaceutical companies, and the government were all described in relation to “profits,” mistrust, and financial motives. In the following excerpt, the second participant uses humor and science fiction talk to express the notion that researchers’ motivations might not be trustworthy.

Being Native American you know trusting the government is kind of to me about the money you know. To me, you look at the pharmaceutical companies and I mean if somebody did find a cure they might pay them not to even tell people you know what was good. I hate to say that about them, but cause it could cost somebody billions you know. (P2: Yeah)

Someone has the good genetics and they start selling them on the black market or something. (Laughter) Creating super humans and then trying to sell them.

Participants also spoke about GR resulting in discoveries that are not broadly shared with the public but rather limited to those who can pay high prices. In two of the focus groups, participants wondered why genetic information required payment, such as with ancestry research websites. In those conversations, participants drew a connection between genetic information and other publicly available and free information, for example, online property tax records.

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them of disease risk. These were connected back to the notion of researcher motives and GR as a social good.

NA FG 1

Pz: Ah, I think if a researcher says, "You’re not going to get anything." And you’re going to ask 500 people in a close knit community, you’re probably going to get 10 people that are like I or you know I’ll do it. And most people are like ‘If you’re not going to give me anything, then I’m not going to give you my tissue.’ I could be wrong, but if that’s just—you’re not—we’re not in any obligation to contact you. You’re giving us this for research, then I’m going to be like ‘Then you don’t get anything.’ Because I’m doing this to help mankind, but if you find something bad for me and you don’t want to take the cost or the time to let me know: No, I ain’t gonna do it.

Content Analysis

Content analysis cataloged the vocabulary used by participants in the focus groups as well as focus group moderators. Table 2 compares vocabulary within the central issues from the discourse analysis to facilitate comparison. In the first category (family and bloodline), there was some common language use across the three focus group populations for several of the central issues. Focus group participants in all three groups used the term “blood” in several contexts across the central issues: giving a blood sample, mixing blood samples (mishandling samples in GR), mixing bloodlines (two parents of a child), adding something dangerous to blood or DNA (potential harm during GR participation), and blood traces in forensics. All used terms like “bloodline” and “ancestors” or “generations” to talk about family links to ancestry and disease. In contrast, the moderators used the terms “ancestry” and “blood relative” sparingly, and they did not use “bloodlines,” “generations,” or “culture.” The term “blood” on its own (i.e., not “blood relative”) was typically used by moderators only in the phrase “blood, saliva, or tissue samples.”

Terms related to faith and Creation were also used by focus group participants but not moderators, often in the context of faith in God or traditional beliefs when compared to research from DNA. Participants in the Hispanic/Latino and Native American focus groups also used the term “culture” in the context of health beliefs, including those related to genetic predisposition in families. All three groups also used language similar to “generation skipping” in conversations about the (un)certainties of GR in understanding why some health conditions were not passed down from one generation to the next.

In these focus groups, there were some differences in how moderators and participants spoke about future benefits of GR, although neither moderators nor focus group participants used the term “altruism.” The moderators made statements such as that GR “involves science and discovering new things that may eventually help patients in the future.” Focus group participants spoke about benefit to family and to future generations, although there was also some reference to people in the future more broadly and “mankind.” The term “community” was used exclusively in the Native American focus groups, but the other focus groups referenced the idea that some racial or ethnic groups or populations might be more susceptible to some diseases, for example, sickle cell disease among African Americans; therefore, GR might benefit some groups in some cases. The closest description given by moderators to the notion of community benefit was in descriptions of biobanks as being able to benefit subgroups of patients due to large numbers of samples from a broad population, for example, “instead of having enough patients to study to know whether a drug worked for cancer patients generally, now we can look at a very specific population or group of people in a certain community or of a certain age group.”

In terms of language in the second category (science and experimentation), participants in all of the focus groups used the word “cloning” or “clone,” and most referenced science fiction and movies. These terms were synonymous with risky “experimenting” and adding to DNA or exposing bodies to risk. There was no similar moderator vocabulary. The only term used by moderators in the context of those participant references was “healthy volunteer,” that is, moderators talked about being a healthy volunteer and participants spoke of potential risk of volunteering for GR as a healthy volunteer. Instead, moderators used terms like “discovery,” and they described GR as “important” to develop targeted treatments for patients, including those with cancer. The content analysis identified emotive language among participants in response to moderator talk such as this, including “excited.”

In terms of GR oversight, moderators acknowledged that GR participants—for example, those who donated a sample to a biobank—might not know how their sample was being used but they also spoke about making sure the “researcher is following rules.” They did not reference history or talk of past research abuse. In contrast, participants in all three populations noted the need for appropriate use of samples in GR and in several groups the language used had a negative valence, for example, “compromised,” with references that may represent perceived lack of transparency, for example, “behind closed doors.”

Similarly, on the central issue of GR as a social good versus profits, moderators referenced “population subgroups” as benefiting from GR, but otherwise they did not use terms that referenced access to GR as a social good. In contrast, participants spoke about “money” and “profits.” We identified the greatest number of these references in the African American and Native American focus groups. Terms referencing historical research misuse were also more prevalent in those groups. Henrietta Lacks, the African American woman whose cancer cells were used in groundbreaking research without her
### Table 2. Content Analysis by Focus Group and Central Issue From Discourse Analysis.

| Central Issue                                      | Focus Group Moderators and Participants |
|---------------------------------------------------|------------------------------------------|
| Category 1: Family and bloodline                  |                                          |
| 1—Genetics as bloodline                           | "Ancestry," "blood relatives," "blood, saliva, or tissue samples," "DNA" | "Related health-wise," "somewhere down the bloodline," "immune system is in your bloodline," "blood trace," "DNA" | "Know who their ancestors are," "disease of my relatives," "disease passed on from the ancestors," inherited from my family," "blood," "DNA," "susceptible" | "Generational" diseases from "ancestors that have passed," "runs in our family," "ancestry," "hereditary diseases," "underlying things," "back with our ancestors," "clans," "carriers," "blood," "DNA," "qualified member" |
| 2—Cultural/religious beliefs                      | "Skipping generations," "merging bloodlines," "finding an answer," "faith that my God is bigger than everything" | "Changeable from generation to generation," "skipping generations," "in my blood or in my culture," "adoption," "faith," "God," "religion," "Creation" | "Spiritual beliefs," "traditional beliefs," "why it skips this generation," "adopting," "different tribes" (diversity of native tribes), "cultures" |
| 3— (Un)certainties of GR                          | "Future," "patients in the future," "the goal is to find something new for the future" | "Ethnic groups," "help someone in the future," "generations" | "We as humans," "benefit humanity," "in our Hispanic culture," "when a Hispanic (is often susceptible to conditions)," "our future generations," "children in the future," "my ancestors and of the future" | "Mankind," "within our community (of Native American people)," "Native Americans in the upper Midwest," "Native American descent," "all Natives," "Native American country," "others in the future," "future generations," "family oriented," "chance to give back" |
| 4—Family donation                                 |                                          |                                          |                                          |
| 5—Future patients                                 | "Future," "patients in the future," "the goal is to find something new for the future" | "Ethnic groups," "help someone in the future," "generations" | "We as humans," "benefit humanity," "in our Hispanic culture," "when a Hispanic (is often susceptible to conditions)," "our future generations," "children in the future," "my ancestors and of the future" | "Mankind," "within our community (of Native American people)," "Native Americans in the upper Midwest," "Native American descent," "all Natives," "Native American country," "others in the future," "future generations," "family oriented," "chance to give back" |
| 6—Helping "community"                             |                                          |                                          |                                          |
| Category 2: Science and experimentation            |                                          |                                          |                                          |
| 7—Futuristic talk and experimenting (caution)      | "Healthy volunteer"                     | "Cloning," "evil robots," "side effects," "experimenting," "you get sick," | "Science fiction," "cloning," "movie from the future," "exposed to something negative" | "Clone army," "super humans," "add anything to DNA," "save your life," "education and knowledge," "health discovery channel," "excited," "amazing" |
| versus discovery (exciting)                        |                                          |                                          |                                          |
| 8—Past (mis)treatment                              | "IRB makes sure that the researcher is following rules as it relates to ethics and privacy," "you probably won't know how your sample is being used" | "Compromised," "misplaced," "mixed," "what they are doing with the samples," "behind closed doors," "once you sign that consent form," "they're not sharing," "right precautions," "who has access" | "Appropriate and correct reasons," "security," "confidentiality," "privacy" | "Research oversight," "happened historically to our people," "ethics," "reputation," "don't know what they're doing with it," "trusting the government" |
| 9—Oversight                                        |                                          |                                          |                                          |
| 10—Social good versus profit                      | Benefits of genetic research to precision medicine among population subgroups | "Henrietta Lacks," "money," "morals," "elite," "money talks" | "Money" | "Money," "profit," "pharmaceutical companies," "black market" |

Legend:
- **Moderators**: African American, Hispanic/Latino, Native American
- **Focus Group**: All three groups discussed the central issues.
- **Categories**: Category 1: Family and bloodline, Category 2: Science and experimentation.
knowledge and without compensation, was named by participants in two of the three African American focus groups.

**Methodological Findings**

Focus groups provided a platform for participants to discuss a topic with which few of them had prior experience. In fact, although 18% of focus group participants \(n = 12\) indicated that they had previously given a blood, tissue, or saliva sample for research, in focus group discussions it appeared that most participants who had given a sample did so as part of ancestry research or genetic testing for medical care (e.g., prenatal screening). In fact, most groups began with a discussion of initial impressions, which often referenced science fiction and the unknown. Through discussion and questions (including questions of each other), though, participants voiced opinions about GR, the science of genetics and health, and the ethics of GR and research more broadly. Participants often referenced previous statements when they voiced their own impressions, as in this example: “Um, and this is something interesting that you’re bringing up um now if we came all from the same parents and we all have such different DNA how did it change?” Back and forth discussions like this aimed to make sense of limited information but they also challenged different viewpoints, as was the case in the focus group that discussed traditional beliefs about the Creation story.

Together, discourse and content analysis provided nuanced and structured views of the data. Discourse analysis showed how participants worked together to make sense of experiences such as personal family history of generational diseases, including diseases that skipped generations. This extended to discussions of how genetics impact health and why GR might be targeted toward disease in subgroups, including people of different racial or ethnic groups. Likewise, these methods provide a way to see how participants connected (in conversations with others) their views of family and science with larger issues from history or politics. These methods provide insights into how individuals from communities underrepresented in GR might think about issues that have an impact on GR participation decisions.

Content analysis complemented the discourse analysis by providing a systematic way to look at language use across categories. It demonstrated ubiquitous use of terms related to blood and bloodline. It also provided concrete examples of language use that may resonate more than generic constructs like “altruism.” It also highlighted the use of futuristic terms like “cloning” among participants more so than “discovery” and other more positively valenced ways that moderators described GR. Understanding vocabulary use is a critical piece of larger efforts to engage communities in conversations about GR and GR participation. While a primary finding was the differences between moderators’ and participants’ language, the content analysis did highlight some differences between participant groups, which could be further explored in future community-engaged research efforts. This includes greater understanding of how individuals define the concept of “family” as the same or different from “blood relative.”

**Discussion**

This research aimed to understand GR perceptions among members from underrepresented communities by studying discourse and language use in focus group discussions. This question is timely and important because advances in GR, including breakthroughs in precision medicine, may not benefit individuals from groups that are under or inadequately represented in GR. The findings from this study are consistent with previous studies on research participation in these communities. Participants cited altruism and beliefs that genetic information could benefit their health or the health of family members as reasons for participation, for example (Buseh et al., 2013; Heredia et al., 2017; Sanderson et al., 2013; Streicher et al., 2011; Trinidad et al., 2015). Similarly, mistrust and personal risk were identified as reasons not to participate in GR (Johnson et al., 2011; Sanderson et al., 2013).

However, research using broad constructs like altruism and mistrust may fail to provide the depth of understanding needed to advance efforts toward broadening participation in GR and ultimately address disparities in who benefits from GR discoveries. This study extended what is known through the study of discourse. In particular, language in group discourse highlighted the dual notion of GR as something futuristic and less familiar—potentially even frightening—with something that seems to be an immutable part of who we are. The process of group sense making, in which participants grappled with personal stories of predisposition and the perceived capabilities and limitations of science provide greater insights into what language may resonate with individuals who may be less familiar with GR. Where prior strategies have focused on the use of “plain language” for informed consent (Drake et al., 2017; Justin, Robert, & Jeff, 2014), this study suggests specific language like “bloodline” and “generation skipping” may help participants connect more familiar ideas with less familiar topics like GR and precision medicine.

This study also identified misperceptions that could potentially be addressed in educational campaigns, including views of GR participation as carrying substantial risk from invasive procedures. Likewise, the idea of being a “healthy volunteer” was taken at face value to mean that the volunteer participant would need to be free from any disease or chronic condition in order to contribute to a biobank or research repository. Some individuals in this study suggested they would not pursue participation as a healthy volunteer because of this misperception. These issues may be effectively addressed through development of educational messages that clarify commonly misunderstood aspects of GR using language that resonates with the intended audiences.

However, confusion around GR may reflect more than misinformation or limited familiarity. Rather, it may highlight a disconnect between expectations held by researchers and by participants. Where researchers used language that magnified
the benefits of future discoveries to society, participants linked the idea of contributing a part of who they are (i.e., their bloodline) and any related risk in doing so with the expectations for benefits that accrued to family or some definition of communities of people. The idea that expectations for GR benefits are based on more than lack of information about GR is further reflected in the fact that participants connected perceptions of GR with larger social and historical conversations. In the Native American groups, the discussion at times referenced prior unethical research practices, leaving unspoken details that may have been presumed to be understood by the other discussants. In the African American groups, the legacy of Henrietta Lacks was cited, specifically the fact that benefits have not always accrued to participants. As one participant stated:

...just like the Henrietta Lacks; you find it, you take it, and then you make all this—you do all this research and you’re making money off it. Meanwhile, my family is still mourning because I’m dead, they ain’t got a lick of money left, and my grandchildren and whoever else, they have no idea that they’re a part of history.

These examples are not of therapeutic misconception but rather of expectations that benefits should accrue from participation. Human subjects protections are meant to ensure that those who bear the burden of research participation share in its benefits; considering benefits of GR in this light should therefore extend to consideration of the fact that participants may view personal, family, and community benefit differently than researchers. This may further extend to considerations of ownership of biologic samples, especially in light of past misconduct using blood samples in research, such as that with the Native American community in the United States. Investments by the research community to engage all populations in GR and to ensure GR benefits are available to all populations, including those who have not been as well represented, is necessary to address health disparities (Bustamante, Burchard, & De la Vega, 2011).

These discussions also highlighted the process of group sense making around the role of race and genetics in health. Where the moderator gave examples of how subgroups in the population might benefit from larger representation in GR, participants in some discussion groups worked to understand why the concepts of genetics and race might be linked, and how science could or could not help explain things like diseases that skipped generations or were more prominent in certain groups (e.g., sickle cell in African Americans). Researchers appealing to future GR participants based on the promise of scientific advances from broad participation in GR may need to consider the manner in which they address issues of race, genetics, and health disparities (Bonham, Green, & Perez-Stable, 2018; Fine, Ibrahim, & Thomas, 2005). This includes the manner in which researchers collect information about race, ethnicity, ancestry, and relevant social factors so that they can report findings in a “socially and scientifically meaningful” way (National Human Genome Research Institute & National Institute for Minority Health and Health Disparities, 2016). Participants in these focus groups demonstrated interest in better understanding the complexities of disease risk as it relates to race or ethnicity, ancestry, genetics, and other factors like gene-environment interactions.

Likewise, there are also implications from this research related to the differences between how researchers and participants talk about future benefits if participants conflate “future patients” with “future generations.” This finding suggests that GR education and the informed consent process should ensure participants understand the intent, but it also challenges researchers to consider how individuals and communities benefit from future research. Increased involvement by community members in the design of research projects that are important to that community may be one way to address this discordance between the goal of researchers (i.e., research for the sake of discovery) and benefits more closely linked to people or communities. This may be particularly important given the complexities of returning research results to individuals or family members (Beskow & O’Rourke, 2015; Dyke et al., 2019; Wolf, 2013). Researchers may also need to consider how benefits might accrue to future generations of communities with which participants identify. In some cultural communities, for example, responsibility for taking care of children may be valued among adults regardless of blood relation. Therefore, participation in GR might be viewed positively if current or future members of that community would benefit.

There are strengths and limitations of this research. The strengths of this study include the involvement of community advisory groups in the development and implementation of the study and study materials. Future work will further engage these groups to provide insights into research findings and make recommendations for action. The involvement of a multidisciplinary study team, including bilingual study team members, served to reduce interpretive bias through discussions that challenged interpretations, and documentation in NVivo Plus (QSR International) provided an audit trail. Study team members’ differing perspectives on analysis of language use were also critical, especially in translated data, although it is possible that there remain differences between the intent of participants’ words and the interpretation of study team members. Other limitations are related to the scope of this work. The small number of groups was suitable for in-depth analysis of group discourse, but they should not be viewed as representing homogeneous cultural perspectives. Preliminary comparison across groups in the content analysis should be viewed as highlighting potential language use in the communities represented. Future research should explore the identified categories and language use with a broader representation of individuals, including those whose cultural identification may intersect with other identities and experiences. This includes the manner in which participants talked about themselves as individuals, as members of cultural groups or faith communities, and as members of families who are predisposed to certain illnesses such as cancer or Alzheimer’s. Furthermore, while the intent of this study was
to understand views shaped by group discourse, future data collection that allows greater privacy and omits group influence may uncover views that challenge group norms. While this study was able to elicit differences in the groups, including differences based on spiritual or traditional beliefs, it is possible that other views were not openly expressed.

Finally, while these focus groups were meant to elicit participants’ unaltered opinions—without educational intervention—participants in all focus groups noted desire for further education on these topics and opportunities to participate in research. Future research on this topic should include opportunities for participants to receive educational information, if desired, in the course of or after the focus group discussion. It should also consider strategies to further engage those who are interested in GR participation.

Conclusions
Focus group discussions served as a platform for understanding perspectives through language use. Discourse analysis highlighted how conceptualization of science and family can influence views on GR risks and benefits, especially if GR donations are seen as contributions of family bloodline. The use of focus group discourse in particular provided an opportunity for group sense making around the science and ethics of GR. Content analysis highlighted differences between the language use of focus group moderators, who spoke about scientific discovery and research oversight, and that of participants, whose talk highlighted ancestral bloodline, personal risk, and ethical concerns. Educational strategies that employ common language may address misperceptions and provide information that helps familiarize community members with GR benefits. However, findings also challenge researchers to consider possible discordance between their own and community members’ language use, especially as it relates to future benefits of GR participation.

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