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Race, Genomics and Chronic Disease: What Patients with African Ancestry Have to Say

Carol R. Horowitz, MD, MPH,
Department of Population Health Science and Policy and The Center for Health Equity and Community Engaged Research, Icahn School of Medicine at Mount Sinai, New York, NY

Kadija Ferryman, MA,
The New School, New York, NY

Rennie Negron, MPH,
Yale Institute for Network Science, Yale University, New Haven, CT

Tatiana Sabin, BA,
Department of Population Health Science and Policy and The Center for Health Equity and Community Engaged Research, Icahn School of Medicine at Mount Sinai, New York, NY

Mayra Rodriguez, MD,
Essen Medical Associates, Bronx, NY

Randi F. Zinberg, MS, CGC,
Department of Genetics and Genomics Sciences, Icahn School of Medicine at Mount Sinai, New York, NY

Erwin Böttinger, MD, and
Berlin Institute of Health, Berlin, Germany and the Institute for Personalized Medicine, Icahn School of Medicine at Mount Sinai, New York, NY

Mimsie Robinson, MA
Bethel Gospel Assembly, New York, NY

Abstract

Background—Variants of the APOL1 gene increase risk for kidney failure 10- fold, and are nearly exclusively found in people with African ancestry. To translate genomic discoveries into practice, we gathered information about effects and challenges incorporating genetic risk in clinical care.

Methods—An academic- community- clinical team tested 26 adults with self- reported African ancestry for APOL1 variants, conducting in- depth interviews about patients' beliefs and attitudes toward genetic testing- before, immediately, and 30 days after receiving test results. We used constant comparative analysis of interview transcripts to identify themes.

Please address all correspondence to Carol Horowitz, Icahn School of Medicine at Mount Sinai, 2nd Floor, Department of Population Health Science and Policy 1425 Madison Avenue, New York, NY 10029. Phone: 212–659–9567; Fax: 212–423–2998; carol.horowitz@mssm.edu.

Results—Themes included: Knowledge of genetic risk for kidney failure may motivate providers and patients to take hypertension more seriously, rather than inspiring fatalism or anxiety. Having genetic risk for a disease may counter stereotypes of Blacks as non- adherent or low- literate, rather than exacerbate stereotypes.

Conclusion—Populations most likely to benefit from genomic research can inform strategies for genetic testing and future research.

Keywords

Genetics; testing; risk; health disparities; African American; race; ancestry

Chronic kidney disease affects 26 million U.S. adults. People of African ancestry (self-identifying as Black, African American, African, Afro- Caribbean, Afro- Latino) with hypertension have two to three- fold increased risk of developing chronic kidney disease and five- fold risk of progressing to end- stage renal disease than Whites.[1–3] Hypertension and chronic kidney disease increase the risk for cardiovascular disease, and blood pressure control can reduce this risk. Multiple social determinants increase renal and cardiovascular risks, morbidity, and mortality in people with African ancestry, including lower- quality health care, lack of insurance, and residing in a poor neighborhood.[4–12]

The discovery of genetic variants that increase kidney disease and kidney failure risk in non-diabetic, hypertensive adults with African ancestry adds to the important dialogue about factors that contribute to racial disparities in chronic disease. Alleles of the *APOL1* gene increase risk for hypertension- associated kidney failure by five to 10- fold, and risk for cardiovascular disease.[13–15] High- risk alleles confer protection from sleeping sickness, a disease in sub- Saharan Africa. These alleles are thus found in one in seven people with African ancestry, but rarely in those with no African ancestry.[16] *APOL1* status may explain 70% of the excess prevalence of non- diabetic chronic kidney disease in hypertensive people with African ancestry.[15] Individuals in the social categories African American or Black have varying contributions of African ancestry, so variants cannot be used to identify someone as a member of the Black racial group. However, this finding has significant health implications and may help reduce renal disease disparities.[17]

The little research about attitudes of people with African ancestry toward genetic testing yields conflicting results. African ancestry patients often have an “earned mistrust” of clinicians, and concerns about racial stereotyping, medical discrimination and stigmatization.[18] Individuals with African ancestry have expressed interest in undergoing genetic testing, but have also expressed more negative perceptions of genetic testing and its effects than Whites/European Americans.[19] In small studies solely of people with African ancestry, increasing knowledge, education, age, and experience with health research are associated with positive attitudes and beliefs towards genetic testing and research.[20–24]

There is even less information on views of genetics related to chronic disease risk, or ancestry-specific genetic testing. Adults with African ancestry tested for high- risk Alzheimer's variants are less knowledgeable about genetics and less concerned about their disease risk than Whites.[24] In a hypothetical scenario, adults of African and European

ancestry with a family member on dialysis want to know their genetic risk for nephropathy, and whether this risk can be reduced.[25] Little information exists on their reactions to actually receiving the results of chronic disease genetic risk testing. We could find no studies of patients' knowledge, beliefs, or reaction to testing for *APOL1*, despite its prevalence and impact.

To explore this uncharted territory, we conducted in- depth interviews of people with self-reported African ancestry before and after receiving *APOL1* testing and results. Two emblematic stakeholder quotations informed the boundaries of our inquiry. A White genetic ethicist said, “Don't touch this—you'll set the disparities movement back 30 years.” A Black community leader said, “Now maybe White doctors won't view Black people on dialysis as not caring enough or not being compliant. They will recognize there's more to sickness than bad behavior.” Will patients tested for these risk variants feel motivated, or fatalistic? Do they think this information will be used to stereotype them, or de- stigmatize their health behaviors and health?

Methods

In this study, we interviewed patients in person at baseline after obtaining informed consent, then collected blood for *APOL1* testing.[26] Patients returned for results from a genetic counselor in about two weeks, and were interviewed immediately afterwards, and again by telephone 30 days later to ascertain more enduring responses. Researchers engaged an eight-member stakeholder board comprising a person with the high- risk *APOL1* variant, community leaders, primary care and renal clinicians. The board informed the research question, recruitment, consent forms, the interview guide, and the analysis. The interview guide (piloted with three patients and revised accordingly), also based on literature review, included questions about patient beliefs and attitudes toward genetic testing; hypertension and chronic kidney disease risk, management, and consequences; *APOL1* consent, testing, return of results; race and the use of genetic testing in health care; motivation to receive *APOL1* testing; anticipated and actual reactions to tests; and the return of results process.

We identified our target population—adults self- identified as having African ancestry, aged 18–70, with hypertension, and no diagnosed diabetes or chronic kidney disease—through a biobank, which has genotyped samples of adult patients for *APOL1* variants.[27] We could not return the results from these samples to patients before they were re- tested in a CLIA (Clinical Laboratory Improvement Amendments) approved laboratory, and this strategy allowed us to oversample those with high- risk variants (positives) in a 2:1 ratio and to then explore the entire testing process. We sent letters to a random sample of 90 adults (60 positive, 30 negative); three were returned as bad addresses, three opted out, we phoned the remaining 84, and we scheduled those interested. We interviewed until reaching theoretical saturation (very little, if any new information emerged from interviews), which occurred after we interviewed 26 people, 19 with and seven without high- risk variants.

An anthropologist and a researcher of African ancestry, and an Afro- Latino Program manager with qualitative expertise conducted interviews, which we audio- recorded and professionally transcribed. A multidisciplinary group (anthropologist, nephrologist, general

internist, researcher, patient educator, genetic counselor, coordinator) of diverse ancestry developed codes using the constant comparative method.[28] Two members read through transcripts and open- coded one transcript, discussed discrepancies, and developed and refined a code list. The group reviewed a second transcript, to make the code list final. The initial two members coded all transcripts. Inter- rater reliability was excellent (Cohen's kappa 0.83). After coding, group members read through the codes, quotations, and field notes to develop themes.

Results

All 26 individuals who agreed to participate had an initial interview, return of results visit, and second interview; 25/26 had a 30- day follow- up interview. Their mean age was 54; most (73%) were female (vs. 64% of the 90 selected); one in three lived below poverty. They had diverse educational attainment (Table 1). Few reported any understanding of genetics, or a personal or family history of receiving a genetic test before enrollment. While most knew someone close to them with kidney disease, were concerned they would develop kidney disease, and knew Blacks had increased kidney disease burden, few knew there was a connection between hypertension and kidney disease. None had heard of *APOL1* or a genetic test that revealed an increased risk for kidney problems. Yet, they rapidly integrated their new knowledge of *APOL1* into subsequent discussions about ways to protect their kidneys and described how genetic risk was similar to other risks they associate with kidney problems, such as unhealthy lifestyle and stress. Reasons to be tested included wanting knowledge, and benefits to self, family, and community. A 49- year old woman said,

> If it doesn't help me, if it doesn't help my son, it'll help somebody in the future, … This is the conversation … We don't want to see our children suffer with this.

All but one expressed good comprehension immediately and 30 days after return of results and accurately described that the variants represented a risk for disease, not a disease itself or guarantee of future illness. A 55- year old man explained,

> … it's just a factor and a risk…. it's not like a stamp, you know, a final or period that says, because oh, it's over, this is what's going to happen. There are still other determining factors … It's just more information for you to use, you adjust to the best of your ability and your conscience, according to the information you have, so I'm good, you know.

Major themes emerged: (1) **Empowerment**: Knowledge of genetic risk will motivate action, not inspire fatalism or decision regret; (2) **Accountability**: Risk assessment and information can motivate clinicians to focus on better care; (3) **Promise**: Genetic testing for people of African ancestry holds more promise than peril; and (4) **Action**: There is a preference to receive brief, action- oriented genetic information from a trusted source.

Theme 1: Empowerment: Knowledge of genetic risk, whether increased or not, will motivate action, not inspire fatalism or decision regret

Participants valued information about their genetic risk and viewed their results optimistically, even if *APOL1* positive. When anticipating or receiving results, they

emphasized actions they could take to lower their blood pressure and forestall kidney failure including eating more healthfully, losing weight, taking medications regularly, getting their blood pressure and kidneys checked, and seeking information. There were no expressions of fatalism. In anticipating a positive result, a 57- year old man said,

> I don't think it would make me too anxious … I 'd just know that there's a possibility in the future that this could happen and take every precaution that I could … It would maybe encourage me to exercise a little more to keep my blood pressure as low as possible.

Most stated they felt informed, not afraid, such as a 45- year old man:

> There's things we're predisposed to that we don't even know about … it's not a stress thing. It's an information thing … If you find that you're at high risk, then you may have to make further adjustments in your diet and everything that pertains to keeping your blood pressure down.

A 58- year old woman described how information would lead to action.

> I'm tired of being a walking drug store, and if taking of the weight is going to help get the pressure back down, then that's something I really have to strive for … it's better, in the end, to be proactive than not proactive.

There was a preponderant lack of decision regret among participants. They felt knowing their status was important and that information reduced uncertainty. A 48- year old woman with a negative test said,

> I would let my mother know so that it'll maybe give her peace of mind knowing that at least one of her kids may not develop the same kidney problems, ‘cause all of us got anxious around the fact that she had to go on dialysis, and then from dialysis she went to the transplant, so it's in the back of our minds … you can be calm because when you know something, it's better.

A 37- year old man with high- risk variants remarked,

> Oh man, I'm happy … knowing is the happiness. I know today, so I can do things differently to help me live longer, to help me not to maybe go to kidney disease … I didn't know what I didn't know, and now I can help myself do things, and make changes, and make things better for me. So poor me, but now I get to help myself.

However, a 47- year old woman with high- risk variants felt it was yet another detrimental thing her parents subjected her to: “I'm a little pissed of at my parents. So they passed their shit onto me too. Lovely.” Despite bitterness about who “gave” her the risk, she did not regret getting tested and having “the knowledge … to not ever let up and really take care of yourself.”

Theme 2: Clinician accountability/Reduction of inertia: Risk information, and even risk assessment, may motivate clinicians to focus on better care and help patients make their providers more accountable for better management

Participants felt that genetic risk would prompt providers to do more to control blood pressure and prevent chronic kidney disease. A 57- year old man said,

> She's can give me the answers that I need, …, tell me the procedures that I need to have done, tell me how should I change my lifestyle.

Even if the result was negative, participants felt that having a cutting edge test done would activate providers to pay closer attention to their hypertension, a problems some felt providers gloss over. A 35- year old man who was *APOL1* negative stated,

> I've got to discuss with my doctor about this … Because I just take the pills and I don't know anything. And he gives me another prescription, and I just take the pills.

Theme 3: Promise of race and genomics—specifically, genetic testing for people of African ancestry holds more promise than peril: countering stereotypes of people with African ancestry as non- adherent or low- literate, and prioritizing African ancestry populations in research

The team was surprised that, despite extensive questioning by interviewers with African ancestry, respondents focused nearly exclusively on the positive impact of testing for this genetic variant. Only one respondent mentioned that she could understand why Black people would be hesitant to undergo genetic testing. More commonly, participants viewed the genetic test as a counter- stigma to the stereotyping of Black people having socio- behavioral reasons for being sicker than Whites. There was also a positive view of this study because it prioritized Black populations in research. A 58- year old woman explained,

> … it always seems that the Caucasians, maybe the Asians were considered first and we were last for assessments … This one lets us know, hey, there are conditions that are prevalent to our race we need to be made more aware of … When you say kidney disease and the majority of the people are us, I'm like okay it's gotta be something else going on within us that makes us more susceptible.

A 45- year old woman felt that by participating, she could help other Black people in her community:

> … it's going to help somebody, and that's pretty much how we live … I don't have a problem with participating in a study if it's going to help us individually and us as a people.

Theme 4: Action- oriented genetics education—Preference to receive brief, action- oriented information from a trusted source

Participants appreciated receiving some background on genetics, but many initially said this overview was too long. They wanted to choose if and how much more information they wanted after receiving their results, so they were no longer “in suspense.” In response, the genetic counselor halved the pre- testing discussion (from over 20, to under 10 minutes) and subsequent participants were comfortable with the shorter discussion. People with negative results had few questions and wanted far less information. Most preferred to speak with a person in whom they could trust and to whom they could relate, and who would be knowledgeable about genes and issues pertaining to people with African ancestry. This did not have to be their provider (as long as providers receive the information). Several were concerned their providers would not understand genetics well enough to explain it. No one

stated this had to be a genetic counselor, but most felt they should be able to speak or meet with a genetic counselor if desired.

Discussion

Our diverse, multidisciplinary team aimed to explore the knowledge and attitudes of people with African ancestry about a genetic variant nearly exclusive to their racial group that greatly increases the risk of a common, chronic disease: chronic kidney disease/end- stage renal disease.[29] Genomics and precision medicine are burgeoning fields of exploration, and in preparation for what will likely be more and more genetic risks linked to both common diseases and to specific ancestry groups, we interviewed patients before and after they were tested and received information about their risk. Participants who had no prior knowledge of ancestry- linked genetic predisposition to kidney failure, understood and accepted the concepts, valued testing, and took their results in stride. If they received *APOL1* testing, whether the results were positive or negative, it could motivate them and their providers to take actions to improve hypertension care and protect their kidneys, rather than causing stress or decision regret. They nearly universally felt genetic testing for people of African ancestry holds more promise than peril, providing opportunities to improve health.

Participants accepted the connection between genetics, ancestry, and kidney disease, valued information about their personal genetic risk, thought the information would be motivational, and did not regret their choice to get tested. The lack of decision regret is consistent with some current data on whole- genome sequencing.[30] In previous studies, African Americans have shown theoretical interest in genetic testing to learn about risks for kidney disease.[31] We extend these findings to patients who were actually tested and received results.[22,25]

Unexpectedly, participants thought the information could motivate providers to overcome inertia in connection with hypertension management, better communicate with patients about how to manage chronic kidney disease risk and blood pressure, and recognize that there is more to bad health than bad behavior. Clinical inertia is common, related to elevated blood pressure, may account for a significant proportion of cardiovascular events,[32,33] and is linked to impaired patient- clinician communication.[34] Our participants wondered if this new test would refocus clinical attention on intensification of care and hold clinicians more accountable to their patients.

Despite careful prompting by skilled interviewers with African ancestry, only one participant expressed any concern that genetic testing among Black people would pose dangers through racial stereotyping, stigmatization, privacy breaches, or insurance discrimination. Instead, in triangulating findings with both study participants and members of the community board, we found a strong belief that *APOL*1 research could counter stereotypes that Black people fare more poorly because of their behaviors or personal characteristics. This does not diminish the importance of social determinants or the fact that they will continue to play a pivotal role in the renal disease outcomes of Black individuals with or without high- risk *APOL*1 variants.[35] All health determinants are potentially stigmatizing, if people inappropriately judge others as being sick because of bad behavior, a bad neighborhood, or bad genes. In

other bodies of literature, such as HIV, scholars have discussed the assumption that disparities are in part driven by stigmatizing socio- behavioral factors, but that biological factors may play roles, and that all determinants of disparities should be discussed openly and without judgment.[36]

Participants wanted relatively brief, action- heavy information from a trusted person who understood their background, while preserving an option for them to receive more genetics information after they received their results. Many mentioned that they would feel comfortable receiving results from anyone knowledgeable, trustworthy, and able to communicate on the subject in plain language. In other diseases where the genetic risk is more tightly linked to devastating consequences for patients and families, genetic counselors are probably more strongly indicated. Our participants also recognized that *APOL1* may be new to their clinicians, and that it may be better for someone with some *APOL1* understanding to explain it, until clinicians are brought up to speed.

This study has important strengths, including studying patients who actually received genetic testing, substantive engagement of diverse stakeholders, and investigation of an emerging field—race, genomics, and chronic disease. However, it has limitations. We conducted only 26 interviews, though we stopped because we had reached theoretical saturation. There may exist bias favoring testing, as people who enrolled receive health care, consented to be part of a biobank and to participate in our study, and to receive health care. Our participants had diverse income and employment status, but were from one urban academic medical center. Most had at least some college education and other research showed an association between education and positive views of genetic testing.[23]

Study findings advance new hypotheses on the role of genetic testing for common chronic diseases, particularly among people of African ancestry. We aimed to understand how to use this information for maximal benefit and minimal harm, and inform initiatives related to genetic risk of chronic disease. We thus incorporated findings into patient and clinician educational materials, surveys, and disseminated lessons learned to local community and clinical groups, genomics, communication, primary care and disparities research audiences, and policymakers. Our use of a transdisciplinary team including patients, advocates, and genetic counselors, many of whom are of African ancestry, may have helped develop communication strategies and materials that were more appealing, understandable, and inspiring for patients, and others should consider using such collaborations, and piloting and revising materials when developing their materials. Future studies should test these hypotheses in larger populations in varied geographic areas and with different socio-demographic characteristics, and study the impact of genetic testing and returning results on patients' psycho- behavioral and health outcomes.

Lessons Learned

1. Substantive patient, advocate and clinician involvement and feedback can be useful to develop communication strategies and materials that are appealing, understandable and inspiring for diverse patient populations.

2. Piloting can be essential before employing large screenings to determine the best method of delivery of information taking into account the population, the complexities of topics such as genomics, and the implications of the findings.
3. There is no “one size fits all” in incorporating genomics into health care.
4. Patients generally believe genetic risk assessment and information can motivate themselves and their clinicians to focus on better care, not inspire fatalism or decision regret.
5. Genetic testing for people of African ancestry may hold more promise than peril by countering negative stereotypes of people with African ancestry as non-adherent or low- literate, and prioritizing African ancestry populations in research.
6. Patients may prefer to receive brief, action- oriented genetic information from a trusted source (who does not need to be a clinician) and follow up clinically if they have further questions.

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Table 1

Participant Demographics

Total (N = 26)	**Participants % (n)**
High Risk *APOL1* Variants	73% (19)
Age (mean years, range)	54 (36–64)
Gender- % (n) female	73% (19)
Income yearly- % (n)	
<$15,000	31% (8)
$15,001–$45,000	46% (12)
>$45,000	23% (6)
Education- % (n)	
< High School	8% (2)
High school/GED	19% (5)
Some college/trade school	42% (11)
College/professional training	31% (8)
Occupation- % (n)	
Working full/part time	42% (11)
Looking for work	15% (4)
Unable to work or disability	27% (7)
Retired	15% (4)