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RESEARCH

Understanding perceptions of tumor genomic profile testing in Black/African American cancer patients in a qualitative study: the role of medical mistrust, provider communication, and family support

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Abstract

Tumor genomic profiling (TGP) examines genes and somatic mutations specific to a patient's tumor to identify targets for cancer treatments but can also uncover secondary hereditary (germline) mutations. Most patients are unprepared to make complex decisions related to this information. Black/African American (AA) cancer patients are especially at risk because of lower health literacy, higher levels of medical mistrust, and lower awareness and knowledge of genetic testing. But little is known about their TGP attitudes or preferences. Five in-person focus groups were conducted with Black/AA cancer patients ($N=33$) from an NCI-designated cancer center and an affiliated oncology unit in an urban safety-net hospital located in Philadelphia. Focus groups explored participants' understanding of TGP, cultural beliefs about genetics, medical mistrust, and how these perceptions informed decision-making. Participants were mostly female (81.8%), and one-third had some college education; mean age was 57 with a SD of 11.35. Of patients, 33.3% reported never having heard of TGP, and 48.5% were not aware of having had TGP as part of their cancer treatment. Qualitative analysis was guided by the principles of applied thematic analysis and yielded five themes: (1) mistrust of medical institutions spurring independent health-information seeking; (2) genetic testing results as both empowering and overwhelming; (3) how provider-patient communication can obviate medical mistrust; (4) how unsupportive patient-family communication undermines interest in secondary-hereditary risk communication; and (5) importance of developing centralized patient support systems outside of treatment decisions. Results improve understanding of how Black/AA patients perceive of TGP and how interventions can be developed to assist with making informed decisions about secondary hereditary results.

Keywords Genetics · Tumor genomic profiling (TGP) · Black/African American cancer patients · Qualitative research

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Introduction

The use of multi-gene tumor genomic profiling (TGP) to examine genes in a patient's tumor for targetable mutations is a cornerstone of personalized oncology. Recent reports find that 3–13% of patients having TGP have a germline mutation predisposing them to hereditary cancer also present in the germline (Catenacci et al. 2014; Schrader et al. 2016; Hall et al. 2015; Robson et al. 2015). Commercial availability of somatic DNA sequencing via TGP has been in place less than a decade, yet the diagnostic power and clinical breadth of testing have expanded substantially (Liu and Stadler 2021; Chakravarty et al. 2022), contributing to a notable lag in establishment of optimal practices related to TGP-associated communication and decision support. In contradistinction, germline genetic testing for hereditary cancer risks has been routinely performed since the late 1990s. Over the past 25 years, extensive behavioral, communication, and decision support research has guided clinical practice related to the medical management of hereditary genetic information (Kohut et al. 2023). Among the pillars of cancer risk assessment and genetic testing are provisions for genetic counseling, informed consent, and respect for individual patient privacy and information preferences (National Cancer Institute 2023) (Cancer Genetics Risk Assessment and Counseling (PDQ®) 2024). Reflecting this precedent toward managing germline genetic information, in 2015, the American Society of Clinical Oncology (ASCO) issued updated guidance related to TGP that mandated communication of TGP risks to patients in 2015 and emphasized the importance of eliciting a patient's preferences for managing information about inheritable risks (Robson et al. 2015) (e.g., "opt-out" of getting the results, undergo genetic counseling). Nonetheless, because most TGP is ordered in the outpatient oncology clinic with a goal of identifying somatic targets for treatment, genetic counseling is most often not provided, and oncologists spend little to no time reviewing secondary hereditary risks (Melika et al. 2021). With the focus on cancer treatment and with limited understanding of genetics and TGP, patients are often unprepared to discuss preferences and personal values with their providers, especially underserved and racial/ethnic minorities (Canedo et al. 2019).

The nuanced and multi-layer results of TGP testing, its conduct in busy oncology clinics, and existing socioeconomic and behavioral barriers towards genetic medicine support an environment where health disparities may be magnified. For example, patients with lower health literacy may be unlikely to be aware that mutations suggestive of increased personal or family cancer risks could be uncovered by TGP and may be unprepared to make complex decisions related to their genetic information, magnifying vulnerability to poor decisions. Similarly, communicating secondary hereditary risk to underserved and minority patients may be especially challenging, particularly for those patients who distrust the medical system (Hoadley et al. 2022; Armstrong et al. 2012). Notably, substantial research has demonstrated that Black/African American (AA) patients experience higher cancer disparities compared to non-Hispanic Whites and undergo TGP at significantly lower rates, even after controlling for other sociodemographic and clinical factors that contribute to disparities in health outcomes (Hardy et al. 2009; Lynch et al. 2018). In cancer care, disparities related to access to care, therapies selected, and referral for specialty services have been extensively documented, while specific to genetics and genomics, studies have demonstrated disparities in uptake of genetic services, availability of genetic counseling and testing, cost barriers, and reporting of genetic test results (Cruz-Correa et al. 2016; Cragun et al. 2017), with racial ethnic minorities being more likely to receive uncertain results of testing or mutations that cannot be clearly called benign or disease-causing (Diaz et al. 2014; Fisher et al. 2020). Taken together, this compendium of research suggests that multi-faceted forces, including both structural and psycho-social factors, may contribute to the differential engagement with TGP among Black/AA oncology patients (Khan et al. 2022). Furthermore, because Black/AA patients overall have increased cancer risk and mortality burden relative to White patients (Zavala et al. 2021), they are an important group to target for genetic decision support.

Little work has been done to understand the psycho-social factors that shape Black/AA perceptions of genetic testing as it relates to their oncological care. Evidence suggests that Black/AA patients express higher concerns about discrimination related to genetic testing, and higher distrust toward the medical community (Hoadley et al. 2022), often related to historical incidents of medical malice (Hammond et al. 2010). Relatedly, mistrust has been shown to interfere with a patient's health literacy development as it affects interactions with the health care system, access to health-related resources, and overall health-related decision-making (Muvuka et al. 2020). Patients with higher levels of health literacy on the other hand report greater self-efficacy in their cancer treatment decision-making processes (Dumenci et al. 2014) and greater health-related quality of life (Halverson et al. 2015).

Compounding the communication challenge is the fact that many oncologists who order TGP for Black/AA patients have a limited understanding of TGP risks and how to effectively convey secondary hereditary risks to their patient (Melika et al. 2021; Hall et al. 2021). Since little research has examined TGP communication approaches, oncologists are

inadequately equipped to optimally communicate these risks to patients who contend with the complexity of medicalization and the emotional labor of having cancer. Hence, it is important for providers to understand how knowledge and cultural perceptions of the medical system impact patient decision making and communication preferences, especially in their Black/AA patients, to redress the underutilization of TGP in this population. If not addressed, Black/AA patients may lack the support they need to make informed decisions regarding their genetic health information. To that end, the objective of this study was to understand Black/AA patients' perceptions of TGP and how they conceptualize the role of their provider in their decision-making processes, including communication about their genetic information.

Instruments and methods

Participants and setting

Black/AA cancer patients ($N=33$) participated in one of five in-person focus groups from October 2017 through January 2018. A purposive sample of participants wa recruited from two sites—an NCI-designated cancer center and an affiliated oncology unit in an urban safety-net hospital located in Philadelphia. Eligibility criteria included (1) 18 years of age or older; (2) self-identify as Black/African American; and (3) have a solid tumor cancer. TGP use and cancer stage were not required for eligibility so that we had a mix of those with and without experience using tumor testing and different cancer stages. Prospective participants were identified by their age and self-reported race in the electronic medical record and through identification via oncology providers. Patients were either approached in person at the cancer center or oncology unit or contacted via phone or letter by a member of the research team. Those who were interested were sent an informed consent via email or mail and consented via electronic or physical signature. They were then scheduled for the group most convenient to them in time and location. Participants were compensated with a gift card in exchange for their participation. Institutional Review Board approved the study (#18–8006).

Implementation

Each focus group was comprised of 4–7 participants and moderated by study staff who have significant experience with qualitative research (Bass et al. 2010, 2011, 2015, 2022a, b). Before the discussion, participants were presented with an informational PowerPoint presentation providing a general overview of TGP and genetic testing to ensure everyone understood what the test is for and the secondary hereditary results that could be uncovered. Afterward, a short survey was distributed to collect demographic information, i.e., gender, age, highest level of education, household income, and insurance type (see Table 1), and participants were able to ask questions about the content. The moderator's guide was developed to identify a range of cognitive and affective issues (Hoadley et al. 2022) that are important in understanding the perceptions of TGP for Black/AA patients (see Table 2), including medical mistrust, perceptions of TGP, attitudes about sharing information with families, and communication issues with doctors and other healthcare providers. Some example questions include, "Can you tell me some reasons you think people would want to get a TGP test done?" How might a TGP test impact your treatment decisions? and Do your feelings about TGP testing differ from these other types of genetic testing?. Results of this formative work were integral to the development of a culturally acceptable electronic decisional-support tool for Black/AA cancer patients to support an improved understanding of TGP and the secondary hereditary results that may be uncovered and better-informed decisions for what they would want to talk to their doctor about should this information be uncovered. Focus groups ranged from 1 to 2 h depending on the engagement of participants, including the informational presentation and discussion.

Evaluation

Audiotapes of focus groups were transcribed and analyzed by investigators using an iterative coding process with consensus and triangulation to develop thematic categories using Dedoose 9.0.107. Summary analysis determined that thematic saturation had been reached after five focus groups, so no further groups were completed. Analysis was guided by the principles of applied thematic analysis (Guest et al. 2012), a qualitative evaluation method that is not tied to a theory and is appropriate for formative work that aims to describe themes found in data. No specific medical mistrust framework was used because this formative research was exploratory and no a priori hypotheses were specified. In this study, Braun and Clarke (2006) suggested stages were used, including becoming familiar with the data, generating initial codes, searching for themes, and deriving meaning. An initial codebook was developed based on the moderator's guide, and two trained analysts independently applied codes to the transcripts to create coded excerpts derive meanings across groups. Discrepancies in code application were resolved through discussion. Two trained analysts reviewed coded excerpts, identified patterns, and met to reach thematic consensus. The coding process was documented and reviewed by the full study team to maximize the reliability and validity of the evaluation methods.

Table 1 Demographic characteristics of focus group participants ($N=33$)

		N (%)
Age (years)		
	Mean	57
	Standard deviation (SD)	11.35
Gender		
	Male	6 (18.2%)
	Female	27 (81.8%)
Education*		
	Some high school	2 (6.1%)
	Graduated from high school	4 (12.1%)
	GED certificate	3 (9.1%)
	Vocational school	1 (3.0%)
	Some college	11 (33.3%)
	Graduate from college	6 (18.2%)
	Graduate degree	5 (15.2%)
Cancer stage		
	Early (stage 1 and stage 2)	18 (54.5%)
	Late (stage 3 and stage 4)	11 (33.3%)
	Unsure	4 (12.1%)
Insurance**		
	Private/commercial	6 (18.2%)
	Medicare or Medicaid	13 (39.4%)
	Multiple insurance coverage	10 (30.3%)
	Not sure	1 (3.0%)
	Other	3 (9.1%)
Income		
	Less than $10,000	6 (18.2%)
	$10,000 to $19,999	4 (12.1%)
	$20,000 to $29,000	6 (18.2%)
	$30,000 to $49,999	5 (15.2%)
	$50,000 to $74,999	2 (6.1%)
	$75,000 or more	4 (12.1%)
	Don't know/not sure	5 (15.2%)
Have you ever had a TGP test done as part of your cancer treatment		
	Yes	7 (21.2%)
	No	13 (39.4%)
	Not sure	13 (39.4%)
Have you ever heard about Tumor Genetic Profiling tests (TGP) from a doctor or other healthcare provider?		
	Yes	18 (54.5%)
	No	11 (33.3%)
	Not sure	4 (12.1%)
Which statement best describes the way you like to make treatment decisions?		
	I prefer to make the final selection about which treatment I will receive	5 (15.2%)
	I prefer to make the final selection of my treatment after seriously considering my doctor's opinion	9 (27.3%)
	I prefer that my doctor and I share responsibility for deciding which treatment is best for me	11 (33.3%)
	I prefer that my doctor makes the final decision about which treatment will be used, but seriously consider my opinion	4 (12.1%)
	I prefer to leave all decisions regarding my treatment to my doctor	4 (12.1%)

$N=1$ missing demographic survey

**M*(SD)

***N*=1 missing

Table 2 Focus group moderators' guide

Domain	Sample questions
Genetic and TGP testing issues	1. Can you tell me some reasons you think people would want to get a TGP test done? [PROBES: What benefits do you see? i.e. helps treat your cancer, improve the quality of your life, benefits others, helps you feel in charge.] 2. Can you tell me some reasons you think people would not want to get a TGP test done? [PROBES: People don't want to know the results? How would your family feel about finding out they may be at increased risk for cancer? Do not want an extra biopsy? Insurance will not cover TGP?] 3. Can you talk about what role you think religious or cultural beliefs might impact how someone would feel about having a TGP test and getting information about secondary hereditary results?
Personal experiences with TGP	1. If you did have the test and there were secondary hereditary results – would you want the doctor to talk to you about this or would you rather meet with a genetic counselor? A genetic counselor is someone trained in genetics who can talk to you about your test results and what they mean 2. How would it feel to share results with your family if the results said that your family was at higher risk of developing cancer?
Perceptions of TGP	1. Do your feelings about TGP testing differ from these other types of genetic testing? How so? 2. Talk to me about your feelings about your genetic information that you might find out from TGP or other genetic tests. Are you worried about how the genetic information will be shared or used? [PROBE: Would you be concerned that the results would be used without you knowing?]
Trust in medical system	1. Some patients have mentioned that a reason for not getting genetic testing is a strong distrust of science or the medical system. What are your thoughts on this? [PROBES: Have you had any specific experiences that make you less trustful of the medical system? Have friends or family shared any specific experiences – what were they?] 2. Do you trust the doctor(s) treating your cancer? Why or why not? - Do you trust the hospital you are getting treatment at? Why or why not? - How about your insurance company? Why or why not? - Do you trust medical researchers? Why or why not? - Do you trust pharmaceutical companies who make the drugs? Why or why not? 3. Are you concerned that you could be discriminated against because of your genetic results? [PROBE: Do you think this is more of a concern for ethnic minorities than others? What ways might you be discriminated against? Any worries about immigration or the process of pursuing citizenship if outside US?] [Not getting health/life insurance? Treated differently by employer?]

Findings

Participants

All participants self-reported their race as Black/AA with a mean age of 57 and a standard deviation of 11.35%. A majority (81.8%) were female, and 33.3% ($N=11$) had some college education. Most (66.7%, $N=21$) reported having Medicare or Medicaid insurance, and the majority (67%) had an average household income below $50,000. Eighty-seven percent reported that this was their first time being diagnosed with cancer. Fifty-four point five percent ($N=18$) reported never having heard of TGP, and 39.4% ($N=13$) were not aware of having had TGP as part of their cancer treatment (Table 1).

Focus group themes

Five themes emerged during focus group discussions: (1) mistrust of medical institutions spurring independent health-information seeking; (2) genetic testing results as both empowering and overwhelming; (3) how provider-patient communication can obviate medical mistrust; (4) how unsupportive patient-family communication undermines interest in secondary-hereditary risk communication; and (5) importance of developing centralized patient support systems. Specific quotes by theme are presented in Table 3.

Mistrust of medical institutions spurring independent health-information seeking

To capture participants' perceptions of medical mistrust, participants were asked about mistrust toward specific types of institutions commonly associated with the medical system, including pharmaceutical companies, insurance companies, and healthcare institutions. Participants' perceptions of mistrust toward the medical system were rooted in two areas—historical medical mistreatment of Black/AA communities and prior individual experiences engaging with the medical system. When speaking about commonly held perceptions of medical mistrust in the Black/AA community, fear of experimentation, concerns of potential medical malice, low-health literacy, and race-based discrimination were all both implicitly and explicitly mentioned. Participants often provided examples of mistrust they or their family members had experienced:

Table 3 Selected quotes by themes

Themes	Excerpts
Mistrust of medical institutions spurred independent health-information seeking	"I just wanna know because it seems like the insurance has a stumbling box for everything, you know, and I want to know how far I can go before they say no." [Cancer Treatment] "And I'll be damned if I'm gonna let anybody try to put some blind folders on my eye and stuff my ears and make me walk and talk like every thing's all good, when it's not. because anytime you live in a democracy, where all of us are paying taxes into this healthcare system and then we got people, and we have a diagnosis that could literally kill us and we got people denying us for treatment"
Genetic testing results can be empowering and overwhelming	"I would think that I would try to approach every avenue to find out all the information that I could because I believe when I first got this, I was talking about. Genetics, you know, um proton therapy." "That's why I didn't have a lot of tests done because I was scared of going under and not coming out and knowing that I was taking care of my mom at the time."
How provider to patient communication can obviate medical mistrust	"For me, my primary doctor called me in, but I knew because the way she wouldn't tell me over the phone. So, I knew something was wrong, you understand what I'm saying?" "I was having a conversation with my gynecologist, um…and that was shortly after my diagnosis with cancer. and um I kinda mentioned it matter of fact and you know my gynecologist and I are very close and when I told him about my history and my Ashkenazi Jewish DNA, that's when he said 'did [Hospital] talk to you about further testing?"
Unsupportive patient-family communication undermines interest in secondary-hereditary risk communication	"You know, in our family you know like in African American families, not as much as it is today- I think we are getting more opened some of us. I had two aunts that had breast cancer, and when I really got sick the first time, not one of them told me. How in the world you- what is the problem?" "Um…and so to this day, I still have literally, my own mother, because of the decision I made [To have genetic testing], she doesn't speak to me as a result of it. [Gasps and wows around the room] Yeah…she's in complete denial."
Importance of developing centralized patient support systems	"Um, my support system consists of a lot of my coworkers. I work in the office with lets say 15 ladies and even though I have two sisters here, because I work here and was getting treatment here, it was a lot easier for my co-workers to basically stay and help." "I was, I have been blessed and fortunate to have two grown daughters who have been very much involved from the very beginning."

"*I think a lot of it is medical mistrust, but I think it's a combination. I'm thinking about my mother in particular…historically the racism that has been experienced by African Americans and I know for a fact that's where her opinions were grounded*."

Participants further expressed their perceptions of insurance companies and pharmaceutical companies' role in their cancer treatment. Many shared the belief that both insurance companies and pharmaceutical companies only care about profit, "money. That's all it is…I have to be real because it ain't in the money, the money ain't in our visits. It's in that pharmaceutical. It's in that medicine. So, the more medicine, the more money they make." Some also discussed their concerns about experimentation and not receiving the same level of treatment by pharmaceutical companies. "Am I being experimented on here? Other people are getting this high level of care, and you don't hear about them suffering anymore." As a result, some participants discussed doing extensive information seeking to ensure feeling that they were getting the best care.

Some participants expressed high levels of mistrust toward their medical providers thinking they were withholding information about treatment information. One participant said, "I think a lot of information that's being provided to other people of color is not being provided to me." A sense of unequal treatment and withholding of information prompted some participants to seek out information about their diagnosis and alternative forms of treatment to best advocate for themselves during their cancer treatment journeys. These attitudes seem to also be reflected in participants' perceptions of how they approach TGP and genetic testing. One participant that had not had TGP shared:

"*I would try to approach every avenue to find out all the information that I could because I believe when I first got this [diagnosed with cancer], … I was talking about genetics, proton therapy. I jot things down, and you know present it to my doctor.*"

A positive outcome is that often they conceptualized the testing as a pathway to arming them with more information to make decisions about their cancer treatment.

Genetic testing results can be empowering but overwhelming

Perceptions of TGP profiling and genetic testing were discussed in the context of three key areas—motivations to test, perceived benefits of testing, and decisional support from a provider. For participants who had not had TGP, questions concerning the validity of the testing were frequent, with questions about what hereditary means, how the test would be done, and whether genes could "skip" generations. Motivations to test and perceived benefits of getting TGP were tightly intertwined. For those who had previously had TGP, a desire for more knowledge about their diagnosis was noted, with participants often describing themselves as "inquisitive" or wanting to "know my chances." Furthermore, the primary benefits associated with TGP were to learn about family health histories and inform relatives of possible secondary hereditary risk. One participant who was tested said, "I have a five-year-old daughter and a two-year-old son, everybody was on my maternal side, so I had all of that done."

While overall perceptions of TGP were mostly positive, some concerns about feeling overwhelmed were raised when discussing if participants wanted to know TGP test results. One participant commented, "I have children. I have grandchildren. So yes, test it, but I just don't want to know." The participant further went on to communicate their reasoning—"sometimes we do feel targeted, with certain things, and that does affect people's thinking when it comes to (medical) things." Lastly, the importance of the role of the provider in offering decisional support about TGP was mentioned. Participants expressed a preference for providers who highlight TGP and genetic testing as a tool early in the treatment journey, as this can afford ample time to make a decision about the testing. One participant said, "I remember when the first suggested that I get the test and I told my doctors, I said 'I don't know about that. So, it took me maybe two months after her initially telling me that I needed to get it done. and I finally did it. And I'm glad I did."

How provider-patient communication can obviate medical mistrust

Throughout the discussions, participants reflected on their encounters with their healthcare providers during their cancer treatment. Perceptions of the quality of their care depended on how satisfied they were about their overall communication with their provider, including dialog about TGP. Often, participants contextualized these forms of communication in their experiences learning about their initial cancer diagnosis and ongoing cancer treatment experiences. Communication styles were illustrated by providers' ability to verbally convey care and concern when communicating information about diagnosis or treatment. Most participants felt their oncologist was "on their side," and they trusted their judgement about their cancer care. These experiences were not ubiquitous, as one participant described a negative interaction when she was diagnosed by saying, "The delivery of the news… She basically said… 'I just called to tell you that your results are in, and you do have cancer… You're calling me at work and getting that news, I basically screamed on the phone 'what are you talking about' [and] busted out crying." Participants noted that these provider conversations color future care planning, including about TGP, and that positive interactions can lessen the impact of overall medical mistrust.

While prior communication about TGP with providers was not widespread within the participant sample, those who did comment on discussing TGP with their provider spoke favorably about the recommendation for the testing. One participant said, "because I had such confidence in him [oncologist], and he was so passionate about it [TGP]…I'm going to call [hospital] as soon as I leave here and set up the appointment for genetic testing." Importantly, participants overall wanted to be active participants in the decision. One participant commented, "It was very difficult, it was like 'okay…they do the work, they're the experts,' but you are a part of your treatment as well." This was echoed by other participants' comments concerning their active involvement in treatment decisions with their providers. Regardless of prior provider communication about TGP, most participants felt confident communicating with their provider about their cancer treatment. In part, this confidence seems to reflect participants' perceptions of self-preparedness and the importance of developing health literacy.

Unsupportive patient-family communication undermines interest in secondary-hereditary risk communication

Although most patients were open to receiving TGP testing, preferences for the involvement of family members in participants' decision making about aspects of their cancer treatment was varied and, for some, a barrier to receiving TGP. Some participants were vocal about not communicating with their families about their diagnosis and treatment. Participants who had family histories of cancer commented on their family's attitudes toward treatment. "I had people in the family that had breast cancer, but many years ago. They

refused treatment," one participant said. Some participants maintained that they "did not want to be around negativity" or feel "dissuaded" by family regarding certain decisions about their cancer treatment. One said, "They can't even come and see me. I don't ever want them around me because I don't want no negativity around me." Others commented on their experiences dealing with family perceptions of their diagnosis. One said, "You know what, I really don't like their attitude about it…I just kept that close knit group but the cousins that would make sarcastic comments you know 'how many radiation treatments? Oh, you gonna glow in the dark'?".

As a result, participants were cautiously selective when disseminating information about their diagnosis and treatment with family members, including communicating their TGP test results. A few participants agreed that they would only communicate their test results if there was a secondary hereditary risk. One said, "If I came back positive [secondary hereditary risk] if that it was genetic, I would have told my sons right away. The only reason I'm not saying anything, because it's no threat to them as far as we know." Furthermore, participants felt that sharing secondary hereditary risk information could run the risk of causing unnecessary distress for family members, "I love my kids but they ain't ready for none of this [TGP test results] and they very hyped and, you know, they don't take stuff like this well." Lastly, communication about family health history and social support were tightly interrelated. In describing their family health histories, participants pointed toward the general lack of communication about sickness by relatives and feeling they were not supported in their decision making about treating their illness. One said, "…so I got to a point… when I can feel advice coming on, I'll change the subject. I'll just shut it down."

Importance of developing centralized patient support systems

To conceptualize participants' social support systems, three sub-themes were noted—the role of family and friends, the role of religion or faith in a higher power, and the lack of support. Some participants commented on the lack of support they received from family members, including making the decision to receive treatment. One said, "I knew that there were people in the family that if I had made a decision to get treatment and get chemo, I knew they wouldn't be supportive. I would be told that I was a guinea pig." In response, some participants described how because of these concerns, they were methodical when establishing their support systems. "I… utilized very specific family members. I had to kind of screen out and make my own support group. Know that there were certain people in my family that just weren't going to support me." Not much was communicated about how support from family/friends was associated with perceptions of TGP, although one offered that being supported by family to have genetic testing would be important to their decision process. Many participants often utilized select family and friends primarily for assisting with day-to-day tasks and emotional support during treatment instead of involving them in treatment decisions.

Religion and faith in a higher power were often discussed as important to making decisions about their treatment options and when coping with symptoms of their diagnosis. In the context of TGP, faith in a higher power was used to reaffirm patients' decisions to have the TGP testing and/or learn about their genetic information. One participant said, "I mean that God empowers me. So that's what I'm talking about. God gives me a voice. God gives me hands to be able to say hold it, this is right. [learning about genetic information]." Some participants highlighted the importance of their churches and faith-based groups that operated in place of their families. One said, "You know, I love my family and they're there for me if I need them, but my support is my church." While lack of support was often contextualized by participants' experiences dealing with "negative" family members, some participants were transparent about feeling "alone" during their cancer treatment journeys, primarily due to feeling that people could not understand what they are going through. "I love my kids but they ain't ready for none of this and they very hyped and, you know, they don't take stuff like this well."

Discussion

The aim of our research was to explore Black/African American cancer patients' perceptions of TGP testing and their decision making about their genetic health information. The inherent connection between TGP, genetic testing more broadly, and family healthcare treatment involvement raised tangential topics of concern for patients, such as mistrust of the healthcare system, the importance of provider support, and family-related information sharing. In turn, broader themes that were stimulated from conversations about TGP were documented, such as the mistrust of medical institutions, how genetic testing results can be empowering but overwhelming, the importance of provider-patient communication, and the effect of unsupportive patient-family communication, all of which can undermine interest in secondary-hereditary risk communication. Our findings suggest that concerns about TGP might be best addressed with interventions that first and foremost inform patients about how TGP works and why it is performed in cancer patients, but that also emphasize not only the benefits of the testing but acknowledge both the psycho-social issues that may impact a decision about testing and what to do with

secondary hereditary risks, and the need to gather information outside of the clinical setting.

A qualitative thematic analysis of the focus groups data revealed several interesting insights about patients' perceptions of TGP. Firstly, overall, attitudes about TGP and genetic testing were positive, especially if the participant believed they had a positive relationship with their oncologist. This was surprising given the extensive discussion in the focus groups about examples of historical medical malice and experimentation in the context of whether they trusted medical research and researchers. These results seem incongruent with the contemporary literature concerning patients making healthcare decisions within Black/AA communities, including how mistrust informs provider to patient communication (Glover et al. 2017; Stevens et al. 2016; Cuevas et al. 2016) and work that has been done with cancer patients or those seeking cancer screening. However, the importance of the role of the provider to ameliorate mistrust, expressed by many participants in this study, has also been seen in other studies with Black or AA cancer patients (Bustillo et al. 2017; Rogers et al. 2022; Sutton et al. 2019a). For example, (Sutton et al. 2019b) in an analysis of a cross-sectional survey with Black/AA breast cancer patients showed that those more satisfied with their providers' technical ability had lower levels of mistrust (Sutton et al. 2019a). In the context of TGP, participants focused on the prescribed benefits of the testing instead of their larger misgivings about the healthcare system, especially if they trusted their own oncologist. However, if oncologists do not appreciate these larger mistrust issues, or do not have a good understanding of how to discuss secondary hereditary results with Black/AA patients, this opportunity may be lost. Our own research has indicated that oncologists generally report informal or no training in interpretation or communication of TGP results, including secondary hereditary information, and believe that additional training is needed (Hall et al. 2021). These skills may be even more important with Black/AA patients who have more and complex barriers in the setting of genetics-related decisions (Hardy et al. 2009; Lynch et al. 2018; Diaz et al. 2014; Fisher et al. 2020).

Indeed, participants indicated that knowing about TGP and the results could make them better informed and empowered, making communication both in and outside of the clinical encounter important. This idea of being "armed with information" was prevalent within the sample, both with patients who were aware that they received TGP and those who had not. But relying only on oncologists to provide that information is not practical and can be overwhelming, given the complexity of genetic results, and may also not be the best way to reach populations who are more likely to have higher levels of mistrust. In our sample, patients with high levels of medical mistrust approached their relationships with their provider more cautiously, frequently engaging in extensive information seeking independent from their provider with the goal of improving self-preparedness to mitigate any potential issues with their treatment. In comparison, patients who expressed having positive relationships with their providers were more willing to engage in dialog about TGP and genetic testing. While the shared decision-making model (SDM) has been suggested as the goal in patient-provider communication, this model usually requires adequate health literacy on the part of the patient and trust in their provider (Durand et al. 2014; Legare et al. 2014; McCaffery et al. 2010). Often, Black/AA patients who have lower trust levels will also be less likely to communicate the preferences and values necessary for successful SDM (Hawley and Morris 2017), making decision support outside the clinical encounter important (Zisman-Ilani et al. 2023). Bridging knowledge and communication gaps for Black/AA oncology patients requires targeted interventions that address their specific needs, preferences, and values. This in turn may potentially increase trust/communication with providers.

Another interesting finding not previously reported was that for participants that were aware that they had undergone TGP testing of their tumor, many were uncertain as to whether they would communicate those results with others, although most said that if results showed a hereditary risk, they would share that information with their children and relatives. However, there are several challenges associated with sharing genetic test results within families (Daly et al. 2016). Patients' willingness to share information about their TGP results and other aspects of their cancer treatment with family seemed contingent on if they believed their family members would be receptive to the information, which could be exacerbated by emotional distance among family members or poor communication skills (Daly et al. 2016). This is counter to studies that indicate that family is integral to medical decision making in Black/AA patients. For example, a qualitative meta-synthesis of literature on the role of women in Black men's prostate cancer screening and treatment decision making noted that women were an important influencer and supporter in decision making (Bergner et al. 2018). Others have noted that lack of access and awareness of genetic testing, fear of discrimination, and concerns about privacy and misuse of information make racial and ethnic minorities less likely to participate in precision medicine (Diaz et al. 2014; Fisher et al. 2020), such as TGP. If Black/AA patients are concerned about how the findings of genetic tests may be used, they may also be less likely to share that information with family that they feel are not supportive of them and their treatment decisions. This was clearly articulated in this study.

As a substitution for potentially unsupportive family systems, many participants noted they turned to religion or faith. Religious involvement and spirituality are historically central to many in Black/African American communities and are an integral part of their culture (Lincoln and Mamiya 1990). Prior studies posit that

spirituality increases hope and psychological well-being, as has been found among Black/African American women with breast cancer (Gibson and Parker 2003) and Black/African American men with prostate cancer (Bowie et al. 2004). In the context of our study, religion and faith-based support groups were noted to be important support systems to help cope with their diagnosis and ongoing cancer treatment. Simon et al. (2007) reported that during the diagnosis phase, spirituality helped with acceptance, treatment decision-making, and the meaning-making process of Black/African American cancer patients. This finding could be extended to TGP and learning about genetic health information, as was articulated by some participants.

Finally, the results from this study are important when thinking of how best to increase patient awareness and health literacy about genetic testing, precision medicine, and TGP in Black/AA patients. With information seeking being an indicator of medical mistrust in participants in this study, addressing information gaps with a culturally relevant intervention could help increase patient health literacy and empower patients to have conversations about what information they would and would not want both in and outside of the clinical encounter. This type of intervention could follow the lead of other cancer education interventions that have used technology like mHealth (Samadbeik, et al. 2023) or web-based applications (Saeidzadeh et al. 2021), one-on-one coaching (Oldenmenger et al. 2018), or training of clinicians (Paladino et al. 2019) or genetic counselors to understand potential differences in perceptions of genetics and genetic testing. Furthermore, given the importance of providers' roles in supporting patients in their cancer treatment decisions, it is important to ensure that providers are culturally competent when engaging in dialog with patients about TGP and their cancer treatment, including the option for patients to opt out of knowing the results of their TGP test, and to understand how medical mistrust and other concerns might drive those decisions.

Limitations

The themes provided are to be considered in the context of certain limitations. Although inherent to formative qualitative work, the findings are not transferrable to other Black/AA cancer patients because the findings represent the perceptions of a small group of patients, in this case, urban Black/AA patients in a large hospital system. Findings may not reflect other groups of Black/AA patients, especially those who may not have easy access to primary medical care or specialty oncology care. The factors that inform medical mistrust are dependent on participants' prior individual cancer treatment experiences, insurance coverage, and varying levels of social support. Findings could have also been affected by patients' prior decisions about other aspects of their diagnosis and treatment, including from which healthcare institution and from what oncologist they received their care. The data were also collected in 2018; attitudes about genetic testing in these populations may have evolved. Also, the sample was composed of mostly women over the age of 57 who have been engaged in care for extended periods, which could have affected levels of medical trust but also levels of health literacy and confidence when speaking with their oncologist and members of their healthcare team. Another limitation was that while some patients had awareness of TGP testing; others were not aware of the test. While important to capture hearing from both types of patients, this may have affected results since some participants were speaking from lived experience and some were only speaking hypothetically about what they would do with their genetic health information. Finally, almost all participants reported being insured (97%), including some patients (30.3%) who reported having multiple insurance coverage. Thus, these findings may not reflect uninsured Black/AA populations.

Conclusions

This study of attitudes about TGP, levels of medical mistrust, and communication experiences with their providers in a population of Black/AA cancer patients provides new insights into how to address knowledge gaps and important potential barriers to how best to communicate with patients about TGP results. Developing culturally competent decision support that addresses these concerns is important to closing cancer health disparity gaps.

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Data availability Data available from the corresponding author upon reasonable request.

Declarations

Institutional review board statement This study was conducted according to the guidelines of the Declaration of Helsinki, and approved by the Institutional Review Board of Fox Chase Cancer Center (IRB18-8006 approved 08/31/2018).

Informed consent statement Informed consent was obtained from all subjects involved in the study.

Competing interests The authors declare no competing interests.

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