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ORIGINAL ARTICLE

"Being proactive, not reactive": exploring perceptions of genetic testing among White, Latinx, and Pacific Islander Populations

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Abstract

Genetic testing is becoming an integral part of healthcare, but evidence suggests that both race and ethnicity influence access to and utilization of genetic testing. Given this barrier, data are needed on the perceptions of genetic testing in racial and ethnic minority groups. The purpose of this study was to explore the perceptions of three types of genetic testing (genetic testing for adult-onset conditions, prenatal screening, and newborn screening) in a sample of US participants who identified as White, Pacific Islander, and Latinx (10 dyads from each group for 60 participants total). Data were collected through semi-structured dyadic interviews and assessed using thematic analysis. The major themes were knowledge as empowering, knowledge as stressful, and predictive nature of prenatal testing and newborn screening. Some differences were seen in themes by race and ethnicity. A sense of collective and familial health appeared to be a more important theme for Pacific Islander and Latinx participants compared to White participants. Adult-onset genetic testing was viewed variously across all groups with some noting how it may increase anxiety, particularly if the disease screened for was unable to be prevented with action. All three groups reported on the positives of prenatal testing and newborn screening yet often were confused on the differences between them. This study presents novel perceptions of genetic testing in participants from diverse communities across three types of genetic testing. Genetic healthcare providers should incorporate participants' perceptions, values, and beliefs into their counseling delivery as a way to engage with diverse communities.

Keywords Genetic testing · Cancer · Prenatal screening · Newborn screening · Latinx · Pacific Islander · Genetic counseling

Introduction

The applications and potential benefits of genetic testing differ across healthcare settings in which genetic testing is utilized. Those in clinical settings, such as oncology, may benefit from testing through personalized prevention, treatment recommendations, or motivation for health behavior change (Green and Guyer 2011; Kaphingst et al. 2015; McBride et al. 2010). Those in prenatal settings may benefit from the ability to make informed reproductive decisions (Etchegary et al. 2008). The use of newborn screening in pediatric settings is the largest application of genetic testing in the USA, and is key for early identification and prevention of genetic disease in newborns (Anderson et al. 2011). Prenatal testing differs from newborn screening in that the former type of assessment is done during pregnancy to determine the likelihood of a specific birth defect(s) (Vass et al. 2019). Newborn screening, on the other hand, collects biospecimens from a

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newborn to screen for whether a newborn may have metabolic and/or hereditary disorders requiring early detection for treatment and diagnosis (Vass et al. 2019). Genetic testing has evolved to become an integral aspect of the healthcare system; however, limitations to the accessibility and diffusion of genetic testing have become apparent (Joseph et al. 2017; McBride et al. 2010). The purpose of this study was to explore the knowledge and perceptions of three types of genetic testing (i.e., genetic testing for adult-onset conditions, prenatal screening, and newborn screening) in a sample of participants from three racial and ethnic groups: White, Latinx, and Pacific Islander.

Several studies have found that access to and utilization of genetic testing is lower among individuals from the United States (US) minority racial and ethnic groups (Alford et al. 2011; Bloss et al. 2010; Canedo et al. 2019; Joseph et al. 2017; Mai et al. 2014; Sussner et al. 2011). Evidence suggests that both race and ethnicity influence access to genetic testing (Alford et al. 2011; Kaphingst et al. 2015). Related literature has shown that genetic testing rates and representation are higher for those who are White with higher socioeconomic status and education levels, those who have insurance coverage, and those with a higher level of health literacy (Bloss et al. 2010; Dean and Fisher 2019; Roberts et al. 2017; Sirugo et al. 2019). Documented barriers to genetic testing are limited awareness of genetic testing among those from minority racial and ethnic groups, including those who are Asian, Hispanic, and African American, as well as those with lower annual household income, lower levels of education, and limited health insurance (Mai et al. 2014). In addition to limited awareness of genetic testing, there is also limited knowledge about what genetic testing entails in minority populations (Canedo et al. 2019; Catz et al. 2005).

Prior research indicates that Latinx (gender-neutral use of Latino/a and Hispanic) individuals can face significant burdens in accessing healthcare services, including cancer genetic testing, due to factors such as lower health literacy, inadequate health insurance, and language barriers (DuBard and Gizlice 2008; Kaphingst et al. 2011; Sussner et al. 2015). Notwithstanding these well-documented barriers to genetic testing, underserved populations have reported interest in receiving genetic testing. Although research is limited, in prior studies, Latinx communities have expressed positive attitudes and interest towards cancer genetic testing, prenatal screening, and newborn screening (Catz et al. 2005; Hann et al. 2017; Kaphingst et al. 2015; Sussner et al. 2015). These various studies found Latinx members in the USA had positive attitudes towards prenatal and *BRCA* genetic testing with preventing disease as the main advantage, and were interested in testing, especially in the context of results benefiting their family. Despite interest in genetic testing, Latinx patients can experience more confusion and misunderstanding when presented with risk information for cancer and within prenatal settings (Etchegary et al. 2008; Joseph et al. 2017; Kamara et al. 2018). Possible reasons that may contribute to greater misunderstandings are healthcare providers who specifically care for Latinx populations are not as knowledgeable about genetics, the use of interpreters, and lack of effective communication (through culturally appropriate Spanish-language materials, *promotoras*, etc.) about the purpose of tests (Cheema et al. 2021; Joseph et al. 2017; Kamara et al. 2018; Vapiwala et al. 2021). To develop better communication strategies, research is needed to investigate current perceptions about different types of genetic testing more fully among Latinx members as a way to increase access through targeted culturally appropriate interventions.

To an even greater extent than for Latinx communities, there is a general lack of health research focusing on Pacific Islander communities, meaning individuals having origins from the Pacific Islands (e.g., Guam, Tonga, Samoa) (Aragones et al. 2014; Cook et al. 2010; Hu et al. 2016; Paniagua and Taylor 2008). In Utah, a state with a substantial Pacific Islander community (1.1% of the total state population compared to the 0.5% in the USA, with Salt Lake City having 85% of Pacific Islander share in surrounding counties; U.S. Census Bureau, 2019), the Utah Department of Health Office of Disparities documents that individuals from Latinx and Pacific Islander communities are more likely to be uninsured, in poverty, and unable to access healthcare due to costs compared with White populations (Utah Department of Health 2016). There has been limited research on the perceptions of genetic testing among Pacific Islanders (Kaphingst and Goodman 2016), despite some Pacific Islander communities having successfully been engaged into donating biospecimen samples for research and biobanking (Kwan et al. 2020; Ma et al. 2014; Tan et al. 2019; Tong et al. 2014). Prenatal screening is often the first experience that the public has with genetic testing; yet, Latinx and Pacific Islander populations both often present late to prenatal care and are unable to utilize early prenatal screening (Eichmeyer et al. 2005; Etchegary et al. 2008; Utah Department of Health 2015). One older study reported interest in receiving cancer genetic counseling and testing among Pacific Islanders (Glanz et al. 1999), while another study focused on perceptions of research found distrust of health and genetic research in the Hawaiian community (Fong et al. 2004). A sense of obligation and service to the broader Pacific Islander community with respect to potential genetic testing results has been noted for the US-, New Zealand-, and Australia-based populations. Based on this sense of collectivism, Pacific Islanders have been found to be more willing to participate in genetic testing as a way to help their communities maintain good health and well-being (Kowal et al. 2015; McElfish et al. 2017; Port et al. 2008). Despite

these findings, there remains a dearth of genetic counseling research focused on Pacific Islander populations, especially when differentiating the various types of genetic testing. As such, there is a need to further explore current Pacific Islander perceptions of different types of genetic testing as a way to increase knowledge of and access to the technology.

Because data on perceptions of different types of genetic testing in racial and ethnic groups other than non-Hispanic Whites is limited, this investigation will help fill gaps in knowledge regarding these perceptions. We will also explore whether and how perceptions may vary across racial and ethnic groups. Exploration of perceptions of genetic testing provides an opportunity to inform the development of culturally competent approaches for working with diverse populations who may benefit from genetic counseling or testing services (Hudson et al. 2015; Kaphingst et al. 2011; O'Daniel 2010; Sussner et al. 2011) and engaging those in underserved populations (Rodríguez et al. 2017).

Materials and methods

The present analysis utilizes data from a larger qualitative study examining family communication about health (Canary et al. 2019; Pokharel et al. 2020). This analysis will focus specifically on data regarding perceptions of different types of genetic testing, which have not previously been reported.

Participants

Participants were recruited in Salt Lake City, with electronic and paper flyers distributed through university academic departments, at community centers, through local Pacific Islander social organizations, and word of mouth. The sample included 60 individuals from 30 family dyads, with ten of the dyads from each of three US racial and ethnic groups: White, Latinx, and Pacific Islanders. The purposive stratified sample was so that we could investigate differences in themes by race and ethnicity. Although we used Hispanic/Latino in our initial intake form, we are using the term Latinx (gender-neutral Latino/a) as an umbrella term to identify self-reporting Latinx individuals (Vidal-Ortiz and Martínez 2018). These groups were selected as they have the sizeable representation within the state in the intermountain west region where this study was conducted. The dyads included various family member combinations consisting of siblings (i.e., sister/sister, brother/brother, sister/brother) and parent–child (i.e., mother or father with daughter or son). All participants were 18 years of age or older and spoke English. Participants were given $50 gift cards to local retail stores as thanks for their participation. The University of Utah Institutional Review Board approved the project.

Data collection

Data were collected through in-depth qualitative semi-structured interviews with each participant separately and then together in a dyadic interview. We used dyadic interviews in order to examine family communication about health risks. Dyadic discussions of the various testing were limited, and thus much of the data presented here come from individual interview sections rather than the dyadic portions. Participants first completed the informed consent process, including a short introduction to the study. The first person interviewed was the individual that contacted the research scheduler. While the first participant was in the interview, the second member of the dyad was in a different room reviewing two different family health history tools and completing demographic items. The second person was then interviewed while the first participant reviewed the tools and demographic items. Finally, the family members were brought together for a dyadic interview. Trained interviewers used a semi-structured interview guide, so that the interviewer could follow the flow of conversation and could use probes to encourage participants to expand upon their answers. After the interview, audio-recordings were sent to a professional transcription service for verbatim transcription. All identifying information were removed during the transcription process. Interviews were an average of 90 min total (10 min for the consent process, including consent for audio-recording and introducing the study, 20 min for each individual interview, and 40 min for the dyadic interview).

Data included in the present analysis were collected in both the individual and dyadic interview components. The individual interview components included data generated by two questions related to genetic testing for adult-onset conditions (Table 1): "Some people are interested in receiving information about diseases that they might get in the future from a test of their genes, so would you be interested in receiving this type of test in the future to learn more about your risk of getting diseases like cancer and Alzheimer's? Why (Why not)?" and "If your genes are tested, this information also gives you information about the risks that your family members may get certain diseases. Would you share the results you get from genetic testing with your family members? Why (Why not)?".

Dyadic interview components included in this analysis were questions related to perceptions of prenatal and newborn screening. We asked about prenatal testing and newborn screening in the dyadic component of the interview in order to capture any dyadic discussion about these risks. Interviewers would first ask participants their opinions on prenatal screening and only probe for knowledge if participants seemed confused or responded with a question. We provided a definition of prenatal screening if asked. The question relating to newborn screening was "All babies

Table 1 Interview questions from which data for this analyses were generated

Interview Guide	
Introduction to questions: Finally, I would like to ask you about your interest in receiving information about disease risks for you or your family members	
Question 1:	Some people are interested in receiving information the disease that they might get in the future from a test of their genes. Would you be interested in receiving this type of testing to learn more about your risk of getting diseases like cancer or Alzheimer's? Why (why not)?
Question 2:	If your genes are tested, this information also gives you information about the risks that your family members may get curtain diseases. Would you share the results you get from genetic testing with your family members? Why (why not)?
Introduction to questions: Now I would like to ask you a few questions about any experiences that you or your family members may have had with some specific types of genetic tests. If you have not been pregnant or had a partner who was pregnant, you may not have thought a lot about these tests, but I would still like to hear your thoughts	
Question 3:	During early pregnancy some women have prenatal screening done. What are your thoughts about prenatal screening? [If they have not heard about prenatal screening please provide this information: Prenatal screening tests if an unborn baby has an increased risk for types of genetic or physical problems. This is usually done with a blood sample from a mother and an ultrasound] Probes: →Why do you think some women would want to have this done? →Why do you think some women wouldn't want to have this done? →How do you think the information might be useful?
Question 4:	All babies receive newborn screening right after birth. This is a state mandated test, which means that everyone has it done. The reason for this screening is that when a baby is born and looks healthy, there may be other problems. If these problems are found within the first weeks of life, then medical treatment can prevent the baby from having problems in the future Probes: →Why do you think some parents would want to have newborn screening done? →Why do you think some parents would not want to have newborn screening done?

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Data analysis

We developed an initial codebook based on the interview guide and previous literature on genetic testing for adult-onset conditions, prenatal, and newborn screening, as described above. During the development of the codebook, a detailed description and examples for each code were included. An iterative process of coding and team discussion was used to refine the codebook. The initial codebook was revised several times with the entire collaborative team before beginning coding. We used the participants' thought unit or sentence as the unit of analysis. After the codebook was finalized, a single coder coded the set of transcripts, and a separate coder independently coded a randomly selected 20% of transcripts in order to calculate inter-coder reliability. For dual-coded transcripts, analysis was based on consensus codes. Kappa coefficients ranged from 0.66 to 1.0 across all final codes. Annotations and memos were utilized during the coding process to document coder thoughts and potential exemplar or discrepant quotes. Collaboration with other members of the project team was utilized in each step of the coding and analysis process. This process was useful in establishing credibility while also checking that the researchers were aware of biases, perspectives, and assumptions about the coding and analysis (Lincoln 2007). We first identified themes overall, and then investigated how the themes differed by racial and ethnic group and type of genetic testing.

Results

Study participants

Demographics of the participants are shown in Table 2. Participants ranged in age from 18 to 74 years old with an average age of 35 years, with 62% being women and 48% were married. In terms of religious affiliation, 63% were Latter Day Saints, 18% had no religious affiliation, and 10% were Catholic. The majority of participants (92%) had at least some college education.

Table 2 Participant demographics ($n = 60$)

Gender	N (%)
Women	37 (62%)
Men	23 (38%)
Race*	
Caucasian/White	35 (58%)
Pacific Islander	19 (32%)
Native American	2 (3%)
Other	7 (12%)
Ethnicity	
Hispanic	20 (33%)
Non-Hispanic	38 (63%)
Unknown	2 (4%)
Age categories	
18–22	13 (22%)
23–29	19 (32%)
30–49	16 (26%)
50–74	12 (20%)
Formal education	
Some H.S. or less	2 (4%)
H.S. degree/GED	9 (15%)
Some college/associate degree	23 (38%)
College degree	11 (18%)
Some graduate classes	9 (15%)
Graduate degree	6 (10%)
Years in the USA†	
Mean	24.5 years
Range	(1–53 years)
Religion	
Catholic	6 (10%)
Latter Day Saints	38 (63%)
Other	5 (8%)
No religious affiliation	11 (19%)

† Only respondents who migrated to the US are noted in the "Years in the USA" variable

*Race is not mutually exclusive (some of the participants noted multiple races)

The themes related to participants' perceptions toward genetic testing are described below. The major themes were knowledge as empowering, knowledge as stressful, and predictive nature of prenatal and newborn screening. For the first two themes, we have further organized them into sub-themes related to the different types of genetic testing (i.e., genetic testing for adult-onset conditions and prenatal testing/newborn screening). Although prenatal testing and newborn screening are distinct, participants viewed them similarly; and thus, they are combined in the presentation of the findings. There were also little discussions of prenatal and newborn screening between members of the dyad, so included data are often from the two individuals rather than the dyad. Subthemes under these major themes such as collectivism and familial health are also described. Exemplar quotes with the participant's family role, community to which each participant belonged, and the type of genetic testing to which they were referring are provided below to illustrate the themes. When differences in themes were observed by race and ethnicity, they are noted below.

Knowledge as empowering

Adult-onset genetic testing as empowering

Across all three types of genetic testing, a major theme was that information from genetic testing could be used for preparation and/or prevention and was empowering for participants. Some participants noted that knowledge from genetic testing for adult-onset conditions could be used to be healthier by using prevention options such as cancer screening or to prepare for a condition such as Alzheimer's.

> Well, I mean, if that's something that's going to happen to you in the future it would be good just to know, and if you were to know something like that beforehand you could probably try to look at preventative things. If you knew beforehand if there are such things that can help you with the prevention and also just preparation for things like that. (Mother 2401/2402 – Adult-Onset GT, Pacific Islander)
>
> Just so you can be prepared for the future, and then if--now it's better to catch it earlier, you know what I mean? Plan for it and just do things to prevent diseases like that. (Brother 801/802 – Adult-Onset GT, Latinx)
>
> You know, I want to live the healthiest life I possibly can, so if there are things that I can do then I've always felt like we've always--our principle has been stay on top of it. Get as much information as you can so that you can make an educated and informed decision about what to do. So we've been very proactive, not reactive. (Mother 701/702 – Adult-Onset GT, White)

Meaning for family and collectivism

Participants from all racial and ethnic groups mentioned that knowledge from genetic testing would be useful for both their family and their personal futures. However, most Pacific Islander and Latinx participants generally reflected a greater interest and sense of obligation to tell their family members about their results, especially if a positive result was found. These participants indicated that the results would be useful to inform their family members of a potential risk so that their family members could have the opportunity to be proactive in regard to a potential disease/health condition via preparation and/or prevention (be proactive, and not reactive). Most Latinx and Pacific Islander participants said they felt a duty to tell their family about their results.

> Because they probably don't have any idea, and so having this knowledge, I feel like I would have a duty to tell them and make health issues a--we're discussing family health issues. Just make a big talk out of it and address it and see what we can do to promote healthiness. (Sister 801/802 – Adult-Onset GT, Latinx)
> Because we share that. Even though we have different things in our DNA, we share that common ancestry. We share the same blood, in essence. They would want to know just as much as I would want to know, or I would hope that they would, so that--depending on--whatever they chose to do with it is fine, but I would feel it almost my duty, my love for them, to pass that on and have them know what I know. (Sister 2 1801/1802 – Adult-Onset GT, Pacific Islander)

In contrast, many White participants noted they would want to share results with their family members but would only do so if their family members wanted to know their results. Our participants often cited that the knowledge from the results may be perceived as stressful, as in the second major theme described below, and that the results may be burdensome to disclose.

> If they wanted to know. I don't think I'd be intrusive and force the information upon them, but if they felt like they wanted to know, I would share that with them. (Mother 701/702 – Adult-Onset GT, White)
> I guess, before I did the thing, I would ask them--I would tell them that I was getting genetically tested, and say--ask them whether they would want to know, because... I guess, in my own personal ethics, I would want to tell them, but I can recognize that maybe some people wouldn't (Sister 1 1101/1102 – Adult-Onset GT, White)
> I guess if they wanted it. I wouldn't want to force it on them. I wouldn't want to be like guess what because I mean that's been happening since I don't know how long with my dad and that hasn't been a pleasant experience. (Daughter 301/302 – Adult-Onset GT, White)

Therefore, respect for privacy and desire to protect family members from burdensome information appeared more common among White participants for this theme, whereas Pacific Islanders and Latinx participants noted a sense of duty and obligation to tell their family as a way to mitigate potential risks.

Uses of prenatal testing/newborn screening

For prenatal and newborn screenings, participants highlighted how the use of the information could help with preparation for a child, should a particular genetic condition arise.

> It helps the parents see if there's anything they need to be worried about or any health risks for the child. Knowing ahead of time. And if you know, you can help prevent it. (Daughter 2301/2302 – Prenatal GT, Pacific Islander)
> That's helpful I think for sure... to detect problems, and then they can help…It'll help your doctors to more efficiently take care of the patient. (Daughter 901/902 – Newborn GT, White)
> It's better knowing than not knowing, you know what I mean? Just so you're aware of what can happen and what steps you should take, all that (Brother 801/802 – Prenatal GT, Latinx)

Termination of pregnancy and the use of these tests to inform reproductive decision making were also mentioned but only by some Latinx and White participants, not by any Pacific Islander participants. While these participants noted that tests were empowering for making reproductive decisions, there were mixed opinions on whether termination would be an actual option after learning information from prenatal screening.

> Now it wouldn't be letting die, it would be like, 'Okay, well, I guess we'll have an abortion then.' But I mean, that's a gross moral and ethical problem, though I don't think that that possibility of that existing should prevent us from advancing our knowledge and information and capabilities of identifying the child. Yeah, I think that they seem good. Yeah. (Son 3001/3002 – Prenatal GT, Latinx)
> Well I had it done because all the prenatal tests that they do that are just standard kept coming back that my baby was going to have Down Syndrome and my husband was like, 'We can't have a baby that has problems like that.' And then on me, there's the, well, I don't believe in having an abortion. So we had to

> research farther and farther which led us to genetic testing. And I felt like well, even though I wouldn't have an abortion regardless, I think it's important for us to find out because then we could at least prepare ourselves and if it was something that he didn't want to deal with then we could have dealt with all of that... (Sister 1301/1302 – Prenatal GT, White)

Despite the moral and ethical dilemma perceived by some participants regarding pregnancy termination, most of these participants did see utility in genetic testing in these settings as a form of empowerment via reproductive decision-making and knowledge regarding potential health conditions of a future child.

Knowledge as stressful

Anxiety, actionable, or abstention

Another major theme related to genetic testing was that the majority of participants felt that some information gained from genetic testing would cause stress, worry, fear, or anxiety. This was seen across all three types of genetic testing and we did not observe a difference in this theme by race/ethnicity. A few participants indicated that they were ambivalent about the decision to pursue genetic testing through weighing the benefits and limitations of the test.

> I don't know, I kind of don't really think so, I don't know though. I mean when you first say it to me, I'd say no…Because if it's there, it's going to happen anyway, so do I want the emotional and mental stress that it brings? But then the other side could be, I could help future generations. So I think it's just something you have to consider and think about and weigh, weigh it out. (Mother 2501/2502 – Adult-Onset, Pacific Islander)

Other participants noted that they would be interested in tests related to conditions for which there are actionable steps (e.g., behavior change, prophylactic survey), primarily in relation to genetic testing for adult-onset conditions. Most participants noted they would want to be selective about which type of information they would receive, often based on whether the condition could be prevented. Most of these participants indicated that they would pursue testing for cancer because there is a possibility for early detection and potentially prevention, rather than an unpreventable condition such as Alzheimer's or Huntington's diseases.

> I don't know, are these things preventable, cancer and Alzheimer's, are they?... Right now I would say no [to testing], but if it arose and I had the information, I probably would, if something came up, but yeah… I don't know, yeah, genetic testing seems, it doesn't seem like there's anything you can prevent with genes, so I don't know. Is it really prevention, I'm not sure that it's prevention. (Daughter, 2501/2502 – Adult-Onset GT, Pacific Islander)
>
> I think a lot of those things I don't know if there's really much I can I can do to control it. I mean like yes, you can avoid smoking and smoking has lots of carcinogens. But like you can't avoid pollution…I think it would just cause more stress for me and more like I don't think and maybe for other people this isn't the case. I think there are some people that might be like motivated to like oh I'm going to get Alzheimer's, I'm going to start doing brain exercises or something. I don't think it would motivate me. I think it would just freak me out… I think, for me it just comes down to is this useful information? Is this something that we see okay this is something that can be prevented. This is something that can be managed. (Daughter 301/302 – Adult-Onset GT, White)

Some participants said that all testing, but especially adult-onset testing would be too stressful and they would not want to undergo genetic testing.

> Because then I'll just sit and wait for it to come. And I'm the type of person that just is too empathic. If I think somebody is sick and I start watching myself I think stop it, you're not the one sick. You know, stop doing the symptoms. No, no, I wouldn't want to know that. (Mother 301/302 – Adult-Onset GT, White)
>
> No [to Adult Onset testing question from interviewer]… I think it would make my anxiety worse, one more thing to worry about. (Sister 401/402 – Adult-Onset GT, Latinx)

Predictive nature of prenatal testing and newborn screening

The third major theme was of the predictive nature that prenatal and newborn screening have, which was found across all participants. Yet, some participants confused prenatal testing and newborn screening with other tests done during pregnancy while others asked what prenatal testing and newborn screening were. Many participants, approximately half, did not understand what prenatal testing and newborn screening were and asked for an explanation. This emergent finding indicates that confusion and/or an unawareness of the differences and purposes of each type of test (i.e., prenatal testing and newborn screening) was seen across all three racial and ethnic groups, and there were no differences across groups with many asking for clarification on what these tests entailed.

Despite this limited awareness, once provided with an explanation, all participants generally viewed prenatal and

newborn screening positively, often noting that if their children are found to have a condition through newborn screening then they are going to prepare by living a healthier lifestyle or taking other recommendations from healthcare providers.

> I think regardless of the outcome of a prenatal screening, I would love a child regardless of disabilities or impairments and things, but I think they are beneficial for future history, for parents who would want to know or educate themselves on what they could do to be better parents as their child--if they know that a child is going to be born with Down's syndrome they can do research and educate themselves right from the start. (Sister 2 1801/1802 – Prenatal GT, Pacific Islander)
>
> Yeah, I think it's really helpful to let you prepare for like if your kid's going to have a disorder, then you can learn more about it before you—it's like not sprung on you, I guess. (Daughter 501/502 – Prenatal GT, White)

Among all participants there appeared to be a general understanding that having a family history of a condition increases one's personal risk for an adult-onset condition, although they had less understanding of how prenatal screening and newborn screening operate.

Discussion

Currently, genetic testing is utilized in the USA mainly by those who are White and educated, and have higher socioeconomic status (Landry et al. 2017). In order to benefit public health and reduce health disparities, genetic counseling research with underserved populations is needed to explore similarities and differences between population subgroups (Hudson et al. 2015; Kaphingst et al. 2011, 2019; Sirugo et al. 2019). Additionally, there is a need for genetic counselors as well as other genetics providers to develop and utilize culturally tailored tools for engaging patients across racial and ethnic groups (Hann et al. 2017). The major findings reported in this study demonstrate knowledge as both empowering and stressful with an overall lack of awareness of prenatal testing/newborn screening. Yet, participants did recognize the importance of its predictive nature and showed more similarities than differences in perceptions of these different types of genetic testing between participants from the three racial and ethnic groups. Even through the use of dyadic interviews, individual responses and combined responses did not differ significantly, but rather often reinforced their perceptions among all the racial/ethnic groups. These data on existing perceptions of genetic testing, noting where differences exist, can be used to engage patients from different racial and ethnic communities as a way to better increase access through improved informed decision-making processes to genetic testing.

Many studies have supported the idea that knowledge gained from genetic testing for adult-onset conditions may increase motivation for risk reduction or preparation for disease-onset (Cameron et al. 2012; Kaphingst et al. 2015; Sussner et al. 2015; Vadaparampil et al. 2010; Waters et al. 2016). Related literature has also supported the idea of genetic testing creating "knowledge [that] is power," which is consistent with our finding of knowledge as empowering (Hall and Olopade 2005). Hall and Olopade (2005) go on to note that through increasing one's knowledge of their cancer risk, more precise estimates of risk can be provided and interventions (clinical or behavioral) can be implemented to mitigate this risk. The phenomenon of using information from genetic testing to empower health decisions is most widely described for genetic testing for adult-onset conditions, such as cancer (Hall and Olopade 2005; McBride et al. 2010; O'Daniel 2010; Sheppard et al. 2014). However, prior research has found that genetic testing has also been noted as empowering for informed reproductive decisions via prenatal testing for women and parents from White and non-White racial minorities groups (Etchegary et al. 2008; Hasegawa et al. 2011; van den Berg et al. 2006). In other words, regardless of racial/ethnic identity, the vast majority of individuals recognize the power genetic testing has for not only adult-onset conditions, but also how results can empower reproductive decisions. Additionally, others have noted that knowledge gained from genetic testing can increase self-efficacy and confidence in preventative and/or preparation health decisions among Black and Latinx populations; however, the majority of this literature has only examined genetic testing for adult-onset conditions, not prenatal or newborn screening (Bellcross et al. 2015; Conley et al. 2019; Kessler et al. 2005; Komenaka et al. 2016; Lagos et al. 2008).

Our findings add to the existing literature in showing similarities and differences in this theme between White, Latinx, and Pacific Islander communities. Overall, the themes were similar across these groups, but subtle differences did emerge. In particular, we found that most Pacific Islanders and Latinx members in our study viewed genetic testing more as a family-focused and collectivist tool compared with Whites who viewed it more individualistically through respect of privacy and autonomy of others. Collectivism generally is understood as a set of feelings, beliefs, behavioral intentions, and behaviors related to solidarity and concern for others (Triandis 1999). The greater family focus in how knowledge from genetic testing may be empowering may stem from more collectivist orientations among the cultural groups included in our study. Among the Pacific Islander participants, providing genetic risk information to their family members was described as a benefit of genetic

testing. Prior work has shown that Native Hawaiians often view their family unit as nuclear family, extended family, and friends, termed collectivistic; this view of family influences a collective and family focused decision-making as it relates to healthcare (Lassetter and Baldwin 2005; Paniagua and Taylor 2008). In a separate analysis of these interviews related to family communication roles and patterns, we observed that, among Pacific Islanders, the oldest daughter within a family typically acted as the central point for maintaining family health history information and, within a collectivist framework, could potentially be a central figure in a culturally targeted intervention (Pokharel et al. 2020). Latinx communities similarly tend to have collectivist cultures and be family focused (Aragones et al. 2014; Vargas and Kemmelmeier 2013), suggesting that interventions to increase awareness of and access to genetic testing should have a family focus. Consistent with these foci, most Pacific Islander and Latinx members mentioned a sense of duty and obligation to report their results or any new information to their family members as a way to encourage their health and well-being as a collective unit. This may be an important framework to further explore among broader populations as well as testing its efficacy in improving informed decision-making processes for genetic testing and prompting behavior change. Previous research in the Pacific Islander communities of the New Zealand Maori and indigenous Australians, which though a particular subethnic group still represents an important Pacific Islander community in shared culture, values, etc., provide additional insight into how collectivism is a useful initial framing for informed decision-making that can also be tailored to the individual (Kowal et al. 2015; Port et al. 2008). Being flexible and practical, building rapport with longer visits, and recognized family structures were identified as important factors in delivering care (Kowal et al. 2015) and can be adapted to various Pacific Islander and Latinx communities. Family-level interventions have also been shown to be successful in other cultures in contexts such as helping families manage chronic conditions and cancer risks and have promise as a way to engage with racial and ethnic minority populations (Goergen et al. 2016; Koehly et al. 2015; Koehly 2017; Lin et al. 2017; Wang et al. 2020).

White participants in this study did recognize the importance of sharing results, but many said they would only share their results if their family members wanted them. Participants cited a desire to not put undue stress or worry on their family members with information gained from genetic testing. This is similar to findings from Europe, Australia, and the USA as reasons patients who undergo genetic testing are hesitant to share high-risk results with family members as a way to respect their autonomy and right not to know (Dugan et al. 2003; Gallo et al. 2010; Mendes et al. 2016; Stol et al. 2010). Sharing testing results can help family members determine their own cancer risks and is generally useful for all possible genetic test results (positive, negative, or VUS results). The recommendations note of the importance of only providing results to family members if they want to know as a way to ensure respected decision-making. This is an intriguing line of inquiry and one we would encourage researchers to further investigate. Compared to White participants, our findings among Pacific Islanders and Latinx members appear to reinforce the collectivist framework and could be an important value and perception to highlight for genetic counselors when delivering services.

Although participants generally felt information generated by genetic testing as empowering, some participants said that they would want to select the type of information learned from genetic testing, giving a sense of control over the knowledge. Those participants were less interested in information about neurological conditions that cannot be prevented such as Alzheimer's disease or Huntington's disease, and had more interest in information related to cancer, which was perceived as more preventable. This is consistent with other prior literature showing the greatest levels of interest in actionable results among adult-onset conditions (Hitch et al. 2014; Kaphingst et al. 2019; Yu et al. 2014). These findings suggest that some participants may view genetic information related to preventable disease as more empowering.

Many participants noted how knowledge from genetic test results could also be stressful, leading to emotions such as anxiety, stress, worry, and fear. Anxiety, distress, and other psychosocial outcomes are commonly investigated in research on communication about cancer genetic testing (Kaphingst et al. 2019), although this research has often found minimal levels of negative emotional responses that are short-term (Butow et al. 2003; Frieser et al. 2018; Heshka et al. 2008). Across groups, specifically racial/ethnic minority groups, a recent systematic review found that African American and Latinx communities had more concerns not only of potential return of genetic results, but also concerns of privacy of data, costs of precision medicine, and the potential for more harm than good when compared to White communities (Canedo et al. 2019). Interestingly, we did not find increased concern for genetic testing among most of our Latinx participants, but this could be due to the fact we included only English-speaking participants, who perhaps are more acculturated and more accepting of novel technologies for healthcare (Landry et al. 2015). While we did find within the study cohort the potential for knowledge to be stressful and the desire for potential control over knowledge, this could inform genetic counselors' practice. For example, genetic counselors could ask patients what information they want to learn and their perceptions of the benefits of genetic testing to help inform the potential clinical or individual interventions that could mitigate risk for particular

adult-onset genetic conditions. Especially for pregnancies, it could prove powerful for genetic counselors and other healthcare providers to have the ability to communicate the purpose and importance of prenatal and newborn screening to patients to ensure a health pregnancy and preparation for a newborn.

However, it appears that knowledge about prenatal and newborn screening, including the purposes of those screenings, was limited among all participants and did not differ substantially across the three racial and ethnic groups. Lack of knowledge about genetic testing has been a consistent problem in many healthcare contexts, including contexts that discuss prenatal and newborn screening (Botkin et al. 2016; Catz et al. 2005; Haga et al. 2013; Ostergren et al. 2015), consistent with our findings. Several studies have shown important gaps in the public's overall understanding of genetics. For example, those that are familiar with terms related to DNA and genes still tend to have knowledge gaps regarding the concepts underlying the terms (Krakow et al. 2017; Lea et al. 2011; Ostergren et al. 2015; Smit et al. 2016). Another study among non-Hispanic White participants with at least some college found that only 60% of those receiving usual obstetric care felt completely or mostly satisfied with the information received about newborn screening (Botkin et al. 2016). Another study found that African American and Latinx women were 56% less likely to know about prenatal and newborn screening in a clinical setting when compared to White women (Bryant et al. 2015). Comparing knowledge of genetic testing in the general public, Whites were 74% more likely to know about genetic testing than non-Whites (Haga et al. 2013). We found fairly consistent gaps in knowledge about prenatal and newborn screening across both our White and racial and ethnic participants. Notably, although the participants in this study were fairly highly educated, with 92% having some college and speaking English, almost half needed explanations of prenatal testing in the interview. While it is encouraging that the participants viewed prenatal and newborn screening positively, our finding of a consistent lack of knowledge of the purpose of these tests further highlights the need for education of the general public about different types of genetic testing and that better educational approaches are needed for prenatal testing and newborn screening in healthcare provider visits. Other opportunities for education beyond healthcare settings could also be explored, such as community-based education.

As with all qualitative data, these findings are not intended to be generalizable to a larger population. All three racial and ethnic groups can be quite heterogeneous in the population and in fact have sub-ethnicities within each group (i.e., Mexican, Cuban, Puerto Rican, etc., among Latinx; Tongan, Samoan, etc., among Pacific Islanders) with distinct demographics. Additionally, our sample was well educated and is not representative of the broader Latinx or Pacific Islander populations. According to the U.S. Census, 12% of Latinx and 16.4% of Pacific Islander individuals hold a bachelor's degree (U.S. Census, 2019), compared to our study participants of whom 18% had at least a bachelor's degree with an additional 25% having some graduate education or holding a graduate degree. Further disaggregated, 38% of our Pacific Islander participants had a bachelor's or graduate education, and 48% of our Latinx respondents had a bachelor's degree or had some graduate education. These findings can be explored in larger quantitative studies that can further investigate differences by sub-ethnicity and other factors. Examination of differences by sub-ethnicity will be important in future, larger quantitative studies as it has been suggested that if these sub-ethnic demographic differences are not well understood health disparities will continue to persist through failed broad assumptive generalized intervention approaches (Aragones et al. 2014). Individuals with lower education attainment or those who are less acculturated may have different perceptions than the participants in this study. Interestingly, testing costs and health insurance were not barriers or issues brought up by the current study participants. This finding perhaps highlights the class gap that may exist between these groups and sub-groups via income and/or education level. It could also highlight the improving access to genetic testing by decreased out of pocket costs and increased insurance coverage (Mardis 2011; Wetterstrand 2020). Additionally, since the interviews were conducted in English, the results likely do not represent those from other language groups. In addition, we only examined perceptions at one point in time. Research could examine how perceptions about genetic testing change over time or in response to educational efforts and what barriers exist for other sub-ethnicities within larger ethnic groups.

We found within the study cohort the potential for knowledge to be stressful and the desire for potential control over knowledge as well as a general lack of knowledge about prenatal and newborn screening, and this could inform genetic counselors' practice. In clinical practice, this information can be used for pre-test counseling as an opportunity to include race and ethnicity into case preparation in addition to medical and family history. For example, in an oncology setting, it is valuable to know that a Pacific Islander patient may view providing genetic testing information to family as a benefit of the testing and this knowledge may be useful for the discussion about impacts of genetic testing with this patient. For prenatal genetic counselors, pre-test counseling preparation could include a reminder to inform patients, regardless of race or ethnicity, of the purpose of both prenatal and newborn screenings. In addition, it may be helpful if other healthcare providers, such as gynecologists and primary care practitioners, discuss the purposes of prenatal and newborn screening. Another applied clinical example is for genetic counselors to use this information during contracting

or during risk assessment to ask patients what information they want to learn and/or their perceptions of genetic testing. This may be a more generalizable recommendation as it applies to genetic counselors who practice in oncology and prenatal as well as other medical specialties, such as nursing and/or midwives. Genetic counselors who provide more culturally appropriate genetic counseling may improve decision making regarding various forms of genetic testing and screening as well as outcomes of genetic counseling, such as cascade testing for family members and adherence to screening plans, through better communication of risk and testing. Additionally, through these targeted questions, genetic counselors, nurses, and midwives are able to tailor management recommendations or the discussion about benefits/limitations of genetic testing, treatment options, and/or birthing plans as a way to address the patient concerns while respecting their cultural beliefs and autonomy.

Conclusion

Genetic testing should benefit individuals of all race and ethnicities in order to close rather than exacerbate health disparities. The potential benefits of specific types of genetic testing are well studied, such as for prevention for hereditary cancer syndromes and treatment of conditions detected in newborn screening (McBride et al. 2016; Reif et al. 2017). Yet, there is limited research on perceptions of different types of genetic testing across population subgroups. This study presents qualitative data on the perceptions of genetic testing (newborn screening, adult-onset testing, and prenatal testing) and how these perceptions presented themselves in a sample of participants from Pacific Islander, Latinx, and White communities.

We found that perceptions of three types of genetic testing were more similar than they were different between our US racial/ethnic groups. We also observed a consistent lack of knowledge about prenatal and newborn screening. It is unclear when and who the best persons would be to communicate the purpose of prenatal testing and newborn screening, but the results of this study suggest that increased communication and education about these tests would benefit all racial/ethnic groups. Since this lack of knowledge spans racial/ethnic groups, it is worthwhile to consider a public health initiative to increase knowledge and awareness of prenatal and newborn screening. Familial and more collectivist messages could better engage US racial/ethnic minorities, in particular Latinx and Pacific Islander populations, in genetic testing fitting a culturally tailored approach. While knowledge can be both empowering and stressful, there seems to be a desire, from at least some participants, for control over what knowledge they receive as well as controlling what preventative actions they decide to take with their healthcare teams (Kaphingst and Goodman 2016). Genetic counseling sessions typically include contracting, which is important to understand their patients' expectations of genetic counseling/testing. Genetic counselors can utilize information to improve contracting to include asking about patients' beliefs and values as well as informing their discussion of genetic testing based on the subtle differences in perceptions presented here. By including these modifications to genetic counseling pre-test sessions, genetic counselors can provide more culturally appropriate and tailored information to their patients. We believe healthcare providers (including genetic counselors) have the responsibility to provide all the necessary information from genetic tests in a way that is congruent to an individuals' values and beliefs. This type of service delivery will not only provide better health outcomes for patients but will also contribute to the diffusion of culturally appropriate service delivery for racial/ethnic minorities and advance health equity.

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Availability of data and materials The data that support the findings of this study are available from the corresponding author upon reasonable request.

Declarations

Conflict of interest The authors declare no competing interests.

Statement of ethics Research involving Human Participants: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent: Informed consent was obtained from all individual participants included in the study. Approval was granted from the University of Utah Institutional Review Board.

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