


ORIGINAL ARTICLE

Pregnant Hispanic women's views and knowledge of prenatal genetic testing

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Abstract

Pregnant Hispanic women are underserved with their needs for genetic counseling, despite birth defects remaining the leading cause of infant death in the United States. We present the qualitative findings of a study to understand knowledge and perceptions of prenatal testing in a sample of hard-to-reach underrepresented Hispanic pregnant women in South Texas. The sample for this study was 10 Hispanic pregnant women who were recruited from a high-risk prenatal clinic in South Texas in 2019. The semi-structured interview questions were created based on the researchers' clinical experiences with this population and were designed to examine knowledge and perceptions of participants toward prenatal testing. Analysis of the qualitative data yielded several themes related to prenatal testing: (a) knowledge, (b) confusion, (c) partner's and support persons' opinions, (d) information sharing from providers, (e) psychological benefits, (f) preparation for baby, (g) obstacles, (h) religious influence, and (i) educational tools to assist with understanding. Women's understanding and knowledge of prenatal testing was limited, specifically regarding its purpose, how it works, the benefits, and why it was recommended by their provider. Lack of clarity about why they should take the test and its risks for them and their babies was perceived as something that could impede their acceptance of prenatal testing. All participants agreed that healthcare providers should share more information about prenatal testing in a way that uses 'everyday language' so that they can understand it better. All respondents mentioned that prenatal testing provides information about their baby's health conditions, alleviates their stress and concerns, and psychologically prepares them and their family for what is to come. Identifying ways to increase culturally appropriate education delivered by genetic counselors such as through the adoption of telemedicine and mobile technology can help fill the gap for this underserved population.

KEYWORDS

attitudes, beliefs, genetic counseling, genetic literacy, genetic testing, prenatal diagnosis, psychosocial, underrepresented populations

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1 | INTRODUCTION

Prenatal care is one of the most widely used methods of preventive healthcare in the United States (Alexander & Kotelchuck, 2001) and has been viewed as a strategy to improve pregnancy outcomes for more than a century (Reiss, 1999). The goals of prenatal care include maternal health promotion and education, psychosocial support, nutritional guidance, laboratory testing, and genetic risk assessment (Illinois Department of Human Services, 2020). Despite efforts aimed at promotion of positive outcomes for both mother and baby, birth defects are the leading cause of infant death in the US (National Center for Health Statistics, 2020).

Within the ambit of prenatal care, genetic risk assessment includes surveillance of genetic disease and birth defects through prenatal screening (Seven et al., 2017). Prenatal testing refers to elective tests that are done during pregnancy to either screen for or diagnose a birth defect. Prenatal testing is designed to assess whether a patient is at increased risk of having a fetus affected by a genetic disorder (Society for Maternal-Fetal Medicine (SMFM) et al., 2016) with the aim of providing pregnant women and their families information to make deliberate informed choices and decisions (Seror et al., 2019).

The American College of Obstetrics and Gynecology (ACOG) and the Society of Maternal Fetal Medicine (SMFM) endorse healthcare providers caring for pregnant women to offer prenatal genetic testing to all women regardless of known risk factors (ACOG, 2007; SMFM et al., 2016). Prenatal genetic screening tests give a probability that a fetus has a genetic disease or birth defect and may indicate the need for a diagnostic test (Stanford Children's Health (SCH), 2020). Screening tests for fetal anomalies include a combination of maternal serum biochemical markers (triple/quad/penta screen) in the second trimester that includes unconjugated estriol, human chorionic gonadotropin, alpha fetoprotein, and inhibin A. This screening test assesses for Trisomy 18, Trisomy 21, and neural tube defects. Other non-invasive screening tests for fetal aneuploidy that can be done in the late first or early second trimester include cell-free DNA (cfDNA) in circulating maternal blood and fetal ultrasound to assess nuchal translucency (NT) or nuchal-fold thickness (NF) (Li et al., 2018). Carrier screening is used to determine genetic carrier status of a recessive genetic disease in maternal or paternal karyotype. Prenatal diagnostic tests detect some chromosomal problems with certainty (SCH, 2020) through fetal karyotyping and include chorionic villus sampling (CVS) and amniocentesis (SMFM et al., 2016).

While most obstetric healthcare providers report offering prenatal testing to all their patients on a routine basis (Colicchia et al., 2016), prior studies suggest that many patients miss the opportunity for prenatal genetic testing and that healthcare providers may not be fully aware of prenatal testing specifics such as false positive or negative rates of screening tests (Bernhardt et al., 1998; Smith, et al., 1994). Other studies suggest that clinicians often do not ensure women's informed decision-making related to prenatal testing (Constantine et al., 2014; Farrell et al., 2011; Shea, 2020). Furthermore, many women who do undergo prenatal testing report

What is known about this topic

Birth defects are a leading cause of infant death in the United States, yet inconsistent and complex information surrounding prenatal testing options contribute to confusion and lack of informed decision-making in pregnant women. Ethnic and minority women, especially Hispanic women, are less likely to undergo prenatal testing. Clinicians often do not ensure women's informed decision-making related to prenatal testing options.

What this study adds to the topic

This paper presents findings from a group of pregnant Hispanic women with known risk factors for congenital anomalies. Genetic counselors working with Hispanic women who have risk factors for birth defects should consider cultural beliefs surrounding support persons' opinions, religious influence, and information sharing from providers when helping them to make informed decisions regarding prenatal testing.

being unaware of what the test was for or what the results meant (van den Berg et al., 2005; Moyer et al., 1999; Smith et al., 1994). Genetic counselors can play an important role in helping pregnant women, particularly those in a high-risk category for fetal genetic anomalies, to understand genetic information and help them make informed decisions (National Society of Genetic Counselors, 2020).

Patient understanding of genetic test results, whether those results are interpreted by a healthcare provider or by the patient, may be especially challenging for patients with limited genetic literacy (Hooker et al., 2014) and limited educational resources (Erby et al., 2008). Therefore, research is needed to understand and clarify influences on women's understanding and uptake of prenatal testing and whether women are making informed decisions about prenatal testing that reflect their personal beliefs and values (Shea, 2020).

1.1 | Hispanic women and prenatal testing

Prenatal genetic testing is commonly recognized in obstetric practices as a means to identify fetal anomalies during pregnancy. However, studies have shown racial and ethnic differences regarding the acceptance of prenatal testing (Browner & Preloran, 2000; Molina et al., 2019). Ethnic minority women are less likely to undergo prenatal testing than non-ethnic minority women (Fransen et al., 2009a, 2009b, 2010; Park et al., 2007). These differences are associated with factors such as cultural and religious beliefs and attitudes toward miscarriage, pregnancy termination, and childhood disability (Bryant et al., 2015; Kuppermann et al., 2006; Learman et al., 2003).

Among cultural and ethnic groups, Hispanic women are less likely to undergo prenatal testing. A study conducted by Seth et al. (2011) reported that religiosity is a key factor that has a significant impact on Hispanic women's decisions related to prenatal testing. Similarly, researchers have found that Hispanic women's knowledge about prenatal testing influences their attitudes related to acceptance of prenatal testing (Farrell et al., 2015; Griffiths & Kuppermann, 2008; Suther & Kiros, 2009). Other studies reported that nearly one-third (31.6%) of Hispanic women determined to be high-risk for fetal anomalies declined prenatal testing (Chetty et al., 2013) due to lack of knowledge and understanding (Farrell et al., 2015).

Although relatively fewer Hispanic women accept prenatal genetic testing, studies have indicated that the results of prenatal testing can offer the pregnant woman information about her baby to make informed decisions and add clarity regarding possible risks her baby may face (Grant, 2005; Tapon, 2010). Additionally, the results of prenatal testing can provide pregnant women and their families information that their baby is developing normally, help parents be prepared for having a baby with special needs, or inform parents' personal choices regarding the affected baby (Yu, 2012). Prenatal genetic testing relieves couples from anxiety and uncertainty related to the pregnancy and prepares them for their baby's arrival and potential complications (Ekberg, 2007).

Hispanic cultural norms and beliefs impact women's relationships, reproductive experiences, and healthcare decisions related to prenatal testing (Seth et al., 2011). In a qualitative study on the role of religiosity and spirituality with Spanish-speaking Latina women, 8 out of 11 participants declined amniocentesis, despite being referred for genetic counseling due to a condition putting their baby at-risk for genetic anomalies. Women who declined often reported concerns about the risks of amniocentesis, more than their religious beliefs, as their reason for declining. Nonetheless, a sense of optimism and acceptance of any outcome was more prevalent in the women who declined, reflecting their tendency to turn to their faith and belief in God for guidance and support during difficult times. For example, one participant described 'however it may be, we are going to love the baby anyway'. (Seth et al., 2011, p. 669). Additionally, the results of this study indicated that participants' faith that their baby would be healthy was driven by their religious and spiritual beliefs that the future was in God's hands (Seth et al., 2011).

Access to culturally sensitive and linguistically appropriate healthcare services that encompasses an understanding of Hispanic values may be difficult to find and are social determinants of health that contribute to health disparities (U.S. Department of Health & Human Services, 2020). Fear of the high cost of prenatal testing may inhibit the pregnant woman's decision to uptake prenatal testing (Allyse et al., 2014). Lack of knowledge and understanding of prenatal testing can complicate the decision-making and increase anxiety for families who lack information resources (Farrell et al., 2015). Religious beliefs surrounding reproductive choice and pregnancy termination can also prevent Hispanic women from choosing to accept prenatal testing (Floyd et al., 2016; Seth et al., 2011). It is the

purpose of this paper to present the qualitative findings of a study aimed at understanding knowledge and perceptions of prenatal testing in a sample of hard-to-reach underrepresented Hispanic pregnant women in South Texas. This study makes an important contribution to the literature by describing the views surrounding prenatal testing from a group of pregnant Hispanic women with known risk factors for congenital anomalies. The findings from this study represent a group of at-risk pregnant women who genetic counselors are likely to encounter through referrals from obstetric providers.

2 | METHODS

2.1 | Study design and sample

A descriptive, exploratory design was used to investigate Hispanic women's perceptions and knowledge of prenatal testing and how it influences their uptake. We used purposive sampling to obtain qualitative descriptive data (Sandelowski, 2000). The sample for this study was 10 Hispanic pregnant women who were recruited from a high-risk prenatal clinic in South Texas in 2019. There are no genetic counselors within 100 miles of the clinic, so genetic counseling for pregnant women in this underserved area is done by referral to the maternal-fetal medicine group. A list of patients with an upcoming scheduled clinic visit who were referred for genetic risks and met inclusion criteria (ages 18–45, read and speak English, currently pregnant, self-identify as Hispanic, current patient in the clinic health system) was obtained from the clinic staff. Patients were referred for genetic counseling for various reasons including, but not limited to, advanced maternal age, abnormal screening ultrasound, or family history. Patients from the list were invited to participate in this study through a preliminary phone call from the research staff (YA). For the total study, we approached 130 individuals and 36 (27%) of them agreed to learn more about the study by meeting with research staff in the provider's office prior to their regularly scheduled appointment. Four of these individuals subsequently could not participate due to transportation, childcare, and other issues. Two individuals did not meet our inclusion criteria. The remaining 30 participants enrolled in the survey portion of the study after obtaining informed consent, with a subset of 10 participating in the interview portion of the study. The interviews were designed to obtain a more detailed, qualitative understanding of how genetic literacy and support persons' viewpoints may influence the decision about prenatal testing. The qualitative findings from the interview portion of the study are the focus of this manuscript.

Those who agreed to participate in the study were met by research staff (YA) who is a male graduate research assistant who was also a doctoral candidate in the Counseling and Educational Psychology department at Texas A&M University Corpus Christi. YA met potential participants an hour before their scheduled visit with the maternal-fetal medicine specialist (RL) to complete the informed consent and the paper and pencil survey questions. The survey questions included sociodemographic information as well

TABLE 1 Demographic characteristics of study participants (N = 10)

Country of birth		Hispanic	
United States	10 (100%)	Yes	10 (100%)
Marital status		Education level	
Single, never married	4 (40%)	High school/equivalent	5 (50%)
Married/partnership, living together	6 (60%)	Associate/junior college	1 (10%)
Employment status		Some college	3 (30%)
Full-time	6 (60%)	Bachelor's	1 (10%)
Part-time	4 (40%)	Healthcare insurance	
Household income per year		Private insurance	2 (20%)
10,000 or less	4 (40%)	Government insurance	8 (80%)
10,001–20,000	1 (10%)	Religious activities attendance	
20,001–50,000	1 (10%)	Never	1 (10%)
50,001–100,000	4 (40%)	Once a year or less	1 (10%)
Gestational age, at interview		A few times a year	3 (30%)
1st Trimester	1 (10%)	A few times a month	2 (20%)
2nd Trimester	6 (60%)	Once a week	2 (20%)
3rd Trimester	3 (30%)	More than once a week	1 (10%)
Gravidity		Real-G estimated literacy level	
1–2 times	3 (30%)	4th–6th grade (22–50)	1 (10%)
3–5 times	5 (50%)	7th–8th grade (51–60)	3 (30%)
6–7 times	2 (20%)	High School (61–63)	6 (60%)
Living children			
0–1 living	40 (40%)		
2–3 living	5 (50%)		
4–5 living	1 (10%)		

as validated measures of familism, religiosity/spirituality, acculturation, and genetic literacy. Informed written consent was obtained from all participants. From those enrolled in the study, we recruited a subset of ten participants, to be interviewed using a recorded semi-structured format. The participants completed the data collection process in a private, closed-door office in the clinic. The study was approved by the Driscoll Healthcare System and Texas A&M University Institutional Review Boards.

The semi-structured interview questions were created based on the Health Belief Model's (Becker, 1974) six constructs (knowledge, benefits, barriers, risk severity, susceptibility, and self-efficacy) that predict health behavior as well as researchers' clinical experiences with this population. The interview questions were designed to examine knowledge and perceptions of participants toward prenatal testing. The interviews were conducted by YA and ranged in time from 15 to 25 min, while data collection time for both study components (written survey and interview) was approximately 60 min total. All activities were completed in a single visit. The interviews were recorded and transcribed verbatim and were de-identified for transcription, analysis, and reporting. Open-ended questions for the semi-structured interviews are presented in Appendix S1.

2.2 | Data analysis

The research team analyzed the qualitative data using Braun and Clarke's (2006) thematic analysis methodology. The analysis and coding process included reading and re-reading transcripts, generating initial codes, finding key themes, reviewing the themes, and defining the themes. This method was repeated to identify and refine themes throughout the coding process. To represent the themes, specific and meaningful quotes were taken from transcripts. To demonstrate rigor and ensure trustworthiness of the study we employed the four criteria of credibility, transferability, dependability, and confirmability of the data (Lincoln & Guba, 1985). Data were analyzed and coded independently by individual research team members before comparing findings. Cross-cultural rigor of this study was also enhanced through diversity in research team identities, independent and collective analysis.

3 | RESULTS

Participant demographic characteristics are presented in Table 1. Frequencies and means for these variables were calculated using

IBM SPSS, Version 24.0. All the participants ($N = 10$) identified themselves as Hispanic and reported that they were born in the United States. Our data indicated that six of the participants were married or living with a domestic partner, and four of them were single or never married. Additionally, six of the participants were employed full-time while four were employed part-time. The data showed that participants' household income varied, with four of the participants reporting a household income of less than \$20,000 and four reporting between \$50,000 and \$100,00. Similarly, participants' educational background varied with half ($n = 5$) of the participants having no more than high-school education, and four of them scoring 8th grade or less on the REAL-G genetic literacy scale (Erby et al., 2008). The majority of the participants ($n = 8$) had government-sponsored insurance. Analysis of the qualitative data yielded several themes related to prenatal testing: (a) knowledge, (b) confusion, (c) partner's and support persons' opinions, (d) information sharing from providers, (e) psychological benefits, (f) preparation for baby, (g) obstacles, (h) religious influence, and (i) educational tools to assist with understanding. Data saturation was evident at the conclusion of the tenth interview.

3.1 | Knowledge of prenatal testing

Women's understanding and knowledge of prenatal testing was limited, specifically regarding its purpose, how it works, the benefits, and why it was recommended by their provider. Participants reported that prenatal testing helped them to understand what was happening with their baby. It also helped them to be better prepared for any abnormalities with their baby. One of the participants described her understanding of prenatal testing in the following terms:

The only thing that I know about genetic testing is that they just told me it was 99% accurate of what may be wrong with my baby or not and so, that's why we decided to do it. Besides that, I don't know anything else about it. It just kinda gets you prepared because I guess the genetic testing is supposed to let you know if there's other abnormalities beside just the one that they were testing for.

Another participant stated, '...they test to see if there's something wrong with your baby. I've never really asked more about it'.

The majority of the participants ($n = 9$) found out about prenatal testing from their doctors or nurses without having any prior knowledge of it. Several participants described that they were told from their doctor that they needed to get prenatal genetic testing done. However, one participant stated that she was familiar with prenatal testing because she had a 4-year-old daughter with a genetic anomaly. She stated, 'whenever you have a sick baby, that's when you learn everything...'cause I didn't know this before I had a sick child'. Another participant stated that she was a registered nurse and had learned a little bit about it in nursing school.

3.2 | Confusion about prenatal testing

When asked how prenatal testing is different from other tests done during pregnancy, the majority ($n = 7$) indicated that they were unaware of genetic tests names or types, while three of the women indicated they had Spina Bifida and Down Syndrome testing. One participant stated that: 'We just did a Down Syndrome screening; we haven't done anything else'.

Probably the prenatal genetic testing would be more accurate... because they'll actually take the baby's... the screening and the diagnostic testing are different. The screening is just like screening for a certain thing and it's not that, it doesn't test for a lot of things, like a genetic testing would.

The majority of participants expressed confusion over the differences of prenatal testing such as carrier screening, aneuploidy screening, and congenital anomalies screening. For example, one participant demonstrated her confusion between carrier screening and fetal aneuploidy screening:

So, that is a little bit different because once they do the prenatal genetic testing on the mother, if they see an abnormality from the mother, sometimes they need the father to be there and get blood from him to compare the samples to make sure the baby is okay; that's a little bit different. Because before, just in pregnancy, it's just the mother that gets tested, the father doesn't really have any input; that's a big difference between the two.

3.3 | Partner's and family/friends' opinions about prenatal testing

The majority of participants ($n = 9$) indicated that although their partner's knowledge of prenatal testing was limited, they were very supportive of undergoing prenatal testing with the exception of amniocentesis and were eager to learn about it. For example, one participant indicated, 'I don't think he knows anything about it. He is supportive of anything any doctor has to say'. Although only three participants shared with their family members that they were undergoing prenatal testing, they thought their family members would be supportive of the process. One of the participants stated 'So, my mom went through it with my younger sister; she's very supportive, she understands it, so that's a good support system for me'. While three participants discussed their prenatal testing options with their peers and found them encouraging, a majority of them had not shared it because they thought their peers were not knowledgeable enough about prenatal testing to be helpful. For example, one participant stated, 'I don't think anybody really knows about it'.

3.4 | Information sharing from healthcare providers about prenatal testing

All participants agreed that healthcare providers should share more information about prenatal testing in a way that uses 'everyday language' so that they can understand it better. Providing more information about what kind of test they are taking, procedures for taking the test, its benefits, why they should take it, and its risks should be discussed by the healthcare provider. For example, one participant stated:

I know that they're going to take, like, fluid from my, I guess, the sac thing. I don't know, that part concerns me; is it safe, is it normal? I just thought that was unsafe; I just want the doctor to clarify more. They just said oh, come in and we're going to take a sample and didn't explain more about it; so, that's why I'm here as well, you know, I want them to explain more to me to see if this is safe, or is it mandatory, or is it better for the baby to take it.

3.5 | Psychological benefits of prenatal testing

In this theme, we found that respondents perceive taking prenatal testing as beneficial. All respondents mentioned that prenatal testing provides information about their baby's health conditions, alleviates their stress and concerns, and psychologically prepares them and their family for what is to come. For example, one participant stated:

I think it helps ease your mind just because you start to get all these worries based off of the blood tests and your mind starts to play tricks on you, and you start fearing the worst, and, you know, especially after being pregnant, your hormones and your emotions are just riled up, so when you are actually going for, into your appointment, it helps settle a lot of things because instead of you guessing about it, you have answers, and it's either good, or bad.

Similarly, several respondents indicated that prenatal testing results helped provide peace of mind for their baby's wellbeing. The feeling of being 'relieved' helped them feel less nervous and less anxious. One respondent expressed 'For me, I was just relieved. I believe in God and so I kinda had the feeling that I didn't need to worry, but the genetic testing just kinda gave me the affirmation that I was fine'. Several participants ($n = 6$) indicated that they took prenatal testing 'to be on the safe side' and make sure their baby is okay and healthy. For example, one participant stated 'just to make sure the baby is healthy with this pregnancy from the start, so we don't run into complications...'.¹

3.6 | Preparation for baby after prenatal testing

Respondents stated that learning about the prenatal testing results not only relieved their stress, but also gave them enough time to be knowledgeable and financially prepared to deal with a child that may have health issues. They stated their belief that it helps family and siblings be prepared for a new family member with special needs. For instance, one of the participants stated:

Well, I mean, if you know you're having a healthy baby, it kinda puts less stress. If I had some sort of previous knowledge, I could know that I had two or three months to prepare myself to deal with a child that has, you know, a heart condition or Spina Bifida, or whatever it is. Financially prepare myself, mentally prepare myself, prepare family, and siblings, if I have to.

The reason other participants underwent testing was because of fear of being a carrier of diseases such as Cystic Fibrosis due to their family history. For example, one of the participants described her main reason for undergoing prenatal testing:

I was a carrier for Cystic Fibrosis, so, when they did that, they wanted to rule out and make sure that the baby was going to be okay, which is why they sent me for that genetic testing over there.

3.7 | Obstacles to prenatal testing

Even though four of our participants reported income of less than \$20,000, none of the them expressed any financial barriers to undergoing prenatal testing. All participants indicated having health insurance, either private or government-sponsored, to cover prenatal testing. Healthcare providers using complex medical terms was perceived as a barrier to understanding and being willing to consent to prenatal testing. Lack of clarity about why they should take the test and its risks for them and their babies was perceived as something that could impede their acceptance of prenatal testing. For example, one participant emphasized how it is important for healthcare providers to use simple words to explain tests:

I think for the people that don't understand what prenatal genetic testing is, there's a lot of verbiage, like, even just reading from the list, they're not going to understand what that is. So, I think you putting it in layman's terms and simplifying it for them, might help them understand a little bit better and that would be my suggestion. They don't understand what [medical conditions are] ... If I explain it you like that, you're, like, okay, now I know what that means. But if you don't have medical background or you don't have family that has that, they're not gonna

understand what you're talking about, so they're just, like, more than likely they're going to agree; yeah, I know what you're talking about, because they don't want you to feel that they're stupid or incompetent.

3.8 | Religious influence on prenatal testing

Participants' frequency of attendance at religious activities was varied. Our quantitative data indicated that three participants participated in religious activities a few times a year, two of them a few times a month, two of them once a week, and one of them more than once a week, while one of them attended once a year or less and one of them never attended. Although the majority of participants indicated that their religious background would not influence their decision for prenatal testing, four participants indicated that they were not sure whether their religious leader or community would support prenatal genetic testing. One participant stated:

There are certain things I'm pretty sure they [religious leaders] don't like, you know, they don't really think, you know, it's right probably, and I don't think they think the genetic testing is right, but I do go about a different, you know, like I said, I do believe in a God and I praise a God, but there's certain things the Catholic church doesn't look upon, but I'm okay with not always following the rules.

3.9 | Educational tools to assist with understanding prenatal testing

In response to the question 'What kind of information would be helpful when learning about prenatal testing', the women responded that it would be helpful for them if concepts were explained in simple terms. Some examples of helpful information suggested by the participants included what specific prenatal testing is being offered, why it is being offered, and the benefits of knowing the results of the testing.

Maybe, like, kinda explain the benefits, like, this is the reason; these are some of the things that can be caught, or, what the results would be for genetic testing, based on, like, someone's health and background; I think that would be helpful. You kinda have a lot of fear based on that, which is hard, you know, but I think a lot of expecting moms have a lot of stress.

When asked specifically about learning new information about prenatal testing via a mobile application, most participants indicated that a prenatal testing mobile application would help them to reach the most accurate knowledge in an easier way. For example, one of the participants discussed the challenges of finding credible, easy-to-understand

information on the Internet. She described the advantage of having reliable, understandable information through a single source at hand via a mobile application. '*... when you look it up on Google, it's kinda scary, because it says, ...you could have a miscarriage and you could do this and that; so...having the mobile application would help them to reach accurate knowledge*'.

A mobile application would not only help pregnant women to have more information about prenatal testing and understand it better, but also would increase their family members' awareness related to prenatal testing. One participant stated, '*That would be good, because then everybody could see it, not just me, official, everybody. It'll bring awareness too*'. Furthermore, a mobile application could help increase knowledge and understanding of prenatal testing concepts and terminology for individuals with limited education. "*I think videos [on mobile application] would be good, just because there are some people that can't read; they're illiterate. So, you are explaining it to them and having videos, you know, along with brochures or poster boards explaining different things to them, is a good tool.*"

4 | DISCUSSION

The findings of this qualitative study of Hispanic women's perceptions of prenatal testing offer information on factors that may influence their decision about prenatal testing. Pregnant Hispanic women are understudied and hard-to-reach—facing many barriers to care, and these findings can offer insight for genetic and obstetric clinicians and researchers. The participants in our study represent a large geographic region including many small rural communities. Such geographic and transportation barriers, in addition to socioeconomic and cultural factors, contribute to the barriers to receiving genetic counseling, even for women with known risk factors. Underserved communities with health inequities may also mistrust and be less engaged in genomics research (Yates et al., 2020). Enhancing our understanding of the factors that influence the decision to undergo prenatal testing in Hispanic women, the themes of knowledge/confusion, support persons' opinions, psychological benefits/preparation for baby, and religious influence emerged from this study.

Other studies have indicated that Hispanic women's overall knowledge about prenatal testing is a significant factor that influences their decision to have the test (Farrell et al., 2015; Floyd et al., 2016). Findings of our research align with these studies that Hispanic women's understanding of prenatal testing, specifically regarding its purpose, how it works, the benefits and risks, is limited. Our results mirror those from previous studies that the majority of women found it challenging to recognize and identify genetic tests names or types (Dixon & Burton, 2014; Griffiths & Kuppermann, 2008). Our findings confirm Hispanic women have confusion over the differences of prenatal testing such as carrier screening, aneuploidy screening, and congenital anomalies screening, even those who have been referred to a high-risk maternal-fetal medicine specialist based on increased risk for a congenital anomaly. Participants in our study specifically indicated it would be beneficial for them to receive more information about what

kinds of tests they are taking, procedures for taking the test, why they should take it, and the benefits and risks of taking the test.

Likewise, the results of our study are in line with findings of other researchers that prenatal testing provided psychological comfort and alleviated stress of parents after they found out their results were normal (Ekberg, 2007; Tsai et al., 2017; Yi et al., 2013). Similar to the psychological relief reported in other studies, our findings suggest that learning about prenatal testing results could give parents with known genetic risk factors time to become knowledgeable about specific genetic conditions that may affect their child and be financially prepared to deal with a child that may have health issues (Ekberg, 2007; Kirkscey, 2017; Tapon, 2010; Tsai et al., 2017). Our results suggest that prenatal testing results not only could help parents but also siblings and other family members to be prepared for a new family member with special needs.

Although the participants in our study did not discuss lack of insurance coverage or financial concerns—despite several with low income—as a barrier to prenatal testing, women who are low-income may perceive a lack of ability to pay for prenatal testing even if covered by insurance. Low-income women who qualify for government-sponsored insurance may hesitate to accept what they perceive as high-cost testing options. This may be out of fear of being financially responsible for an expensive test if the insurance company unexpectedly does not pay for the testing. Immigrant women who are undocumented may also fear that acceptance of high-cost testing may impact their future ability to qualify for other government-sponsored assistance.

While most women in our study reported support from partners and family members, there could be implications for carrier screening results for blood relatives of the woman. This could become a sensitive topic for family members whose own carrier status may be unknown and who may not wish to learn of genetic risks related to their own health or carrier status. The 'right not to know' genetic risk assessment information is firmly established in healthcare ethics (Takala, 1999). Disclosure of carrier status can raise ethical dilemmas for pregnant women and their relatives because a right to relevant genetic information does not create an obligation to be informed (Institute of Medicine (US) Committee on Assessing Genetic Risks et al., 1994).

Other studies suggest religiosity as central to Hispanic culture, particularly as a means of coping with stress (Sanchez et al., 2012) and may be a factor in Hispanic women's decision to accept prenatal testing. Moreover, the results of our study align with prior studies suggesting that religious values, including views on abortion, could influence prenatal testing preferences (Floyd et al., 2016). Even though most of our participants reported that they were not actively engaged in religious activities and did not feel that their religious beliefs influenced their decisions, many discussed religious principles throughout the interviews. This suggests that perhaps religious doctrine may have unconscious influences on decisions that guide their lives.

Our results are congruent with the other researchers' findings that women rely on their healthcare providers to inform them about prenatal testing (Floyd et al., 2016; Molina et al., 2019; Tsai

et al., 2017). The lack of certified genetic counselors is evident throughout the vast region of South Texas (National Society of Genetic Counselors (NSGC), 2020). The majority of our participants indicated that they found out about prenatal testing from their healthcare provider without having any prior knowledge of it. In terms of genetic literacy, our sample was overall well-educated; all women had at least a high-school education and half had at least some college. Despite their education levels, four of the women scored at an 8th grade level or below on the genetic literacy scale. It is important to recognize that even in women with some college, their understanding of genetic concepts may be limited, and the use of medical terms can be confusing for patients. Providers' use of simple, direct language to meet the needs of their patients is crucial.

Our study is designed to better identify barriers to informed decision-making regarding prenatal testing and in the ongoing second phase, attempt novel education interventions to improve genetic literacy and patients' confidence in their decisions. Participants in our study indicated that a prenatal testing mobile application would help individuals to acquire the most accurate knowledge in a more accessible way, as suggested by other researchers (Choi & Kim, 2014; Smith et al., 2018; Yee et al., 2014). For example, one of the participants discussed the difficulties of finding trustworthy, easy-to-understand information on the Internet. Our results also revealed that a mobile application would not only aid pregnant women to have more information about prenatal testing using consistent terminology and grasp it better, but also would increase information access to enhance their family members' understanding of prenatal testing. The vast majority of Hispanic women who are served in our clinic region—even those who are low-income and/or reside in rural or underserved areas—have access to mobile devices. This is consistent with findings from other studies with low-income pregnant women reporting pregnant women widely use mobile applications during pregnancy and almost exclusively rely on their mobile phones to access the Internet (Guerra-Reyes et al., 2016). Despite the widespread use of mobile devices in poor and underserved communities, technology limitations such as consistent and reliable cell or Internet service could impede progress to enhance access to healthcare information through mobile sources (Chippis, 2020).

4.1 | Study limitations

The participants in our study were already designated as 'high-risk' patients having been referred to a specialist (maternal-fetal medicine). Although interviews were conducted immediately preceding their visit with the maternal-fetal medicine specialist, the fact they were referred to a high-risk specialist could affect their perception of risk to their babies. Women with low-risk pregnancies may be less inclined to accept prenatal testing based on perception of lower risk for fetal anomalies. Nonetheless, the fact that our sample included only high-risk pregnant women has important implications for genetic counselors, who are most likely to encounter patients with known risk factors by referral.

Our sample included only self-reported US-born, English-speaking Hispanic women, which may not represent the views of Hispanic women with less acculturation. Hispanic women represent a diverse population with a broad geographic range. Our sample included English-speaking Hispanic women residing in the coastal gateway to the Texas-Mexico border which may not represent Hispanic populations in other parts of the US. Latina immigrant women may face additional challenges and stressors related to their decision to accept or decline prenatal testing, so these findings may not represent their views (Garza et al., 2020). The sample size of this qualitative study, although small, allowed for evidence of data saturation by the tenth participant.

4.2 | Practice and research recommendations

Our findings present results from an underrepresented population of hard-to-reach Hispanic women in South Texas, where birth defects are the leading cause of infant death (Texas Department of State Health Services, 2020). Genetic information presents challenges to all patients, but particularly those with low and marginal literacy combined with limited access to educational resources, such as those offered by genetic counselors.

The women in our study affirmed the need for an easily accessible and understandable educational tool for prenatal testing. Our findings include suggestions from pregnant Hispanic women about ways to assist with understanding prenatal testing, such as simple descriptions of tests using basic terminology and brief explanations of the risks and benefits of prenatal testing. One way to meet the needs of medically underserved and rural population is with a culturally and linguistically appropriate mobile application (U.S. Department of Health & Human Services, 2020). The use of communication modalities for prenatal testing education adapted to linguistic and cultural needs is a future area for development.

Interdisciplinary education, training and collaboration between genetic counselors and obstetric providers would expand access to and quality of prenatal testing patient education and services (NSGC, 2020). Lack of access to genetic counselors could be a barrier to high-risk pregnant women making informed decisions by receiving culturally and linguistically appropriate education related to genetic testing. The ability to offer genetic counseling services via telemedicine through the use of mobile technology could help increase access to these services.

5 | CONCLUSIONS

These findings provide data to guide those providing genetic counseling services to pregnant Hispanic women. Perceptions of prenatal testing and factors that may influence the decision to undergo prenatal testing in underserved women are illuminated. These findings also serve as the basis to plan and develop an evidence-based

prenatal testing education intervention to increase informed decision-making among Hispanic pregnant women, an underserved population in South Texas. With a better understanding of factors such as religiosity, family values, and genetic literacy influencing their perceptions of prenatal testing, culturally appropriate education tools can be developed.

AUTHOR CONTRIBUTIONS

Robin Page, PhD APRN, CNM assisted in creating the study aims, contributed to development of the interview guide, coded and analyzed transcripts for themes, and contributed substantially to writing of the manuscript. Christina Murphey, PhD, RN assisted in creating the study aims, contributed to development of the interview guide, coded and analyzed transcripts for themes, and contributed substantially to manuscript draft edits, including approval of the final version of the manuscript for submission. Yahyahan Aras, M.Ed. conducted all 10 interviews, coded and analyzed transcripts for themes, and contributed substantially to writing the manuscript. He approved the final version of the manuscript for submission. Lei-Shih Chen, PhD provided feedback on the interview guide, and edits for the manuscript. She approved the final version of the manuscript for submission. Ryan Loftin, MD, facilitated the research staff (YA) to conduct interviews and gave final approval of the submitted version of the manuscript.

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COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

Robin Page, Christina Murphey, Yahyahan Aras, Lei-Shih Chen, and Ryan Loftin declare they have no conflict of interest.

HUMAN STUDIES AND INFORMED CONSENT

The study was approved by the Institutional Review Boards of Driscoll Children's Hospital and Texas A&M University. Informed consent was obtained from all participants for being included in the study.

ANIMAL STUDIES

No non-human animal studies were carried out by the authors of this article.

DATA SHARING AND DATA ACCESSIBILITY

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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