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Exploring Experiences & Expectations of Prenatal Healthcare and Genetic Counseling/Testing in Immigrant Latinas

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EXPLORING EXPERIENCES & EXPECTATIONS OF PRENATAL HEALTHCARE AND
GENETIC COUNSELING/TESTING IN IMMIGRANT LATINAS

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A

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The University of Texas

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for the Degree of

MASTER OF SCIENCE

by

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In recent years, the Latino population of the United States has continued to increase, but the specific needs of Latinos in the genetic counseling setting have yet to be explored. Genetic counselors tailor sessions to the needs of the patient, and more information regarding general attitudes of a population can assist in building rapport. We aimed to investigate the relationship between acculturation, prenatal care, genetic testing experiences, and expectations for their prenatal care in an immigrant Latino population. A total of 20 Spanish-speaking, pregnant Latinas from various Latin American countries were interviewed after completing a prenatal genetic counseling session. The semi-structured phone interview included questions about the participants' experiences with genetic counseling/testing, prenatal health care in their home country, their current prenatal care in the United States, and information they feel is important to know during their pregnancy. The study showed no associations between acculturation and prenatal care and genetic counseling/testing experiences. However, six major domains were identified throughout the topics explored with the participants. Overall, we found that immigrant Latinas desire to know prenatal risk information as it can help them prepare, relieve guilt, and help make screening/testing/family planning decisions. Additionally, information discussed in prenatal genetic counseling sessions, such as complex genetic information, can be internalized by these women and utilized to make decisions about their care. Women reported the genetic counselor helped provide a sense of autonomy and empowerment to make their own decisions regarding prenatal screening/testing. The participants also spoke about stressors unique to the immigrant population, most notably being away from their older children and other family

members. Identifying themes about the lived experience of this population can help genetic counselors better address patient needs, focus contracting in a session around their possible guilt and/or isolation, and identify women who could benefit from group prenatal care, such as delivered via Centering, support groups, or referrals to social work.

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Introduction:

Of note: The ethnic terms Latino or Hispanic refer to a diverse population of Latin American descent that includes many nationalities and races. Latino refers to a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race (Juckett, Gregory, MD, MPH, 2013). For the purpose of this paper, Latino/a will be used to describe our population.

Over the last year Latinos constituted 18.1 percent of the United States total population, making people of Latino origin the nation's largest ethnic or racial minority. More specifically, the proportion of Latinos immigrating to the United States (US) was more than half of the approximately 2.2 million people added to the nation's total population during July 2016 to July 2017. The projected Latino population of the United States in 2060 is expected to constitute about 28% of the national population (National Hispanic Heritage Month, 2017; 2018).

As the US population continues to become more diverse, the specific needs of our potential patient populations should be investigated. Genetic counseling sessions are tailored to individual patient. In prenatal genetic counseling, knowing more about the women we counsel allows us to build not only rapport, but also trust with our patients (Caal et al., 2012). Knowing more about patients' experiences with prenatal care in their home countries and how these past experiences may influence their future expectations of prenatal care in the United States, may lead to a more beneficial encounter for all parties (Caal et al., 2012).

It has been seen in previous reports that acculturation has a negative effect on immigrant Latina women and their families. Latinas who have been in the US for five years or more have higher incidences of obesity, hypertension, and heart disease than those who have been here for less than five years (Sanchez-Birkhead et al., 2011). This is known as the Latino acculturation paradox (Fox et al., 2015).

This appears to be reflected in prenatal care experience as well. A study found that among women with infants delivered at term and with normal weight, less acculturated and non-privately insured women reported better prenatal care experiences than more acculturated or US-born women and privately insured women (Fuentes-Afflick et al., 2014). This lower level of acculturation, or resistance to host culture, is often seen in first-generation Mexican women who still have high levels of social support (Callister & Birkhead, 2002). Those who have social support see greater healthcare benefits in comparison with those who have higher levels of acculturation, who often have lost their social support in the transition (Callister & Birkhead, 2002).

It is essential for communities of immigrant women to maintain a level of social support similar to their home country (Callister & Birkhead, 2002). Networks of support with other immigrant women are often formed as they can help each other adjust to the United States and motherhood. This network type of maternal support has been seen to be helpful in the transition in Mexican immigrant mothers (Callister & Birkhead, 2002).

With more acculturation, women may lose an important source of social support during pregnancy (Fox et al., 2015). This loss of support can put women at risk for poor perinatal outcomes (Callister & Birkhead, 2002). In Latin countries, medical care is handled in a more social way (Sanchez-Birkhead et al., 2011). Pregnant women will often seek the advice of mothers or other female relatives, known as *comadres*, prior to seeking care from a recognized healthcare provider (Sanchez-Birkhead et al., 2011). As acculturation progresses, the degree of community and family support may diminish (Fox et al., 2015).

Some patients will have only had experience with public sector health/prenatal care in their home country, which can differ with care provided in the US. A 2016 study using data collected from The Demographic and Health Surveys found that in Latin America the majority

of women in need of prenatal care sought their care through the public sector, with only 12% from the private sector (Campbell et al., 2016). Additionally, the authors also saw that in Latin America the use of private sector prenatal care increased with wealth (Campbell et al., 2016). However, Berendes et al., found that while there is a greater responsiveness and effort with healthcare providers in the private sector, quality in both the private and public sector are low with no difference in patient satisfaction in low to middle income countries (LMIC) (including Latin America) (Berendes, et al. 2011).

In a systematic review, comparing performance of private and public sector healthcare systems in LMIC, it was reported that the public sector had increased waiting times, less hospitality towards patients, limited availability of equipment, trained healthcare workers, and medications (Basu et al., 2012). The review also found that in both sectors there was poor accountability and transparency as well as financial barriers to healthcare. Therefore, it is possible some individuals immigrating to the US may be facing unique challenges as they integrate themselves into a healthcare system that could differ greatly from that in their home country.

Learning more about the relationship between acculturation, prenatal care, genetic testing experiences, and expectations could allow genetic counselor to relate better to their Latina patients. Additionally, it could provide an opportunity for intervention and education about the importance of early, consistent prenatal care on health outcomes for infants. With more information about a patient's ability to understand their health care needs, experiences with prenatal care and genetic counseling/testing (either in the United States and/or their country of origin), and their current level of acculturation genetic counselors may be able to better anticipate their potential questions and needs during a genetic counseling session.

The aims of this study were (1) to explore participants' past prenatal healthcare experiences and (2) to compare and contrast participants' past prenatal healthcare experiences with current expectations for prenatal care and genetic counseling in the US with regard to acculturation, age, parity and country of origin (CoO).

To our knowledge, there have been limited studies to date that have explored prenatal health care and genetic counseling/testing experiences and expectations of immigrant Latina women based on acculturation, age, parity, and country of origin.

Methods

Sampling and Recruitment

Participants were recruited from Lyndon B. Johnson (LBJ) Hospital, an affiliate of the Harris Health System in Houston, Texas. Harris Health System is a fully integrated healthcare system that cares for all residents of Harris County, TX. Harris Health patient demographics include 58.9% Latinos, while the patient payor mix includes 60.2% uninsured and 20.2% Medicaid and CHIP. ("Facts and Figures," n.d). Eligible participants were pregnant, Spanish speaking immigrants, at least 18 years old, who were seen for prenatal genetic counseling and had at least one pregnancy in their home country. Exclusion criteria included women who were not Spanish speaking, women under the age of 18, had not had a pregnancy in their home country, or women who were later found to have fetal anomalies. A letter of invitation/consent form was presented following their prenatal genetic counseling appointment. The certified genetic counselor who conducted the prenatal genetic counseling sessions at LBJ is a UTHealth faculty member who has the appropriate CITI training: SJN. Individuals who were invited to participate were contacted via phone to schedule an interview at their convenience. Of note, all participants received counseling by a Spanish speaking genetic counselor.

Procedures and Setting

Institutional review board approval was obtained from the University of Texas Health Science Center at Houston CPHS and LBJ Hospital. Verbal consent was obtained from each participant after being contacted by the principal investigator (PI), GG, via phone. Interviews were conducted in the Fall of 2018 through January 2019. A semi-structured script was created and translated into Spanish by a native Spanish speaking genetic counselor (PH). The script utilized mostly open-ended questions to assess three domains: (1) participant's experiences with genetic counseling/testing, (2) personal experiences with prenatal health care in their home country and their current prenatal care in the United States, as well as (3) prenatal care education and information. The first domain inquired into the individual's overall experience with genetic counseling, recollection of information from the session, and motivators for pursuing or declining genetic testing. The second domain, gathered information on the overall experience with prenatal care in the participant's home country and the US, such as what was included in their care, type of prenatal provider, and their interactions with their provider. The third domain asked about what information is important to these women such as being educated on chromosome and age-related risks, as well as the availability of prenatal genetic testing.

Data Collection

The participants were contacted by telephone and completed the interview at an agreed upon date and time. These interviews ranged from 22 to 55 minutes and were completed by the principal investigator.

Data Analysis

All interviews were completed in Spanish and recorded by GG then transcribed by Trint, a web-based computer software, and reviewed for accuracy by GG. GG and PH translated the Spanish transcripts into English. The transcripts were then entered into the qualitative data analysis and research software program ATLAS.ti. ATLAS.ti provides tools to help code,

organize, and visualize complex relationships in qualitative data. Inter-rater reliability was performed on a preliminary basis where 15% (3/20) of the transcripts were coded independently by 3 investigators. Descriptive statistics were also taken from the participants including age, gravity and parity, home country, and years in the United States.

Results

Demographics

Of the 32 women who were invited to participate in the study following their genetic counseling appointment, 2 (6.25%) declined to participate, 10 (31.25%) were not able to be reached via phone, 20 (62.35%) were reached by phone and provided additional verbal consent to participate in the study. Demographic characteristics of the 20 participants are summarized in Table 1. The greatest number of women were from Honduras. All of the participants, with the exception of one (a 22-year old with an abnormal maternal serum screen) were referred to genetic counseling due to advanced maternal age (AMA). Additionally, half of the participants had not yet had a first child in the United States). Of the 20 participants, 10 pursued prenatal genetic testing, specifically non-invasive prenatal testing (NIPT). None of the participants underwent invasive testing. Testing decisions are summarized in Table 2.

Table 1: Demographic Characteristics of Study Participants

| Characteristic (N = 20) | | Mean | Mode | Range | N = 20 | |
|--------------------------|-------------|------------|----------|--------------|----------|-----|
| | | | | | <i>n</i> | % |
| Age | | 36.5 years | 37 years | 22 – 40 yrs. | | |
| Years in US | | 7.6 years | 2 years | 2 – 15 yrs. | | |
| Country of Origin | Cuba | | | | 1 | 5% |
| | El Salvador | | | | 5 | 25% |
| | Guatemala | | | | 1 | 5% |
| | Honduras | | | | 8 | 40% |
| | Mexico | | | | 5 | 25% |
| Pregnancy History | G2P1 | | | | 3 | 15% |
| | G3P1 | | | | 1 | 5% |
| | G3P2 | | | | 2 | 10% |

| | | | |
|---|------|----|-----|
| | G4P2 | 1 | 5% |
| | G4P3 | 3 | 15% |
| | G5P3 | 1 | 5% |
| | G5P4 | 1 | 5% |
| | G6P2 | 2 | 10% |
| | G6P4 | 3 | 15% |
| | G6P5 | 2 | 10% |
| | G8P7 | 1 | 5% |
| Children Born in Country of Origin | 1 | 11 | 55% |
| | 2 | 4 | 20% |
| | 3 | 3 | 15% |
| | 4 | 2 | 10% |
| Children Born in US | 0 | 10 | 50% |
| | 1 | 3 | 15% |
| | 2 | 1 | 5% |
| | 3 | 4 | 20% |
| | 4 | 2 | 10% |

Table 2: Prenatal Genetic Testing Decisions Post-Genetic Counseling Session

| Testing Decision | Frequency |
|--|-----------|
| Pursued NIPT | 10 |
| Declined prenatal testing * | 6 |
| Declined further invasive genetic testing ** | 4 |

*1 participant declined testing due to time constraints, another participant declined, as she needed to discuss with her partner

**All of these participants had negative NIPT results from another clinic and were only offered amniocentesis during their genetic counseling appointment

Lived Experience Themes

The transcripts were coded and analyzed and from the initial three domains in the interview script, six domains emerged: (1) genetic counseling, (2) testing motivators/influencers, (3) prenatal care experiences in CoO, (4) prenatal care experiences in US, (5) interaction with healthcare providers in the US, and (6) prenatal education and information. The scripts were coded using interpretative phenomenological analysis to uncover the lived experience of this population. Within each of the six major domains, there were 3 to 6

themes (Table 3). The frequency of each theme observed across the interviews is presented in Table 3. There were no associations or differences among interview responses based on acculturation, age, parity and country of origin (CoO), with the exception of one participant from Cuba. Level of acculturation was determined based on the years in the United States and the preference to speak Spanish as their primary language. For example, 2 years in the US is less acculturated while 15 years in the US is more acculturated.

Table 3: Major Themes from the Lived Experience of Immigrant Latinas

| Domain | Theme (n) | Quote |
|--------------------------------|---|---|
| Genetic Counseling | <i>Retained complex genetics information (83)</i> | “... [the genetic counselor] told me that the girl with Down syndrome has 47 chromosomes and that an [unaffected] person only has 46 chromosomes. That she has one more and that is why she was born like that...” |
| | <i>Interested in genetic counseling and risk information (65)</i> | “...as a mother, [the information discussed in the session] is something very interesting.” “Exactly. Yes, many people are ignorant [pause] thinking that it is his fault or her fault – no, no. I think it is good to know so you don’t believe that.” |
| | <i>Information discussed during session helped facilitate a testing decision (22)</i> | “Well, for me and my husband we already had an idea more or less, but with the information she gave us, it ended up convincing me that it was better to have the test done.” “Yes, yes it was very useful to make a decision. We understood exactly what she wanted to tell us.” |
| Testing Motivators/Influencers | <i>Want to be educated about the risks to the pregnancy (17)</i> | “...as always it is good to be more informed. So that’s why I did the blood test...” |
| | <i>Aids in preparing the family for the child (13)</i> | “Yes, it is very important, because you can begin preparing [pause] to accept the fact that your child is like that or not.” |

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| | <p><i>Fear of having a child with a genetic condition (24)</i></p> | <p>“Yes, to have a child [pause] like that your whole life.”</p> <p>“Truthfully yes, I am scared, because as they say, I am almost going to be 38 years old.”</p> <p>“I did not want [more children]. My daughter she is already 11 years old and my son he is already 16. I was not thinking about having more and the risk [of having a child with a genetic condition] did scare me a little bit.”</p> |
| | <p><i>Family/friend influence and past experience (16)</i></p> | <p>“[my friend] is older than me in her case she was 42 years old when she was pregnant and she had the baby when she was 43, but she said ‘Go and do it, they’ll tell you, they’ll explain everything to you there. Nothing happens.’ The truth is it encouraged me a lot.”</p> <p>“Yes, and a friend told me that if I do the exam that I shouldn’t do the needle one.”</p> |
| | <p><i>Faith (19)</i></p> | <p>“Doesn’t change anything for me. All in God’s hands. If He says something, well it’s because He knows.”</p> |
| | <p><i>Fear of undergoing amniocentesis (15)</i></p> | <p>Yes, well, I only did the blood test because I am afraid the other one could do something to the baby. What if the baby is fine and then it does something to the baby.”</p> |
| <p>Prenatal Care Experience in CoO</p> | <p><i>Felt treated with minimum to inadequate care (53)</i></p> | <p>“Well, in Mexico [prenatal care] is not something you have, really. You barely go to clinics, just your midwife, the one that helps you with the pregnancy, and nothing else, that’s it.”</p> <p>“...one only goes for the prenatals and well they only do the ultrasound, it’s normal, then it is all done. There is not a lot of information, there is not a lot of care.”</p> <p>“No, truthfully, no comparing with the [care] here, it is better here. I love my country, but well [pause] it does not work over there, they do not attend to you.”</p> |
| | <p><i>Lack of infrastructure to support adequate</i></p> | <p>“In my country, over there one delivers her children like a dog. Over there, there is nothing, lots of poverty.”</p> <p>“My mom said ‘Hija’ like it was the first daughter truthfully, ‘if you can have the baby in the house with a midwife it is better’.</p> |

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| | <p><i>prenatal care (28)</i></p> | <p>In the hospital over there, it is not like here that you have your room and the nurse attends to you [pause] over there, no. There is a ton of women, everyone in one room, you understand me? [pause] Then that made me a little scared and I preferred to stay [at home].”</p> <p>“When I had appointments, I had to wait like 2, 3 hours. The doctors are not like they are here, that they explain to you. Well, lots of things. The postpartum depression over there in Guatemala, they would only check me...that everything was good and that’s it. And like I told you, [when you deliver], well they did not give me medication, 6 women in one room.”</p> <p>“...well everything you have to purchase. And sometimes if you can’t, then you have to figure out how. Because one lives in countries where the economic situation doesn’t allow you [to buy things].”</p> |
| | <p><i>Barriers to prenatal care (32)</i></p> | <p>“To go to the doctor and make sure everything is ok, how is the pregnancy looking [pause] one needs to have money.”</p> <p>“No, [referring to convenience to get to prenatal appointments] it was an hour away, walking.”</p> |
| <p>Prenatal Care Experience in US</p> | <p><i>External stress (23)</i></p> | <p>“Yes, well I didn’t go very early [for prenatal care] because the problem here is well, one does not have papers [undocumented immigrant].”</p> <p>“It is a lot. Also, it is different because in our country we have our mother supporting us and here you are alone. It is more complicated how one does it here.”</p> <p>“I had a bad experience with the father of my children over there when they were small children. That is why I came over here, but I have not heard anything from him. Uh-huh. My son has grown and [pause] well I could only bring one [child], I haven’t been able to bring my other [child].”</p> |
| | <p><i>Felt prenatal care is more comprehensive (106)</i></p> | <p>“That here is better, more confidence, more information, there is nothing to worry about, well here you are better cared for than there.”</p> <p>“Yes, well, yes here they’re more advanced I think that [pause] yes here there is more advanced [technology] , well for me it was a very different pregnancy. Many things that I didn’t know, well they have done a lot of studies, I believe that I am surer of the doctors here, they are more qualified.”</p> |

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| | <i>Barriers to prenatal care (29)</i> | <p>“Well here it was more difficult because of the insurance. It was hard for them to give me insurance.”</p> <p>“Yes, sometimes I feel a little bad because there are things that I do not understand and I do not have a way to have a conversation with them. I need someone to help me.”</p> |
| Interaction with US Healthcare Providers | <i>Amable (32)</i> | <p>“Ah, well I felt as if [the genetic counselor] was a friend.”</p> |
| | | <p>“Sometimes in our country they are stricter or they don’t take care of you very well. Here, they attend to you with <i>amabilidad</i> and that gives you the confidence to ask any questions you have.”</p> |
| | <i>Felt empowered following discussion with GC (37)</i> | <p>“I did not feel like she was forcing me to take the exam. She explained to me perfectly that it was my sole decision if I wanted to take it, if I did not, that was also good if I did not take [the exam]. That I liked a lot.”</p> |
| | <i>Communication /information sharing improves level of comfort (32)</i> | <p>“Also, everything they explained. Because here it is very different, and for me it is better here than there [Mexico] because here you can know more about the baby and they explain things to you.”</p> |
| Prenatal Education and Information | <i>Prenatal risk and genetic testing information allows for family planning and preparation (47)</i> | <p>“I did not know anything, and if I would have known I would have planned. I mean, I think about it because some [chromosome conditions] are very difficult. I think that yes, it would be very [good] for the future to spread the information, that way they can plan for things.”</p> <p>“Well because of one’s age. I am 38 years old and that already makes me think twice about having another baby later on because there is a higher risk because I will be even older.”</p> <p>“To know how to prepare yourself for how the baby is coming. If the baby has a malformation or a genetic problem.”</p> |
| | <i>Prenatal advice creates community and provides education (37)</i> | <p>“Yes, it is important, it is useful – the advice and all that. That way one can learn things that one does not know.”</p> |

| | | |
|--|--|---|
| | | <p>“What you do in group there, we all share our concerns, how we feel, then what we share. You see...that it is not only me [with a concern or question]...”</p> <p>“...well in my case it has been 14 years since having a baby and well...it is not like you forget some things, but it is more difficult to be a mother again.”</p> |
|--|--|---|

Discussion

Genetic Counseling

Overall, all patients had a positive experience with genetic counseling. They all expressed interest in knowing the genetic and chromosome risk information. The participants felt that this was interesting and important information to know during pregnancy. Only the Cuban participant (n = 1) had some experience with genetic counseling prior to coming to the United States, however this is not unexpected as there is a dense population of genetic counselors in Cuba, 1 genetic counselor for every 14,144 citizens (Cruz, 2013). It is possible that the proportion of genetic counselors to patients may be even greater in recent years. The remaining participants (n = 19) had not had experience with genetic counseling prior to immigrating to the United States. Some of the participants expressed gratitude after being informed of the mechanism of common chromosome conditions such as Down syndrome and Trisomy 18/Trisomy 13, as it alleviated feelings of guilt. Participants reported that knowing the sporadic nature of these conditions helps remove blame from parents, particularly the woman, should the child be born with a chromosome condition. The participants were able to recollect complex genetic information from their session such as, increasing age correlates with an increasing chromosome risk to the pregnancy, the correct number of chromosomes for an unaffected individual, as well as being able to comprehend their own individual age-related risk. A previous study done among South Texas Latinas found that this population had a misunderstanding of genetic testing technology due to their lack of exposure with it in their

home country (Urdaneta et al. 2002). Additionally, the study reported this population often did not fully comprehend the information discussed during their genetic counseling session.

However, we found that the majority of participants were able to express an understanding of the risks and benefits of amniocentesis as a diagnostic test and NIPT as a screening test.

Furthermore, participants felt they were able to utilize the content from the genetic counseling session in order to inform their personal decision.

Testing Motivators/Influencers

A major motivator to pursue testing was that the information could aid the participant's family by providing the necessary information to prepare, should the result be positive. However, the greatest motivator to pursue testing was the fear of having a child with a chromosome condition. While it was not explicitly stated throughout the interviews, a couple of participants reported they would not want to continue the pregnancy if they had a positive genetic testing result for Down syndrome. Participants also relied on the experiences of trusted friends and family members, or *comadares*, when it came to deciding on which test to pursue (amniocentesis versus NIPT). This is consistent with a previous study that found that Latina women are highly influenced by their social network (friends, mothers, sisters) when electing a contraceptive. The social network was seen as more valuable than physician input when they did not have firsthand experience with the situation (Yee and Simon, 2010). Additionally, participants expressed their faith as an important part of their decision making. Some stated she would accept their child however they came; should the baby have a genetic condition, as it was part of God's plan. Others put the health of their child in God's hands and stated they trusted in God to bring them a healthy a baby.

Overall, the greatest motivator to elect NIPT versus invasive testing via amniocentesis was the fear of undergoing the procedure of an amniocentesis. Participants reported they feared

that it could possibly lead to a miscarriage of their pregnancy and therefore elected non-invasive testing, which is consistent with another study focusing on Latinas feelings behind amniocentesis (Seth, et al. 2011).

Prenatal Care Experience in Country of Origin

The majority of patients interviewed (n = 19) reported that they felt as though they received minimal care in their home countries. The patients cited specific issues with their care including, minimal check-ups during appointments, lack of privacy during delivery, and lack of communication and personal care from healthcare providers. Often, women reported poverty or finances as a barrier to care in their CoO. To receive adequate prenatal care, such as ultrasounds, patients were required to pay an out-of-pocket cost. Participants who had both private and public sector insurance during their previous pregnancies expressed these same sentiments, which is consistent with previous studies (Berendes, et al. 2011; Basu et al., 2011). Those with private insurance stated that they still felt they did not receive adequate care from their healthcare providers while expressing empathy for those with fewer resources than themselves. A few of the women cited their country's poor economic situation and overall lack of infrastructure as the reason for their poor experience with prenatal care.

Prenatal Care Experience in US

All participants felt they were receiving more comprehensive prenatal care in the US including but not limited to, better access to and availability of technology, prenatal studies (prenatal genetic testing and gestational diabetes screening), better access to care overall, and communication and information from their healthcare team. This population of patients desired having information about their pregnancies and while not all of them (n = 6) underwent prenatal genetic testing, they stated that it was important just to be informed.

Participants did express different types of barriers to receiving care, the two largest being obtaining insurance to begin prenatal care in the US and the language barrier. Completing the necessary documents to obtain Perinatal CHIP (Children's Health Insurance Program), a program in Texas that provides temporary insurance coverage for pregnant women who are not able to obtain Medicaid since they are not citizens, proved to be complicated and burdensome for some patients (n = 3). To overcome that obstacle, participants had to reach out for help from friends, go to different clinics to be able to get the necessary information, or endure submitting forms multiple times. Another barrier expressed by patients (n = 5) was the language barrier with non-Spanish speaking healthcare providers. Interestingly, a couple participants blamed themselves for not knowing English. They made learning English their responsibility rather than being frustrated with their providers for not knowing Spanish. One of those women has been in the US for 20 years and the other woman has been in the US less than 5 years. However, the majority of participants did not report major issues with an English-speaking healthcare provider or having to use an interpreter.

Many participants described external stressors that are relatively unique to immigrants such as, distance from family members. In Latino cultures, healthcare decisions and advice are often provided through the family unit (Sanchez-Birkhead et al., 2011). For some of our participants, not only were they far away from family, they had also left a child(ren) behind in their CoO. This could be an important factor to keep in mind when providing care for these patients. Their new pregnancy may be complicated by feelings of guilt, as their other children are not going to have the same opportunities. This could be especially sensitive when completing a pedigree during a genetic counseling appointment. This presents an opportunity to connect better with our immigrant Latina patients by asking a few more questions about their family dynamics and their support system.

Healthcare Providers in the US

All patients expressed positive feelings, specifically feelings of *amabilidad*, toward their personal interaction with the genetic counselor and there were multiple incidences where patients also felt this from their obstetrical healthcare providers. Often participants described the genetic counselor as *amable*. This term directly translated in Spanish means kind and friendly, however it is often more encompassing, including traits such as welcoming and charismatic. Participants also stated that they appreciated the amount of information their obstetrical healthcare providers and genetic counselor shared with them, as it helped create trust between the patient and the provider, in that they felt they were being well taken care of. Most importantly, participants often enjoyed their interaction with the genetic counselor due to her ability to help the patient feel empowered to make their own decision about genetic screening/testing options. In general, the patients felt they were granted a sense of autonomy, which is a goal of genetic counseling. Many participants stated they felt comfortable with the genetic counselor because they felt that the decision to proceed with or decline prenatal genetic testing/screening was theirs alone.

Prenatal Education and Information

All participants reported a desire to be educated about age-related risk information, chromosomes, and prenatal genetic screening/testing availability during pregnancy. They reported that this information and these services are important, as they aid the family with both family planning and preparation. Some participants stated that based on their age-related risk they are not planning future pregnancies, as they are aware their risk for a chromosome condition will continue to increase. Additionally, several participants stressed the importance of prenatal testing as it could help provide the family with information, should a result come back positive for a chromosome condition in the pregnancy. During the interview, we inquired as to

how these women prefer to receive this type of new information, either verbally, written, or both. The majority of the women (n = 14) preferred to receive this type of information verbally.

Group prenatal care, or Centering, where groups of women receive prenatal care together, was seen as important and valuable to these women. Centering is a common prenatal care model utilized within the Harris Health System. Specifically, in this study, half of the women were having their first child in the United States and/or were considered high risk (due to their age) for the first time and were navigating a new healthcare system. They expressed that Centering provided an educational opportunity to learn new information such as genetic counseling and testing information and prenatal care from the healthcare provider as well as the other women in attendance. Furthermore, this group dynamic helped give some participants a sense of community as many are not near their relatives such as their mothers. Previous studies have found that patients who feel a sense of community where they can learn from each other is important in pregnancy in the Latino community (Callister and Birkhead, 2002; Thompson et al. 2015).

Limitations and Strengths

There were several limitations to this study. First being that 20 is a small sample size and thus our findings may not be generalizable to larger populations. Additionally, the sampling, while purposeful, was somewhat biased in that all except for one were over the age of 35. These women were considered to be in a high-risk category, this could be why their experiences in the US differ from their experiences in their home country. Additionally, being in a high-risk category could also be why they were more motivated to learn pregnancy information. The study participants were also highly concentrated from one Latin American country, Honduras. This could be explained by the recent large influx of Hondurans due to emergence of political unrest, police corruption, and violence in the country (“World Report 2018: Rights Trends in

Honduras”, 2018; Grillo, 2018). Another limitation of the study is that all of the participants were counseled by one genetic counselor or genetic counseling students who were under the supervision of that same genetic counselor. However, this consistency could also be noted as a strength as all patients were counseled in a similar fashion. While, the PI completed all the coding, we performed a preliminary inter-rater reliability by having two additional investigators (SJN and GP) code 15% of the transcripts to assess the validity and consistency of the coding. However, we appreciate that there is the possibility of introducing bias having had one investigator conduct all the interviews, translate half of the transcripts, and code all the transcripts.

Conclusions

While there were no associations with past or current prenatal care experiences and expectations in relation to acculturation, age, parity and CoO we found that based on the results of this study, genetic counselors should continue to be an active member of the prenatal care team for immigrant Latinas. This population will likely continue to increase in the coming years and having explored this population’s experience with prenatal care, we better understand our role in their prenatal care. Through this study, we found that:

- Immigrant Latinas desire to know prenatal risk information as it can help prepare them, relieve guilt, and help make testing/screening/family planning decisions;
- Immigrant Latinas are able to comprehend the complex genetic information discussed in a prenatal genetic counseling session and are able to use that information to make informed decisions about their care;
- Genetic counselors help instill a feeling of autonomy in these patients’ prenatal care when it comes to electing or declining prenatal screening/testing; and

- This population experiences unique stressors, most notably, being away from their loved ones, including children.

Using these findings there are changes we can integrate into genetic counseling practice. We can create stronger relationships with immigrant Latina patients, most notably, during contracting and family history gathering. In contracting, we should ask questions to learn more about patients' experiences with the current pregnancy, such as her overall pregnancy experience in the US, how she is navigating the new healthcare system, and what support systems the patient has. If we learn that a patient is feeling overwhelmed or isolated, we can at that time recommend/refer to Centering, social work, or a support group for mothers. We can build more rapport during family history gathering when we are asking about their family (older children, mothers, fathers). Here we should ask questions to further investigate the relationship patients have with their older children and their extended family. Should a woman feel isolated from her family or guilt for having a new pregnancy while her older child(ren) are in her home country we can utilize our psychosocial skills to provide empathy and support. Inquiring about their family members can show the patient we are invested in them and their well-being, which can help our immigrant Latina patients trust us more.

Future studies could use this information to help create a larger quantitative study into the lived experience of this population. Having begun the exploration into the area of prenatal care and genetic counseling/testing amongst immigrant Latinas, perhaps a survey can be created with targeted questions to see if perhaps, with a larger sampling, there are differences in the lived experiences of immigrant Latinas from different countries, with the goal in mind of improving care for them here in the US.

Appendix 1: Semi-structured Interview Script
Exploring Experiences & Expectations of Prenatal Healthcare and Genetic Counseling/Testing in Immigrant Latinas

Consent to Participate

Hello, my name is Georgiann Garza. I am a genetic counseling graduate student at The University of Texas. I am working with Sarah J. Noblin who spoke with you about a study we are conducting. We are interested in learning more about the experience of Latinas, Spanish-speaking women, who are receiving prenatal care. We are especially interested in hearing about your experience with the genetic counseling received at LBJ Hospital.

If you decide to participate in this study it will take about 30-45 minutes of your time. We will ask a few questions about your recent prenatal genetic counseling experience. We will also ask about your past experiences with prenatal care in the country you were born.

There are no known discomforts associated with participating. Participating in this project is completely voluntary and you may withdraw at any time. Your answers will be kept anonymous. Any report of this research that is shared with the public will not include your name or other identifiable information. The healthcare you receive within the Harris Health system will not be impacted whether you decide to or not to participate in this study.

Once you complete this survey, you will be compensated with a \$10 Wal-Mart gift card.

Would you like to participate in this study? Yes _____ No _____
 Unsure _____

If you are unsure or if this is not a good time to complete the survey, when would be a convenient time to call you back? _____

If you are not home or there is no answer, would it be all right to leave a message a) on your answering machine and/or b) with the person who answered the call?

If the participant does not wish to participate, thank them for their time and stop the interview. Log patient's information as "Declined to Participate" so they will not be approached again.

A. Screening and Demographic Background

I am going to ask some questions which were covered during your genetic counseling session. I want to be sure your information is correct.

1. What is your current age? _____
2. In what country were you born in? Where is your family?

3. Would you tell me how many years have you lived in the US? Are you here with your family? _____
4. What is your preferred language? _____
5. Can you tell me how many times have you been pregnant including your current pregnancy?

6. How many children do you have? _____
7. How many of your children were born in _____?
8. How many of your children have been born in the US? _____

B. Genetic Counseling/Testing:

Sometimes, women who are pregnant meet with a person called a genetic counselor to talk about the chances of having a baby with a problem at birth. This counselor also talks about the genetic tests that are available that can give more information about the health of the baby during pregnancy.

1. Can you tell me if you were offered any genetic testing during your visit? What did you talk about with the genetic counselor? Which types of tests were discussed with you?
 - a. *Prompt: Were you given information on tests such as amniocentesis/needle test, or blood tests for Down syndrome? Was this information helpful in making a decision on which test to proceed with?*
 - b. *Probe: Were you expecting to meet with a genetic counselor during your current pregnancy? If yes, what kind of information did your provider (doctor/midwife) give you about what to expect during the genetic counseling session and did you feel prepared to discuss that information? If no, when the Genetic Counselor explained what kind of information would be discussed, was that information was interesting or important to you?*
2. What parts of the genetic counseling session were the most helpful to you?
 - a. *Probe: What parts of the counseling helped you best understand the possible problems your baby may face? Were the figures/pictures helpful? Were the numbers helpful?*
3. Was any information not helpful? Was there anything that was discussed that you felt that you did not need or want to know?

- a. *If you were going to tell someone, such as a family member, about your genetic counseling experience what would you tell them that would be most helpful? What information would not be helpful?*
4. Overall, how was your session with the genetic counselor?
5. Did you feel comfortable with the genetic counselor? Did you feel comfortable discussing your concerns and to ask her questions?
6. Did you decide to pursue testing following your appointment with the genetic counselor?
7. Is there anything else you would like to add about your feelings or your experience with the session?

C. Prenatal Care in Home Country vs. in the United States

1. What does prenatal care mean to you?

Probes:

- a. *What type of information, activities, and overall health care do you feel must be done when getting ready to give birth?*
- b. *What changes do you make in your daily routine to prepare for the pregnancy? For example, changing your diet, taking prenatal vitamins, or how often you went to the doctor.*
2. How far along in the pregnancy were you when you first sought prenatal care in your home country? How about in the US? If there is a difference: why did you seek care earlier in ___ vs ___?

3. Please tell me about your experiences with prenatal care in [insert name of the country respondent was born in]? In your opinion how did the care differ from your home country?

Probes:

- a. *How often did you see a healthcare provider about your pregnancy?*
- b. *What kind of healthcare provider did you see? A physician? A midwife? A nurse?*
- c. *Where did you see the healthcare provider? In a hospital? In a clinic? In your home? In their home?*
- d. *Was it convenient to see them or make appointments?*
- e. *Did you have an ultrasound during the pregnancy? If so, when and what did it tell you about the baby?*
- f. *Did you have any genetic counseling/screening/testing during the pregnancy? (prompt: blood tests or a needle test that could give you more information about the health of the baby)*
4. Is there anything about your prenatal care experience in your home country that you would like to add?

D. Education and Information about Prenatal Care

We are interested in learning how genetic counselors and other health care providers can help women better understand the importance of early, consistent, prenatal care and the availability of genetic counseling/testing.

- a. *Do you think it is helpful to know about the risk of chromosome abnormalities, like Down syndrome? Why?*
 - b. *Do you think it is helpful to know about the risks associated with a woman's age? Why?*
 - c. *Do you think it is helpful to know about testing options that are available to you? Why?*
 - d. *Do you think it is helpful to know about tips/advice for prenatal care? Why?*
1. How do you prefer to receive new information? Verbally during a visit or written so you can take it with you?
 2. Is there anything you would like your healthcare providers to know about you and/or your experiences to better take care of you?
 - a. *Probe: Is there something about your county's culture that would help us take better care of you during your pregnancy?*
 - b. *Probe: Do you feel the same level of comfort talking about your health care concerns with your physician in the United States like you did back in ____? Why?*
 3. If you were going to tell someone, such as a family member, about your prenatal experience what would you tell them that would be most helpful? What information would not be helpful?

E. Concluding Remarks:

Before we close, do you have any other thoughts you would like to share with me?

Thank you so much for taking time to talk with me and share your thoughts. I hope the rest of your pregnancy goes well. If you have any questions about this project, please feel free to reach out to [Genetic Counselor name and contact information].

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VITA

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After completing her work at John B. Alexander High School Health Science Magnet School in Laredo, Texas in 2011, she entered St. Edward's University in Austin, Texas. She received her Bachelor of Science with a major in Biology and minor in Spanish from St. Edward's University in May 2015. In August of 2017 she entered the University of Texas MD Anderson Cancer Center UTHealth Graduate School of Biomedical Sciences.

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