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EFFECT OF ANCHORING ON PERCEIVED AMNIOCENTESIS RELATED MISCARRIAGE RISK WITHIN A LATINA POPULATION

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EFFECT OF ANCHORING IN PERCEIVED AMNIOCENTESIS RELATED MISCARRIAGE RISK WITHIN A LATINA POPULATION

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Most recognized pregnancies are completed without difficulty, yet there is always a 3-5% background risk to have a child with a birth defect. Amniocentesis, the most common type of prenatal diagnostic test, is used to detect chromosomal abnormalities, such as Down syndrome. Amniocentesis is associated with a risk of complications that can lead to a miscarriage, which is typically quoted to be between 1 in 300 and 1 in 500. Amniocentesis uptake rates are typically lowest within the Latina community, and although the factors related to this have been studied before, no specific conclusions have been reached.

The general population has a difficult time interpreting risks, as individuals vary in numeracy skills as well as personal factors that can influence risk perception. A recent study by Nuccio (2010) investigated the effect of anchoring, where a patient's prior knowledge about a subject affects her risk perception, and how it relates to the uptake of amniocentesis within a diverse population in Houston, TX. The effect of anchoring on perceived amniocentesis-related miscarriage risk within the Latina population has not been previously examined.

A two-part questionnaire was completed by 96 Latinas receiving prenatal genetic counseling due to an increased risk to have a baby with a chromosome abnormality at various clinics in Houston, TX. The genetic counselor involved in the session completed a separate survey. This population was largely unfamiliar with surveys, risk figures, and

prenatal testing. Only one individual was able to quantify the risk associated with amniocentesis prior to the genetic counseling. While the majority of women felt that the risk association with amniocentesis is very low to average, only 7 individuals pursued diagnostic testing through amniocentesis. Most women did not feel like the information gained from an amniocentesis would change the management of their pregnancy and/or they did not believe that their baby had a problem. Women, regardless of ethnicity, deserve individualized genetic counseling sessions that cater to their needs and desires regarding their prenatal care.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

BACKGROUND

Prenatal Testing and Screening

Most pregnancies lead to the birth of a healthy child, but even for individuals with no personal or family history of birth defects there is a 3-5% background risk (Lary & Paulozzi, 2001). Common birth defects include cleft lip and palate, clubfoot, neural tube defects, and heart defects. Women also have a risk to have a child born with a chromosome abnormality. The most well-known chromosome abnormality is trisomy 21, more commonly referred to as Down syndrome. Owing to advances in technology over the last 50 years, there are several ways to personalize a woman's risk to have a child with a chromosome abnormality, as well as options for prenatal diagnosis.

In the 1960's prenatal diagnosis of chromosome abnormalities using amniocentesis was introduced as a way to detect certain genetic conditions prior to birth by testing fetal cells collected from amniotic fluid (Steele & Breg, 1966). Chromosome abnormalities could be detected by karyotyping these fetal cells. Initially invasive prenatal diagnostic procedures, such as an amniocentesis, were used primarily for women over the age of 35, considered advanced maternal age. As women age their risk to have a child with a chromosome abnormality increases, and 35 years of age was chosen as a cut-off for offering amniocentesis based on this increased risk (Hook, 1981). However, women at any age have a risk to have a child with a chromosomal abnormality and so, in 2007 the American College of Obstetricians and Gynecologists (ACOG) recommended that all women be offered diagnostic testing (ACOG Practice Bulletin No. 77: Screening for Fetal Chromosome Abnormalities, 2007).

Genetic counseling is typically offered to all women of advanced maternal age, as well as women with other indications such as a positive maternal serum screen, ultrasound anomaly, or family history of genetic disease. During a genetic counseling session the risks, benefits, and limitations of an amniocentesis are explained. Although the risk of miscarriage is quantitatively small, it can have a large role in the decision making process surrounding diagnostic testing (Eddleman, Malone, Sullivan, Dukes, Berkowitz, Kharbutli, et al., 2006). Following a study in 1995, the Centers for Disease Control and Prevention (CDC) recommended that genetic counselors quote a 0.25-0.50% risk for mid-trimester amniocentesis related complications. (Olney, Moore, Khoury, Erickson, Edmonds & Botto, 1995). This figure, which could also be quoted as 1/200-1/400, was derived from a review of the available literature examining the risks of miscarriage. However, since the inception of prenatal diagnosis, the techniques used have improved and the risks associated with the procedure have likely decreased. Many studies have taken this into account in an attempt to determine what the exact miscarriage-related risk is. Eddleman et al. (2006) published data showing the pregnancy loss rates for women enrolled in the First and Second Trimester Evaluation of Risk for Aneuploidy (FASTER) trial. They estimated that the procedure-related risk was 1/1600, or 0.06% (Eddleman et al., 2006). Despite this low risk figure, many institutions quote a higher risk, such as 1/300 to 1/500, which ACOG endorsed in 2007 after conducting a literature review (ACOG Practice Bulletin No. 88: Invasive Prenatal Testing for Aneuploidy, 2007).

Regardless of what the actual risk is, many women feel that imposing any risk on their pregnancy is frightening (Hunt, de Voogd, & Castendeda, 2005). Today's technology allows the offering of prenatal screening options that pose no risk for miscarriage; however

these options cannot diagnose chromosome abnormalities. Maternal serum screening during the second trimester has been widely used since the 1980s to provide a non-invasive approach to estimate the risk for chromosomal abnormalities (Kupperman, Learman, Gates, Gregorich, Nease, & Lewis, 2006). This screening tool can be used to formulate a new, more personalized risk for conditions such as Down syndrome, trisomy 18, and open neural tube defects. Since maternal serum screening was introduced, the number of women referred for genetic counseling has increased, and so has the number of women that are offered an amniocentesis (Browner, Preloran, & Cox, 1999).

Maternal serum screening is offered to all women, regardless of age or indication, and many women who may have otherwise sought an amniocentesis are reassured with a negative screening result and do not feel inclined to pursue diagnostic testing (ACOG Practice Bulletin No. 77: Screening for Fetal Chromosome Abnormalities, 2007; Nakata, Wang, & Bhatt, 2010). The actual uptake of diagnostic testing varies across countries and between geographical regions within countries (Marteau, Johnston, Kidd, Michie, & Cook, 1991; Reid, 1988; Edwards & Webb, 1979. One factor that affects amniocentesis uptake is age, which is not surprising since age is a common indication for an amniocentesis. In a large prospective cohort, Kupperman et al. (2006) showed that women under 35 are more likely to start with screening methods (84.8%) rather than go directly to diagnostic testing (4.4%). Women older than 35 were divided; 53.5% went straight to diagnostic testing and 34.7% started with screening.

Age is only one of many personal factors that can influence a woman's choice to pursue amniocentesis. Kupperman et al (2006) also found that women with higher educational achievement and more income were more likely to accept an amniocentesis than

others. These women were found to have lower perceived miscarriage risks as well as lower faith and fatalism scores (Kupperman et al., 2006). Other studies have also shown that women in the United States who have typically accepted an amniocentesis based on their age-related risks were Caucasian, middle-to-upper class, and educated (Browner et al., 1999; Dormandy, Michie, Hooper, & Marteau, 2005). This could be due to easier access to healthcare, a better understanding of the information presented, a higher desire for the information gained from an amniocentesis, or because they place less of an emphasis on faith (Kupperman et al., 2006).

Women in lower socioeconomic groups, are those with lower incomes and less education, and may be less likely to make informed decisions regarding prenatal testing (Dormandy et al., 2005). Dormandy et al. (2005) surveyed women presenting for care in the UK about their feelings and knowledge of prenatal screening. They reported that uptake differences are most likely due to a lack of informed choice, rather than an individual's personal beliefs or attitudes about testing. Informed choices were made in 59% of socioecomically advantaged women, and only 45% of women of lower SES groups (Dormandy et al., 2005). They saw that women in disadvantaged groups that had positive attitudes regarding testing during pregnancy were still less likely to pursue testing than women in other SES groups due to healthcare providers failing to facilitate informed decision making among their patients.

Another variable that has been shown to affect a woman's choice to pursue diagnostic testing is her view on pregnancy termination (Marteau et al., 1991). Interviews with women who declined testing in the past have indicated that their reasons included unwillingness to consider abortion, and a belief that the baby was healthy (Marteau et al.,

1991) Other studies have found that attitudes towards termination overlap significantly between women that accept and refuse an amniocentesis because a woman's views on termination were independent and unrelated to her views on diagnostic invasive testing (Browner, 1999; Pryde, Drugan, Johnson, Isada, & Evans, 1993).

Decision Making and Risk Interpretation

As previously discussed, variables such as age, indication, socioeconomic status and attitude towards pregnancy termination may impact decision-making regarding diagnostic testing. These variables as well as other personal factors, including religion, culture, ethical beliefs, and social ideals may contribute to a woman's risk perception regarding an amniocentesis (Marteau et al., 1991). These personal factors, combined with pre-existing beliefs, affect how women assess and perceive risk and make decisions about amniocenteses (Pryde et al., 1993). The process of risk perception differs among individuals and among cultures, affecting the uptake of amniocentesis in different regions and among populations (Reid, 1988; Edwards & Webb, 1979).

The general population has a difficult time interpreting risks, especially when they are given within a numerical structure, such as fractions, percentages, and ratios (Keller & Siegrist, 2009). These numerical concepts are hard to interpret, and even more so for people who struggle with processing probability. The ability to understand mathematical concepts is called numeracy (Keller & Siegrist, 2009). People differ in their numerical capabilities; moreover many people are completely innumerate and unable to process numerical concepts (Keller & Siegrist, 2009). Keller and Siegriest (2009) assessed the risk perception of low numerate women by presenting them with the risk to have a child with Down syndrome and

the risk to have colon cancer in multiple formats. They found that these low numerate women did not assess their risk differently regardless of presentation: a pictogram, ratio, or a perspective scale. Women with high numeracy were able to assess risk the best with the pictogram, but even they were unable to differentiate between high and low risk situations with a ratio format (Keller & Siegriest, 2009). Alternatively, Griffiths and Kupperman (2008) found that in a population with low levels of literacy a visual representation of risk aided women in comprehending both the risk to have a miscarriage and the risk to have a baby with a chromosome abnormality. In groups with low numeracy and low education, some researchers feel like there is no ideal way to explain risk, but rather as little information as possible should be provided to these individuals so as not to confuse them (Keller & Siegriest, 2009). Others have indicated that the influence of framing has a significant role in the decision making process (Bijma, Wildshut, van der Heide, Passchier, Wladimiroff, & van der Maas, 2005). Women with low numeracy are less likely to attend to the numeric risk information being presented and are more likely to hold on to the way the information was presented or framed (Senay & Kaphingst, 2009; Peters, Vadaparampil, Kramer, Moser, Court, Loud et al., 2006; Pryde et al., 1993). Framing refers to the contextual setting that a risk is presented in that has the potential to influence the patient's perception (Bijma et al., 2005). The same risk can be phrased in different ways, which could lead to different risk perceptions.

Stevens (2008) found that the most common reason for declining an amniocentesis was the risk associated with the procedure. This could be due to fear associated with the actual risk, discordance between true and perceived risks, or only having the ability to interpret qualitative risks. Understanding the risk presented during a genetic counseling

session is important to the decision making process. Stevens (2008) found that the quoted miscarriage risk associated with amniocentesis played a role in the decision-making process, but that women's actual perception of that risk was even more significant. Other studies have confirmed that a woman's perceived risk to have a child with an abnormality can be a more significant variable when deciding about an amniocentesis than the age-related risk presented to her in a genetic counseling session (Martaeu et al., 1991; Pryde et al., 1993). This perceived risk may be due to pre-existing beliefs or emotions, which can affect risk perception processes even in women who usually are able to process numbers rationally (Bijma et al., 2005).

It has been shown that individuals differ in both the ways they understand and perceive risks. The objective, or actual, probability that an event may happen is commonly misconstrued based on an individual's preexisting beliefs. These pre-existing beliefs are often supported by the use of heuristics such as availability, representativeness, and anchoring, all of which can affect an individual's risk perception (Tversky & Kahneman, 1984). Heuristics can inhibit the ability to alter a prior opinion or belief when new or contradictory information is presented (Senay & Kaphingst, 2009). Heuristics can be very useful in risk perception, but can also be misleading and has the potential to lead to errors in decision making. Often times the final perceived risk may fall somewhere between the patient's preexisting beliefs and the objective risks presented to them (Senay & Kaphingst, 2009).

One heuristic, availability, is a process that refers to the ease at which someone can think of examples of the potential outcomes of a situation (Tversky & Kahneman, 1984). If the patient is only familiar with women having healthy babies, that may be the only concept

available to her, and she may be overly confident that her baby will be fine. On the other hand if she or someone she knows has had a procedure-related miscarriage, that negative outcome will be "available" to her, and she may overestimate the risk for miscarriage. The concept of representativeness is similar. Individuals may inappropriately use characteristics of a similar situation and apply that outcome to the current situation (Tversky & Kahneman, 1984). For example, if a young couple knows another couple who just had a baby with Down syndrome, they may think that they have a significant chance to have a similar outcome when, in reality, the chance is probably quite small.

A third heuristic is anchoring, where individuals use a prior belief about the magnitude of risk as a framework. Individuals have a certain starting point, or initial risk value, that they associate with a specific outcome. Additional information presented to them may only partially affect their final risk value. The use of anchoring could be affected by the way in which information was presented, the order it was presented in, or the context surrounding the information (Weil, 2000). Additionally, if patients were told one thing previously it may be very difficult for them to accept a new risk value. This bias to hold on to previous beliefs and risk perceptions can affect their decision making.

Anchoring has been found to affect decision making in multiple areas of healthcare. Patient risk perceptions and their true objective risks are often divergent, even after counseling (Pryde et al., 1993). A study exploring breast cancer risk biases found that women who presented to clinic with higher perceived risk values were unable to adequately decrease their perceived risk values (Cull, Anderson, Campbell, Mackay, Smyth, & Steel, 1999). Similarly women with lower risk values were unable to adequately raise their risk perception after counseling. However, the bias introduced by anchoring is malleable, more

so when the anchoring bias is self-generated and not influenced by an outsider. Eliminating such biases could decrease patients' worries about adverse outcomes and lead to better informed decisions (Senay & Kaphingst, 2009).

Anchoring may lead individuals to insufficiently adjust their perceived risk value regardless of the information a healthcare provider gives them due to the risk perception they had prior to counseling (Senay & Kaphingst, 2009). Vergani, Locatelli, Biffi, Ciriello, Zagarella, Pezzullo, et al. (2002) found that two key determinants in decision making regarding amniocentesis were the patient's opinions about amniocentesis prior to counseling and their ultrasound findings. The patient's initial opinions regarding the risk and utility of an amniocentesis were used to anchor, and insufficiently adjust, their final risk perception. Women who came in thinking they would not have an amniocentesis were unlikely to pursue one unless an abnormality was found, regardless of what information was presented by the counselor in regards to the amniocentesis. After counseling many women still have perceived risks that were higher than the actual risks given to them (Tercyak & Kahneman, 2000).

A woman with a low perception of risk may be using anchoring as well. In general, women who have had successful amniocenteses in previous pregnancies are more likely to accept additional amniocenteses (Tercyak & Kahneman, 2000), which could be due to anchoring. Since they have had a successful pregnancy their perceived risk is low and may not be affected by the risk number the genetic counselor gives them. Personalized genetic counseling sessions have helped women realize their actual risk, but seem to be unable to completely overcome biases due to anchoring (Tercyak & Kahneman, 2000).

Latino Culture

Latinos are the largest minority in the United States of America, constituting 16% of the United States population (United States Census Bureau, 2010). An even larger proportion of Texans are Latinos, making up 37.6% of the state's population (United States Census Bureau, 2010). Although Latinos make up the largest minority group in the United States, they accept amniocenteses the least (Baker, Teklehaimanot, Hassan, & Guze, 2004; Cunningham, 1998). Understanding Latinas' healthcare beliefs may help providers understand their needs regarding prenatal genetic testing.

Ransford, Carrillo, and Rivera (2010) surveyed 96 random Latinos throughout Los Angeles about their health beliefs. They found that prayer and faith are considered part of an alternative system of healing. Furthermore, prayer serves as a source of stability. Most individuals acknowledged that prayer needed to be combined with some sort of medical treatment, be it alternative medicine or traditional Western healthcare. Ransford et al. (2010) postulated that this may be a coping mechanism, or it may be helping individuals gain control over improving their health. The extent of religiosity did not seem to matter; individuals were just as likely to indicate that prayer was important regardless of how often they attended church (Ransford et al., 2010). Graham, Ahn, Davis, O'Connor, Eisenberg, and Phillips (2005) analyzed data from the National Health Interview Survey in 2002 and concluded that 27% of Latinos use complementary and/or alternative medicines. A cross-sectional study that surveyed Latinos at a clinic and outpatient pharmacy found that alternative medicines or herbal remedies are commonly used because they are perceived as affordable, convenient, and better at treating the ailment than traditional medicine. (Gupchup, Abhyankar, Worley, Raisch, Marfatia, & Namdar, 2006). Because of the beliefs

that religion and alternative medicines can be just as beneficial as traditional healthcare, Latinos are likely to have different ideas regarding seeking healthcare within the United States than mainstream Americans.

The process of acculturation is associated with a range of health behaviors and outcomes in minority groups (Alegria, 2009). Acculturation is defined as the process of accommodating with assimilation into a dominant group in an irreversible manner (Gordon, 1964). John Berry described the process of acculturation as maintenance of the original culture while developing relationships with the new culture (Berry, 2003). Investigators such as Thomson and Hoffman-Goetz (2009) have attempted to find the best way to measure acculturation, but have concluded that it is a very difficult task. Proxy methods of evaluating acculturation are used most commonly and include measures such as language spoken, amount of time in the host country, and place of birth (Thomson & Hoffman-Goetz, 2009). These short, unidimensional proxy methods have utility when a quick screen is needed to view some aspects of acculturation, but have limitations as they are not validated measures.

Women born in Mexico, and thus presumed to be less acculturated than Latinas that were born in the United States, have been shown to be significantly more likely to decline the option of invasive prenatal testing than US-born Latinas (Browner et al., 1999). Miscommunication, including difficulties in overcoming language and cultural barriers between healthcare professionals and Mexican-born women, has been shown to impact amniocentesis uptake rates (Browner, Preloran, Casado, Bass, & Walker, 2003). Aside from miscommunication, general confusion may also affect lower amniocentesis uptake rates in less acculturated populations. Women in predominantly Spanish-speaking, lower

socioeconomic groups typically had no knowledge of their maternal serum screen results or pending appointments with genetic counselors (Baker et al., 2004). This confusion could cause women to be less likely to understand and/or desire invasive testing.

Often Latina women take on a different approach to pregnancy than many of their non-Latina counterparts. For Latina women pregnancy is normal and considered an extension of the healthy state of being, causing them to seek prenatal care later that others (Callister, 2002; Conrad, Hollenback, Fullerton, & Feigelson, 1998). Latina women may have their own beliefs on how to prevent birth defects such as by having a strong social and financial support system, avoiding extreme temperatures, staying active, and by not becoming angry (Pearce, 1998; Berry, 1999). Interviews in the Central Valley of California revealed that Latinas thought that by avoiding illicit substances, avoiding stress, listening to their doctor's recommendation, and eating well they could prevent birth defects (Griffiths & Kupperman, 2008). Up to a third of these individuals thought that by taking care of themselves during pregnancy they could guarantee the birth of a healthy child. Others thought that birth defects were God's will. In a questionnaire administered by Ruiz, Dolbier, and Fleschler (2006), Latinas report lower levels of stress during pregnancy, perhaps due to the different approach they take on pregnancy.

Since Latina women have their own beliefs and ideals and are less accustomed to the beliefs and ideals in Western medicine, they are less likely to pursue an amniocentesis (Kupperman et al., 2006). Latina women present for genetic counseling from diverse backgrounds and may not share mainstream views about the role of medicine, prenatal care, the meaning of disabilities, and the appropriate way to respond to empiric risks (Browner et al., 1999). As previously stated, the uptake of amniocentesis within the Latino community

is the lowest among all other ethnic groups (Cunningham, 1998; Saucier, Johnston, Wicklund, Robbins-Furman, Hecht, & Monga, 2005). Studies report that Latinas accept an amniocentesis 51.5-66.1% of the time, while uptake in other ethnic groups ranged from 75.8-84% (Saucier et al., 2005; Browner et al., 1999). In fact, ethnicity when examined in regression models has been shown to be the most predictive demographic variable in amniocentesis decision making (Saucier et al., 2005). Studies have shown that by adjusting amniocentesis uptake results for age and socioeconomic status (SES), a patient's ethnic background is significantly related to her prenatal testing participation (Fransen, Schoonen, Mackenbach, Steegers, de Koning, Laudy et al., 2010; Fransen, Wildschut, Mackenbach, Steegers, Galjaard, & Essink-Bot, 2010). Lack of knowledge or understanding of prenatal care, transportation and financial obstacles, and language barriers have been shown to be obstacles in obtaining amniocenteses, and prenatal care in general.

Browner (1999) reported that many Latina women were unprepared for the offer of an amniocentesis and were unsure of how to respond, while others thought this additional decision was burdensome. In the past prenatal care was approached more paternalistically, especially in the Latina population, but now women are making informed decisions for themselves and their unborn child (Dahl, Kesmodel, Hvidman, & Olesen, 2006). It may be that the number of options and possibilities are overwhelming (Browner, 1999). Understanding the reasons why Latina women have different preferences regarding prenatal testing can help healthcare providers including genetic counselors provide more personalized prenatal care to this large minority population.

In a qualitative study within a rural Latina population, the majority of participants initially stated they would undergo an amniocentesis if their maternal serum screening

results were positive because they wanted to gain knowledge, to be reassured, and to prepare for a child with special needs (Griffiths & Kupperman, 2008). Upon learning about the risk associated with amniocentesis, many changed their minds. In both a study by Griffiths and Kupperman (2008) and a study by Baker et al. (2004) women reported that the risk of miscarriage was too high and they would not consider a termination. Studies have shown that the perceived risk of miscarriage is an influential factor in a Latina's decision-making regarding amniocentesis. Browner et al. (1999) conducted a series of interviews and found that 62% of Latinas reported the risks of an amniocentesis as being extremely or rather risky for the fetus and 22% described the procedure as extremely or rather risky for the mother, even after counseling. Fear of miscarriage was a statistically significant reason for refusing the amniocentesis (Browner et al., 1999). Browner et al. (1999) also reported that Latinas were more likely to accept an amniocentesis if they had positive opinions regarding their doctors' suggestions, wanted reassurance from the test results, or thought the doctors could benefit from the results.

By interviewing 33 Latina women, Griffiths and Kupperman (2008) found that personal risk perspectives were based on family history, previous pregnancy history, their health during the pregnancy, and experiences that other women from their community have had. Another potential reason for low amniocentesis uptake is that Latina women did not entirely believe the information presented to them in a genetic counseling session. Many of these women stated that they knew about advanced maternal age, but doubted its legitimacy (Griffiths & Kupperman, 2008), and others were concerned about the needle harming the baby (Baker et al., 2004).

Hunt and de Voogd (2005) were interested in physician's opinions of why Latinas had lower uptake rates of amniocenteses. They interviewed 40 patients, 50 clinicians, and observed 100 genetic counseling sessions. Although the physicians reported that Latinas were from a male-dominated culture and did not pursue amniocenteses in order to appease their partners, the participants said their husbands were a source of support, and not influential in their decision. Additionally, the physicians listed several other reasons why they believed Latinas declined amniocenteses including: religion, fatalism, famialism, and superstitions about lunar eclipses, witchcraft, and evil eyes. Many of the women who thought God was responsible for their health were less likely to take action in pursuing prenatal testing (Hunt & de Voogd, 2005). Most women interviewed about the acceptance of birth defects said they would accept any child (Hunt & de Voogd, 2005; Griffiths & Kupperman, 2008). This concept is called fatalism, the idea where all events are meant to happen and will happen regardless of any intervention. Kupperman et al. (2006) reported that the differences in prenatal testing uptake among different racial and ethnic groups may be attributable to issues of faith and fatalism.

The fact that Latinos are comfortable with the concept of fatalism is often attributed to the fact that many Latinos are of the Roman Catholic faith, yet many Latinos do not indicate their religion as a decision making factor in prenatal diagnosis (Browner et al., 1999). Both Latinas who accept and decline amniocentesis are likely to believe that their pregnancy is in the hands of God (Browner et al., 1999). Similar to how Latinas use prayer as a source of support in healthcare, they report that religion is a source of comfort for whatever decision they make regarding the amniocentesis, and that it provides them with support and validation for their choice (Seth, 2008).

Browner et al. (1999) also reported that women who had had previous miscarriages were less likely to pursue an amniocentesis which could be evidence of anchoring. In addition, Latina women have been shown to believe the amniocentesis will touch the baby. Even after watching a video and participating in a counseling session patients still held on to this belief (Baker et al., 2004).

Additionally, even more so than the general population, Latinos typically have less experience with quantifying numbers. In a study comparing numeracy of emergency room patients of different ethnic backgrounds, Ginde, Clark, Goldstein, and Camargo (2008) found an odds ratio of 0.36 [95%CI, 0.19-0.69] for Latino patients' numeracy when compared to that of Caucasian patients. This means that the odds of a Latino understanding numeracy are about a third of the Caucasian population. However, as in all ethnic groups, the actual extent of an individual's numeracy is typically related to their level of education and income (Ginde et al., 2008). A study looking at asthma patients' numeracy aimed to identify commonalities between people with poor numeracy also found Latinos to have lower numeracy scores than the other populations (Apter, Wang, Bogen, Bennett, Jennings, Garcia, et al., 2009). They suggested that limited formal educational opportunities could be related to this trend.

Previous work

The majority of studies regarding anchoring and its effects on genetic counseling are based on breast cancer risk counseling (Senay & Kaphingst, 2009). Studying anchoring on amniocentesis-related complications within a prenatal genetic counseling setting is significantly different than a cancer setting because the numerical risk values are much

lower. A procedure-related miscarriage rate is less than 1%, while a lifetime risk of developing breast cancer may be as high as 87.5% in BRCA1/2 mutation carriers (Van der Kolk, de Bock, Leegte, Schaapveld, Mourits, de Vries, et al., 2010). Larger, more recognizable numbers are less likely to be misconstrued.

Nuccio (2010) explored anchoring in amniocentesis decision making within a diverse group of women seeking prenatal care in Houston, TX. She found that women who viewed the risk of amniocentesis to be low before counseling generally felt the same way after counseling and were more likely to pursue testing than others. Similarly she found that women who came in with a high risk perception were likely to still find the risk of amniocentesis related complications high after counseling, and these women were least likely to pursue the procedure. Women who showed the most significant anchoring effect were those who knew someone with a genetic birth defect. Overall women seemed to bring unique circumstances to the counseling session and few specific trends were seen.

The exact effect of anchoring on the amniocentesis decision making process is unexplored in the Latina population. To date, there have been no studies reported examining the effect of anchoring within the Latina population in regard to amniocentesis risk perception. Given that the Latina population is less comfortable with numbers and is less acculturated to US medicine, we hypothesize that Latinas may have more homogenous anchoring in religion and culture. We also hypothesize that anchoring will play a significant role in their risk perception and in the decision making process regarding the choice to pursue or decline an amniocentesis.

MATERIALS AND METHODS

Study Approval

The study protocol was submitted to the UT Health Office of Research Support Committees. The project was reviewed by the Institutional Review Board (IRB) and was approved by expedited review (UT IRB HSC-GSBS-10-0351). The study was also submitted to and approved by the Harris County Hospital District Department of Research and Sponsored Programs.

Study Population

English and Spanish speaking pregnant women ages 18 and older who self identified as Latinas were included in the study. The inclusion criteria included women who were having genetic counseling due to advanced maternal age (35 years of age or older at the time of delivery) and/or because of an abnormal maternal serum screen, indicating an increased risk for a chromosomal abnormality. Women seeking genetic counseling for other indications such as a family history of disease or ultrasound findings were excluded from the study. Recruitment began on October 11, 2010 and ended on February 28, 2011.

Study Sites

Participants were recruited from Lyndon B. Johnson General Hospital and St. Joseph's Hospital, which are staffed by Maternal Fetal Medicine fellows and faculty from the Department of Obstetrics, Gynecology and Reproductive Sciences at UT Health. Genetic Counseling services were provided by board certified genetic counselors as well as by students in the University of Texas Genetic Counseling Program. Students were

supervised by board certified genetic counselors and their participation in the session was indicated on the survey.

Participants were also recruited from several Harris County Hospital District clinics, which offer prenatal genetic counseling services through UT Health, as well as obstetric services. A board certified genetic counselor provides services at these clinics as well.

Study Design

A letter of invitation and part one of the questionnaire were distributed by the office staff upon check-in. Women who chose to participate completed part one of the survey prior to genetic counseling. The second part of the survey was administered by the genetic counselor after the genetic counseling session. The genetic counselor also completed a third portion of the survey.

Survey Instrument

A two-part anonymous survey was used to collect data from participants and a single follow-up survey was used to collect data from the genetic counselor involved in the session. No personal information that could later be used to identify the patient was included in the survey. The cover letter included a description of the study as well as a brief overview of an amniocentesis.

The first part of the survey collected demographic information, knowledge of amniocentesis, experience with amniocentesis and genetic disease, and opinions on the risk of amniocentesis-associated miscarriage. The demographic information included several questions aimed at assessing the participant's acculturation. These included languages

spoken, languages spoken at home, time in the United States, and country of origin. Participants who indicated that they or an acquaintance or family member had had a previous amniocentesis were asked to share the results and any complications associated with the procedure. Participants were also asked to share if they had a child or knew of a child with a genetic condition, and were asked to share the diagnosis, if known.

The second part of the survey asked the same questions regarding the risk of amniocentesis and their perception of that risk, and asked the participant what her decision was regarding the amniocentesis and what lead her to that decision. The question on this portion of the survey regarding amniocentesis decision was designed to be a multi-step question where the participant indicates yes, no, or undecided regarding pursuing an amniocentesis, and then selects reasons for their decision.

The counselor portion of the survey collected additional demographic data and data relating to the participant's pregnancy history. Citizenship status, gestational age, indication for genetic counseling, and number of previous pregnancies were all recorded by the counselor. Additionally the counselors were asked to say what the participant's amniocentesis decision was and why. Information was also collected on who the genetic counselor was for the session, if a student was present, what language the session was conducted in, and if there was an interpreter present.

The survey instrument was modeled from a previous study examining anchoring in amniocentesis decision making in a diverse English speaking population (Nuccio, 2010). Additional questions were added to assess levels of acculturation, and the order of questions was rearranged. The rationale for rearranging the survey questions was to have the easy to answer demographic questions at the beginning, making the women more comfortable with

the format of the survey. Much thought went into the best way to ascertain what women thought the risk of an amniocentesis was before and after counseling. Based on experience from the study by Nuccio we chose to ask what percentage of women would have an amniocentesis, and provided a space for a free-response answer. Asking women to express the risk in fraction format proved to be difficult in the Nuccio study.

Survey Administration

The front desk staff members at both hospital locations were responsible for distributing the first portion of the survey to women who met the qualifications for enrollment. The participants completed the first part of the survey (Appendix A) in the waiting room and returned the survey to the front desk staff. At the Harris Country Outreach Clinics the genetic counselor distributed this portion of the survey.

After the first portion of the survey was filled out, the participant had a genetic counseling session. During the genetic counseling session a detailed family history was obtained, the patient's individual risk to have a child with a chromosomal abnormality was explained, as well as the risks, benefits, and limitations of an amniocentesis. The majority of women received a high-resolution ultrasound on the same day as the genetic counseling session and those who chose to do so underwent an amniocentesis.

The genetic counselor was responsible for matching survey ID numbers and distributing the second part of the survey (Appendix B) as well as completing the counselor portion (Appendix C). The second part of the survey was completed in the counseling room or in the patient waiting room, depending on participant and/or counselor preference.

Completed surveys had no identifying information and were stored temporarily at clinic sites and then collected by the principal investigator.

Statistical Analysis

Each survey was assigned a unique number. Data from all three portions of the surveys were entered into a Microsoft Access database. The access database was used to query data and transfer information from the compilation of survey questions to statistical analysis.

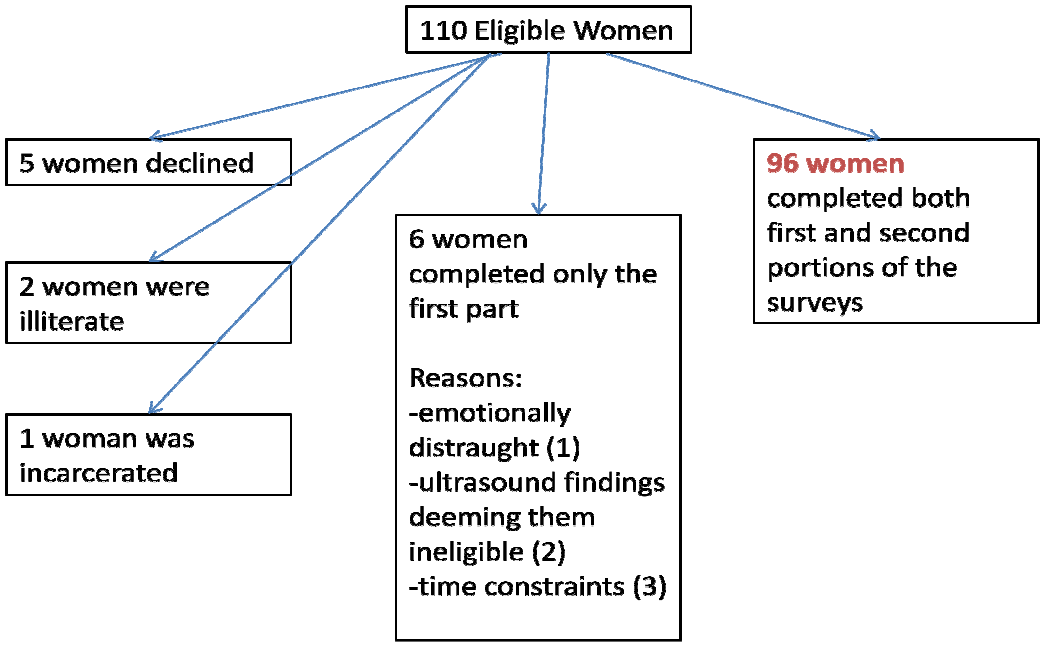
Statistical analysis was performed in STATA/IC v.11.0 for Windows (College Station, TX) and included Fisher's exact tests, Wilcoxon rank sum tests, and Kruskal-Wallis tests. Statistical significance was assumed at $p<0.05$. Additional data was reported in a descriptive manner.

RESULTS

A total of 110 women were originally identified to participate in our study. Five women declined our offer to participate, two women were illiterate, and one woman was incarcerated and unable to participate. Additionally, six women participated in only the pre-counseling portion due to time constraints (n=3), ultrasound findings (n=2), or emotional duress (n=1). The remaining 96 (88%) women filled out both the pre and post counseling portions of the questionnaire (Figure 1) and were thus included in the study. In addition, the genetic counselor involved with each of these cases completed the counselor portion of the survey.

Although 96 surveys were filled out, some participants left questions unanswered on the pre-counseling portion. Therefore, the sample size varied for the different questions.

Figure 1: Participation Flowchart



Demographics

All of the participants self-identified as being Latina. The majority of surveys were completed in Spanish (n=85, 88.5%), while the remainder were completed in English. Only 6.3% (n=6) of the participants indicated that they spoke both English and Spanish in their home, while 87.5% (n=84) spoke only Spanish, and 4.2% (n=4) spoke only English. Most of the genetic counselors conducting the genetic counseling sessions spoke Spanish; however others (n=12, 12.5%) used a professional interpreter during the session (Table 1).

Only 4.2% (n=4) of the participants were born in the United States, while 75.0% (n=72) were born in Mexico, 5.2% in Honduras, and 8.3% in El Salvador. Other individuals were born elsewhere (7.3%) or did not indicate their birthplace on the questionnaire. Individuals born in the United States (n=4, 4.2%) had lived in the United States their entire lives. One woman moved to the United States within a year of her genetic counseling appointment, 14 (14.6%) had lived in the United States for 1-5 years, 27 (28.1%) for 6-10 years, 27 (28.1%) for 11-15 years, and 21 (21.9%) for more than 15 years. Two women (2.1%) did not indicate how long they had lived in the United States. Citizenship or residency status was collected on 86 of the 96 participants. Only 8.4% (n=8) were United States citizens and 11.6% (n=11) were US Residents (Table 1).

Over half of the participants (n=52) had not earned a high school diploma or GED. Approximately 1/3 (n=32) of the participants had less than an 8th grade education while 20.8% (n=20) had some high school. Less than a 1/3 of the participants had a high school diploma or GED (n=27), 8.3% had some college, 1.0% had a college degree, and 3.1% had a graduate level education. Five women did not respond (Table 1).

Overall the population surveyed was quite impoverished. Only 8.3% indicated that their household made more than $2,100 a month, while 7.3% made between $1,800-$2,100, 12.5% made between $1,500-$1,800, 19.8% made between $1,200-$1,500, and 42.7% made less than $1,200. Nine women (9.4%) did not provide any information about income (Table 1).

The participants ranged in age from 18-44, with a mean age of 36.7. The majority of participants were 35 or older at the time of counseling (92.8%). One woman did not respond. The majority of the participants self-identified as being Catholic (78.1%). Others were Protestant Christians (12.5%) or a Jehovah's Witness (1%). Four women (4.2%) said they had no religion, while 2.1% indicated "other," and 2.1% did not provide a response (Table 1).

Table 1: Demographic Information

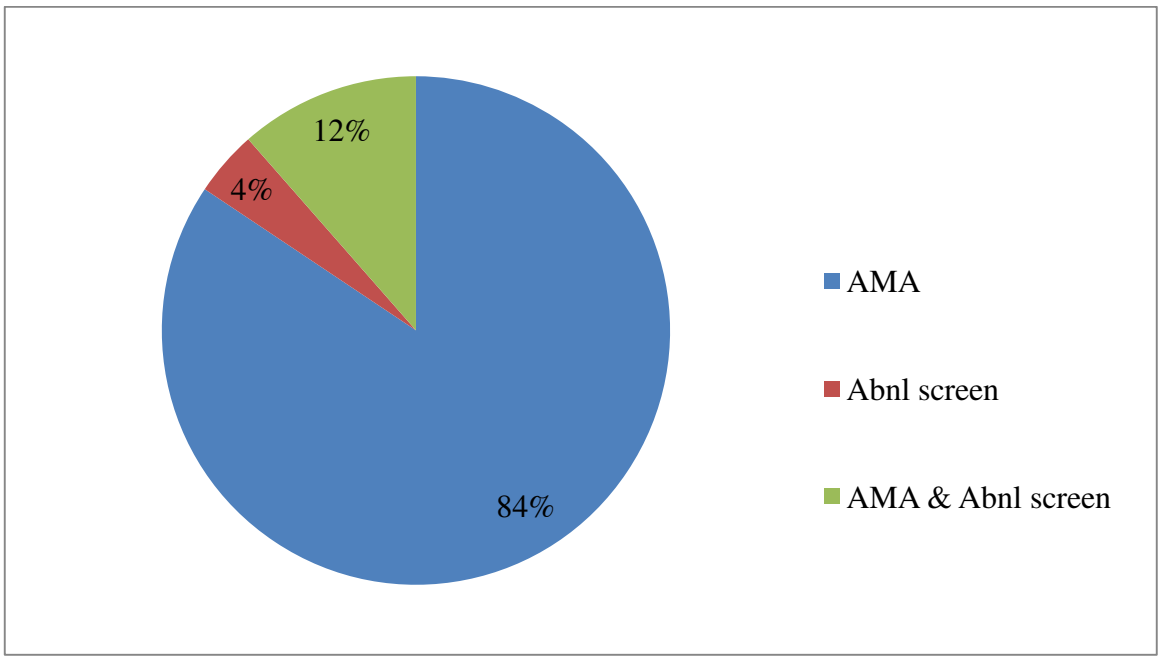
	n (%)		n (%)
Language at home		Education	
Spanish	84 (87.5%)	>8th grade	32 (33.3%)
English	4 (4.2%)	Some HS	20 (20.8%)
Both	6 (6.3%)	HS or GED	27 (28.1%)
No Response	2 (2.1%)	Some College	8 (8.3%)
		College	1 (1.0%)
Birthplace		Graduate Sch.	3 (3.1%)
Mexico	72 (75.0%)	No Response	5 (5.2%)
US	4 (4.2%)		
El Salvador	8 (8.3%)	Monthly Income	
Honduras	5 (5.2%)	<$1,200	41 (42.7%)
Other	6 (6.3%)	$1,200-1,500	19 (19.8%)
No Response	1 (1.0%)	$1,500-1,800	12 (12.5%)
		$1,800-2,100	7 (7.3%)
Time in US		>$2,100	8 (8.3%)
< 1 year	1 (1.0%)	No Response	9 (9.4%)
1-5 years	14 (14.6%)		
6-10 years	27 (28.1%)	Age	
11-15 years	27 (28.1%)	<35 years	6 (6.3%)
> 15 years	21 (21.9%)	35-39 years	71 (74.0%)
Whole life	4 (4.2%)	>40 years	19 (19.8%)
No Response	2 (2.1%)	No Response	1 (1.0%)
Residency		Religion	
Resident	11(11.6%)	Protestant	12 (12.5%)
US citizen	8 (8.4%)	Catholic	75 (78.1%)
Other	67 (70.5%)	None	4 (4.2%)
Unknown	10 (9.5%)	Other	3 (3.1%)
		No Response	2 (2.1%)

Data tabulated for all respondents (N=96)

Genetic Counseling

Participants were asked if they knew about their genetic counseling appointment prior to the appointment. Seventy-six (79%) of the women we interviewed knew that they had an appointment while 20 (21%) did not. Of the 76 women who knew they had a genetic counseling appointment, 64 (84%) knew why, while 12 (16%) did not. The indications for genetic counseling are listed below in Figure 2.

Figure 2: Genetic Counseling Indications



Two participants had a previous amniocentesis in a prior pregnancy. Neither woman had any complications associated with the procedure or had results that indicated pregnancy complications.

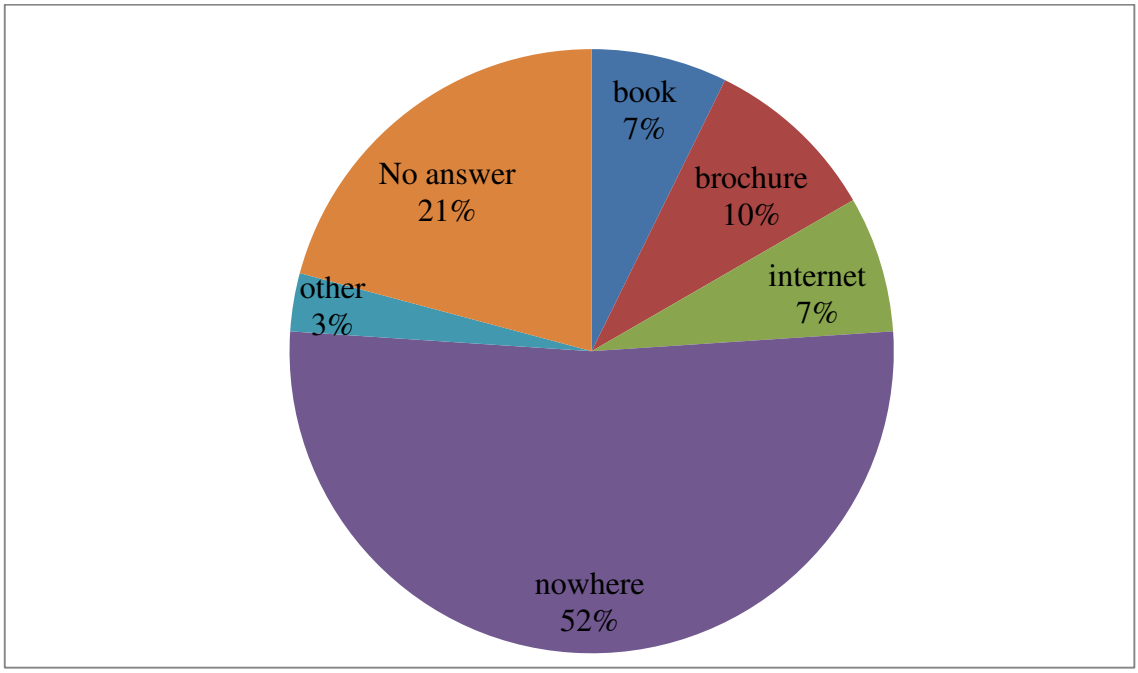
Forty-three (50%) of the individuals had heard of an amniocentesis prior to counseling, while the other half had never heard of the procedure. Thirty-nine of the individuals who had heard of the amniocentesis had spoken to others about the procedure

(90.1%). The survey allowed women to select multiple people that they had spoken to, and a few of the individuals indicated speaking to more than one person. Participants were also asked to indicate if the person they had spoken to had suggested they get an amniocentesis, not get an amniocentesis, or did not give a suggestion. The responses are listed in Table 2. Participants were also asked if they read anything about an amniocentesis prior to counseling. The results are displayed in Figure 3.

Table 2: Who individuals spoke to about an amniocentesis prior to genetic counseling

Who did you speak to? Did they suggest it?	Yes	No	No Suggestion	Total
Doctor	9	7	3	**19**
Spouse	0	3	1	**4**
Mom	0	2	2	**4**
Sister	0	3	0	**3**
Friends	3	6	1	**10**
Co-workers	1	1	0	**2**
Other	0	1	0	**1**
Missing	1	3	0	**4**
Total	**14**	**26**	**7**	**47**

Figure 3: Did women read about the amniocentesis prior to counseling?



Individuals were asked to report on the amniocentesis experiences of their friends and family. Ten (10.4%) women said they knew someone who had had an amniocentesis in the past, and 68 (70.8%) said they did not. One (1.0%) woman was unsure, while 17 (17.7%) did not answer the question.

Eight of the ten women were able to indicate the person they knew that had had an amniocentesis in the past. Those responses are listed in table 3. Four of the women said that the amniocentesis showed problems with the baby, and two women reported that the amniocentesis caused problems with the pregnancy (fever and miscarriage).

Table 3: Who individuals knew that had had an amniocentesis

Who had the amniocentesis?	Frequency
Friend	5
Co-worker	1
Other	1
Other Family	1
Total	**8**

Fourteen (14.6%) women had had genetic counseling previously, 55 (57%) had not, 8 (8%) did not know, and 19 (20%) did not answer the question. Of the fourteen women who had had genetic counseling in the past, 11 were referred for advanced maternal age, one for a maternal serum screen, and 2 did not know why they had been referred for genetic counseling in the past.

Fourteen (14.6%) women knew someone who had a child with a genetic disorder, 66 (68.8%) did not, and 1 (1.0%) did not know. Fifteen (15.6%) women did not answer the question. We asked individuals to indicate who they knew who had a child with a genetic disease, as well as what condition they had. (Tables 4 and 5). None of the individuals indicated that they had a child with a genetic condition themselves.

Table 4: Who did the participant know who had a child with a genetic condition?

Whose Child?	Frequency
Friend	7 (50%)
Sister	1 (7.1%)
Co-worker	3 (21.4%)
Other	2 (14.3%)
No Response	1 (7.1%)
Total	**14**

Table 5: What disorder did participant's friend's child have?

What disorder do they have?	Frequency
Don't Know	1 (7.1%)
Down Syndrome	6 (42.9%)
Motor development delay	1 (7.1%)
Muscle Problems	1 (7.1%)
Small kidneys	1 (7.1%)
Syndrome	1 (7.1%)
Mentally retarded	1 (7.1%)
No Response	2 (14.3%)
Total	**14**

Pre-Counseling Risk Quantification and Risk Perception

Participants were asked to write down what percentage of women would have a miscarriage following an amniocentesis. Prior to counseling, only one woman provided a percentage, indicating that 1% of women would have a miscarriage following the procedure. Sixty women (62.5%) indicated that they did not know the percentage, while 35 women (36.5%) left the response field blank (Table 6).

Participants were also asked "How would you rate the risk of miscarriage from amniocentesis?" within a Likert scale from very low to very high. While the majority of women did not provide a response, 27 did. Nine (9.4%) women viewed the risk as very low, 7 (7.3%) as low, 8 (8.3%) as average, 2(2.1%) as high, and 1(1.0%) as very high (Table 7).

Table 6: Pre-Counseling Risk Quantification

Miscarriage Risk	1%	Don't Know	No Response
N=96 (%)	1 (1.0%)	60 (62.5%)	35 (36.5%)

Table 7: Pre-Counseling Risk Perception

Risk Perception	Very Low	Low	Average	High	Very High
N=27 (%)	9 (33.3%)	7 (25.9%)	8 (29.6%)	2 (7.4%)	1 (3.7%)

The responses of risk quantification are compared to risk perception in Table 8. Although many women indicated that they did not know the risk of miscarriage associated with an amniocentesis, some were still able to express their perception of that risk. The majority of women who did not know the risk quantification, but did answer the risk perception question, found the risk to be very low to average (Table 8).

Table 8: Pre-Counseling Risk Quantification & Risk Perception

Risk Perception	1%	I don't know	No Response
Very Low	0	8	1
Low	1	5	1
Average	0	8	0
High	0	2	0
Very High	0	1	0
No Response	0	36	33
Total	**1 (1.0%)**	**60 (62.5%)**	**35 (36.5%)**

N=96

As only one person answered the pre-counseling risk quantification question, no statistical analyses were performed with the variables. Kruskal-Wallis tests were run on demographic variables compared to the pre-counseling risk perception responses that were collected. None of the comparisons showed any statistical significance.

The genetic counselors indicated information about the participant's pregnancy including gestational age, gravidity, parity, and whether or not the individual had had an ultrasound in the pregnancy, and if so, if it was on the same day as the appointment. These individual personal pregnancy variables were also compared to the pre-counseling risk perception. There were no significant findings.

As previously stated, personal knowledge about an individual's genetic counseling appointment as well as their familiarity with amniocentesis was also obtained. Participants were also asked about the genetic counseling experiences of their friends and family members. All of these "experience" variables were compared to the pre-counseling risk perception and again there were no significant findings. As no participants had a child with a genetic disorder, this variable was not analyzed.

Post-Counseling Risk Quantification

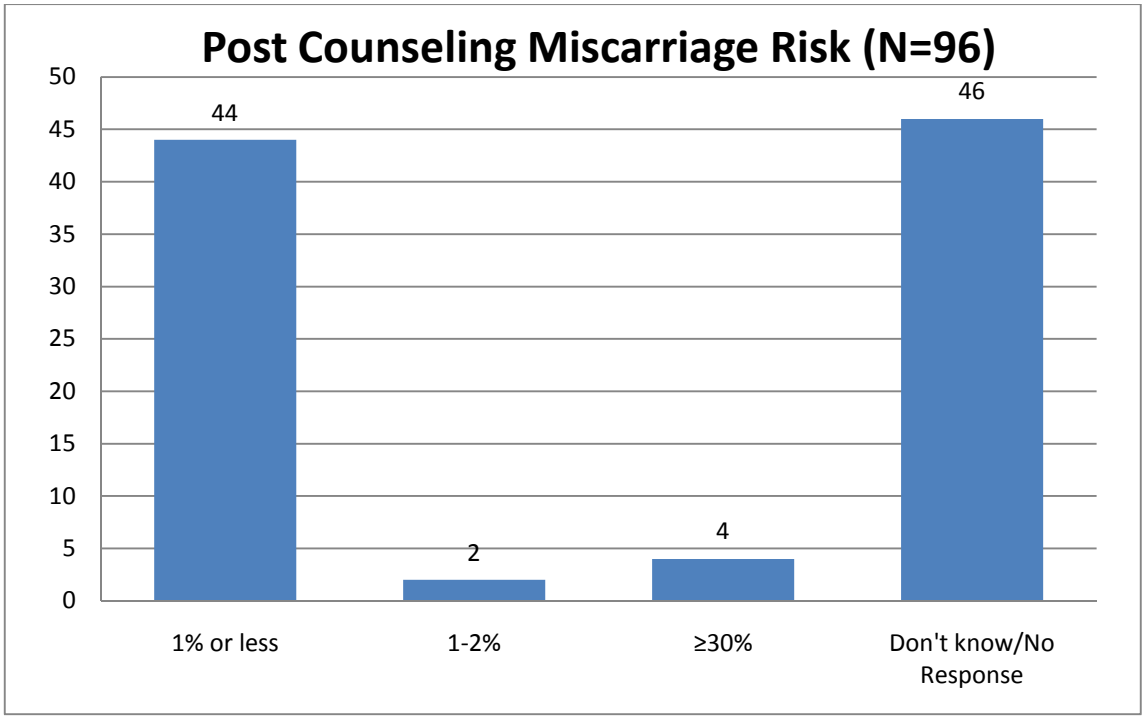
Women were asked the same two questions about the risk of amniocentesis after their genetic counseling session. After counseling, many more women were able to write in a response for the risk of miscarriage associated with an amniocentesis. Thirty-one women (32.3%) indicated that the risk of miscarriage was "1% or less". Some of these women (n=13, 13.6%) reported actual values, either fractions or percentages, that were less than 1% (eg 1/300, 1/200, or 0.33%). One woman thought the risk was 1.5%, and another woman thought the risk was 2%. Four individuals had answers much higher than the risk figure given to them in the counseling session; indicating risks of 30%, 50%, 98%, and 99%. Forty-four women (45.8%) indicated that after counseling they still did not know the risk of miscarriage associated with the amniocentesis. Two women did not give a response (Table 9).

Table 9: Post-Counseling: Risk Quantification

Miscarriage Risk	Frequency	Percent
0	3	3.1%
0.2	1	1.0%
0.33	4	4.2%
0.5	5	5.2%
1	31	32.3%
1.5	1	1.0%
2	1	1.0%
30	1	1.0%
50	1	1.0%
98	1	1.0%
99	1	1.0%
Don't know	44	45.8%
No Response	2	2.1%
Total	**96**	**100%**

Since the miscarriage risk quantification results were quite varied, they were simplified into groups of responses for ease of analysis (Figure 4). Women who did not respond to the question (n=2) were included with those who answered "I do not know."

Figure 4: Condensed Responses to Post-Counseling Risk Quantification



Statistical analyses were performed by comparing risk quantification values after counseling with demographic variables. Fisher's exact tests were used to calculate significance. There was a significant association between post-counseling risk quantification and residency ($p = 0.001$); non-residents were more likely to indicate that they did not know the risk associated with an amniocentesis than citizens or residents (Table 10). When an interpreter was used in the session the individuals were more likely to indicate that the risk of a miscarriage associated with an amniocentesis was 1% or less than indicating

that they did not know, p value = 0.035 (Table 11). The other demographic variables were not statistically significant when compared to post-counseling risk quantification.

Table 10: Post-Counseling Risk Quantification and Residency

	Resident	Citizen	Non-Resident	Unknown
1% or less	8	6	22	8
1-2%	0	1	1	0
≥30%	1	0	3	0
Don't Know/No Response	2	1	41	2
Total	**11**	**8**	**67**	**10**

N=96/p=0.001

Table 11: Post-Counseling Risk Quantification and Interpreter Used

	No	Yes
1% or less	35 (41.7%)	9(75%)
1-2%	1(1.2%)	1(8.3%)
≥30%	4(4.8%)	0(0%)
Don't Know/No Response	44(52.4%)	2(16.7%)
Total	**84(100%)**	**12(100%)**

N=96/p=0.035

Post-counseling risk quantification was also compared to pregnancy history. Women of advanced gestational age (greater than 24 weeks) at the time of their participation were more likely to report that they did not know the amniocentesis associated miscarriage risk or indicate that it was above 30% compared to women at earlier gestational ages, p = 0.028 (Table 12). A higher percentage of patients who had not had a previous ultrasound were more likely to indicate a risk of 30% or more for amniocentesis related miscarriages, p = 0.041 (Table 13). Other pregnancy variables such as gravidity, and number of previous miscarriages were compared, yet yielded no statistically significant associations.

Table 12: Post-Counseling Risk Quantification and Gestation

Gestation	1% or less	1-2%	≥30%	Don't Know
Less than 16 weeks	4	0	1	7
16-24 weeks	38	1	1	33
Greater than 24 weeks	2	1	2	6

N=96/p=0.028

Table 13: Post-Counseling Risk Quantification and Previous Ultrasound

	No	Yes	Total
1% or less	7	37	44
1-2%	0	2	2
>30%	3	1	4
Don't Know	9	37	46

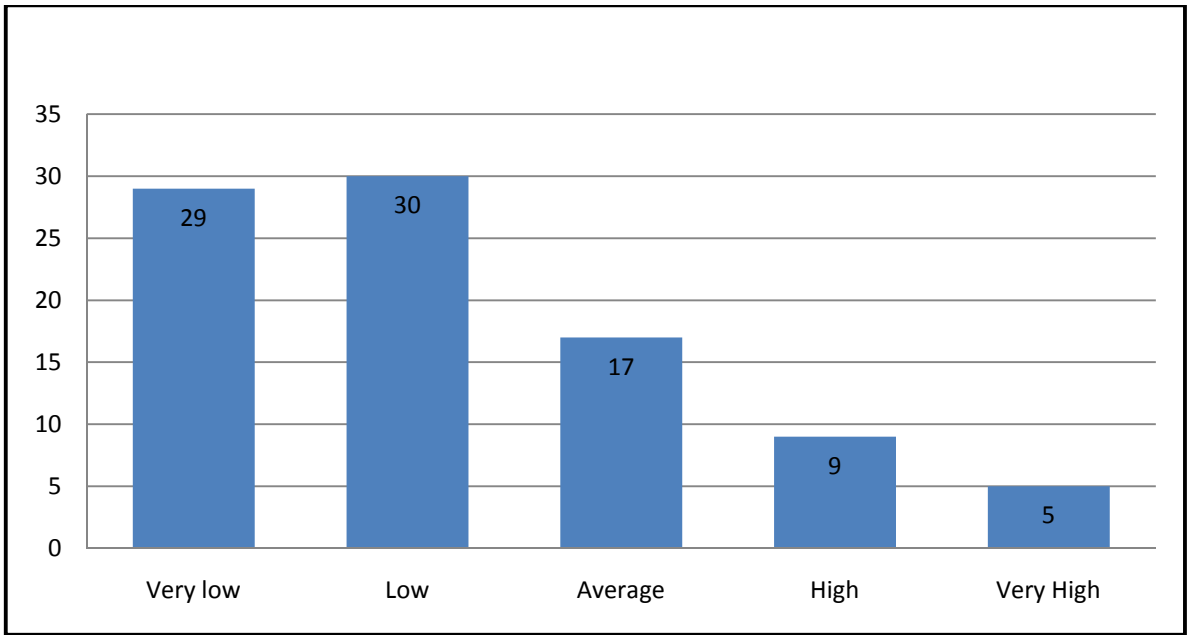
N=96/p=0.041

Other variables were compared to the patients' post counseling risk quantifications as well. Their familiarity with genetic counseling and amniocentesis, experience with genetic counseling and amniocentesis, as well as factors pertinent to the genetic counseling session were compared with their risk quantifications. However, no additional comparisons were statistically significant.

Post – Counseling Risk Perception

Ninety (93.8%) women provided a response to the question about their perception of the risk of an amniocentesis after counseling, while only six women did not. While the majority (n=59, 65.6%) felt the risk was either very low or low, there were also women who indicated that they felt like the risk was average to very high (Figure 5).

Figure 5: Post-Counseling Risk Perception



In the same manner as pre-counseling risk perception, post-counseling risk perception values were compared to multiple variables. Statistical significance was assessed using Kruskal-Wallis analyses. When religion was compared to post-counseling perception there was a significant finding ($p = 0.050$). The majority of respondents were Catholic, and although many of these women viewed the risk as "very low" or "low," Catholics were more likely than the other religions to choose "high" or "very high" as their miscarriage risk perception (Table 14). No other demographic variables were significant.

Table 14: Post-Counseling Risk Perception Compared with Religion (N=88)

Religion	Very Low	Low	Average	High	Very High
Protestant	6	3	1	0	0
Catholic	22	26	13	7	4
None	0	0	2	0	1
Jehovah's Witness	0	0	0	1	0
Other	1	0	1	0	0
Total	**29 (33.0%)**	**29 (33.0%)**	**17(19.3%)**	**8(9.1%)**	**5(5.7%)**

Patients' pregnancy histories were compared to their response about risk perception after counseling. No significant variables were found. Their knowledge and experience about genetic counseling and amniocentesis were also analyzed. Again no significant associations were found.

The information provided to the patient was also analyzed, which included the way the risk was presented to the patient, their indication, and the risk associated with the indication. Other variables about the session included the patient's indication, the syndrome the patient was at risk for due to the maternal serum screen, the patient's risk from the maternal serum screen, and their actual decision about the amniocentesis. We also analyzed the effect of patients' risk perceptions depending on the genetic counselor running the session, including students. None of these variables were significant.

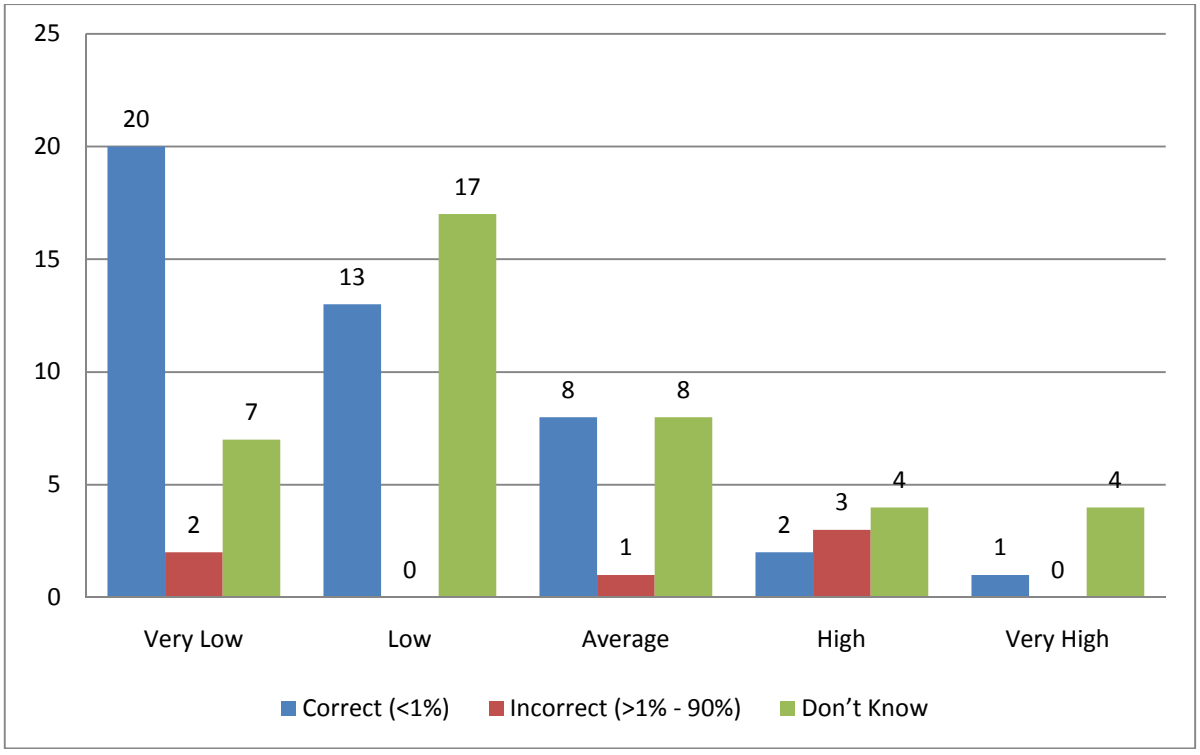
The participants' quantitative risk and perception of risk after counseling were compared (n=90). At this point the responses were classified into "correct" for values that were 1% or less, "incorrect" for values greater than 1%, and "don't know" for women who left the response field blank (n=2) and women who responded that they did not know (n=42). A Kruskal-Wallis test was run on the two variables and the relationship was

determined to be significant, p value= 0.027. Women who chose the correct risk quantification were more likely to choose very low or low for their perception, whereas women who could not quantify the risk, by answering incorrectly or failing to answer the question, were more likely to select high or very high for their risk perceptions. (Table 15, Figure 6).

Table 15: Comparison of Post-Counseling Risk Perception and Quantification (N=90)

	Very Low	Low	Average	High	Very High
Correct (<1%)	20	13	8	2	1
Incorrect (>1% - 90%)	2	0	1	3	0
Don't Know/No Response	7	17	8	4	4
Total	**29**	**30**	**17**	**9**	**5**

Figure 6: Comparison of Post-Counseling Risk Perception and Quantification (N=90)



How Risk Perception and Quantification Changed After Counseling

The risk quantification responses that women gave before and after the genetic counseling session were compared to assess if their risk quantification changed significantly after receiving genetic counseling. About half (n=28) of the individuals who indicated that they did not know the risk of an amniocentesis before counseling were able to identify a risk of miscarriage of 1% or less afterwards. In the same regard, 15 women who initially left the field blank were able to correctly identify the risk of miscarriage associated with the procedure (Table 16). After counseling, a Fisher's exact test was performed to analyze the change in risk perception before and after counseling and no significance was established (p=0.728).

Table 16: Pre and Post Counseling Risk Quantification (N=96)

	Responses Before Counseling			
Responses After Counseling	**1%**	**Don't Know**	**No Answer**	**Total**
0-1%	1	28	15	44
1.5%-2%	0	2	0	2
30% or greater	0	2	2	4
Don't know/No Response	0	28	18	46
Total	**1**	**60**	**35**	**96**

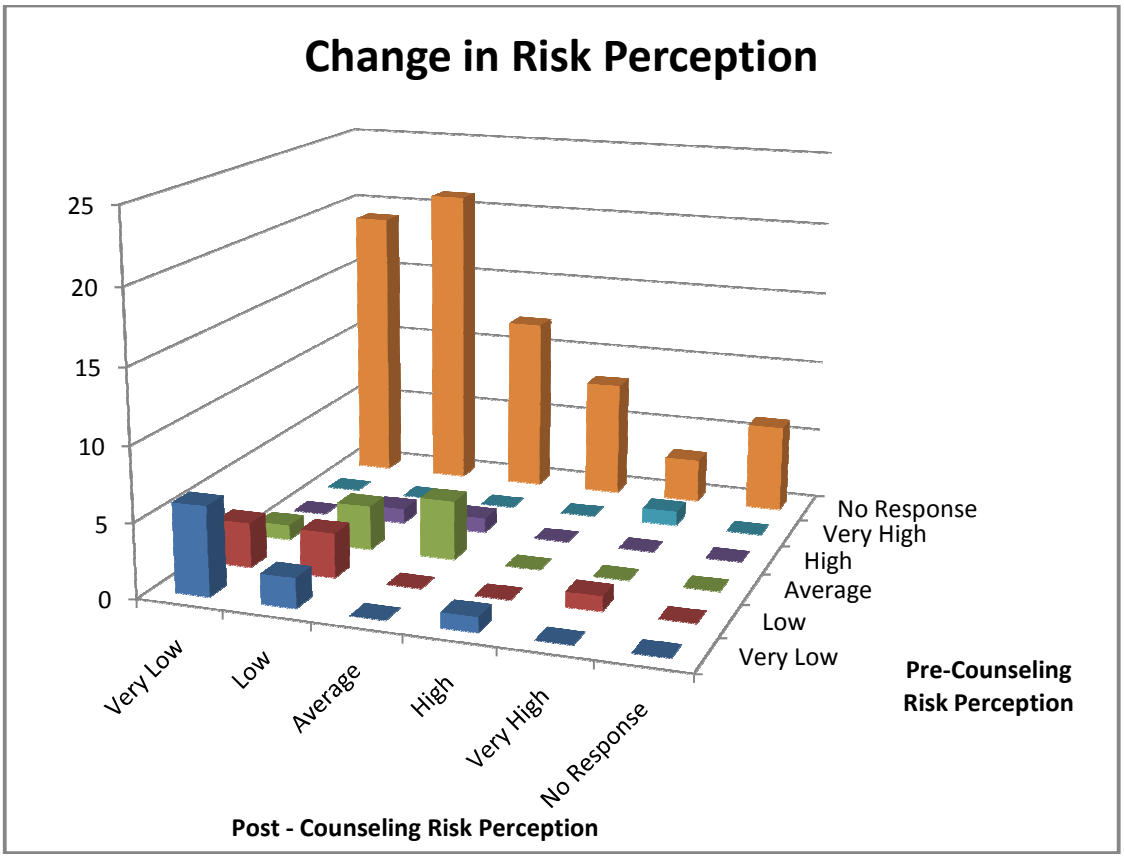
In the same manner, participants risk perception of an amniocentesis was compared before and after counseling. Most of the participants who indicated a risk perception prior to counseling stayed the same, and if an individual did change their perception they were more likely to respond that the procedure was less risky after counseling. The women who initially did not indicate an answer before counseling indicated a variety of feelings after counseling ranging from very low to very high, with the majority being very low to low

(Table 17; Figure 7). A Wilcoxon rank sum test was performed and no statistical significance was identified (p=0.23).

Table 17: Pre and Post Counseling Risk Perception

	Responses Before Counseling						
Responses After Counseling	**Very Low**	**Low**	**Average**	**High**	**Very High**	**No Response**	**Total**
Very Low	6	3	1	0	0	19	29
Low	2	3	3	1	0	21	30
Average	0	0	4	1	0	12	17
High	1	0	0	0	0	8	9
Very High	0	1	0	0	1	3	5
No Answer	0	0	0	0	0	6	6
Total	**9**	**7**	**8**	**2**	**1**	**69**	**96**

Figure 7: Pre and Post Counseling Risk Perception



Amniocentesis Decision Making

The final question on the second portion of the participant survey asked the individual to indicate whether or not they were going to have an amniocentesis and why. Seven individuals said they were having an amniocentesis (7.29%), 72 said they were not (75%), 14 individuals said they were unsure (14.58%) and 3 (3.13%) did not answer the question (Table 18). We did not follow the participants throughout their pregnancy to see if they truly had an amniocentesis or not.

As with the risk perception and risk quantification, the decision whether or not to have an amniocentesis was compared with multiple variables to determine significance. An individual was found to be more likely to pursue an amniocentesis if they were from El Salvador and less likely to pursue an amniocentesis if they were born in the United States or Mexico ($p = 0.021$). Countries of origin and amniocentesis decision are described in Table 19. No other variables were found to be statistically significant.

Table 18: Amniocentesis Decision

Amniocentesis Decision	Yes	No	Don't Know	No Response
N=96	7 (7.29%)	72 (75%)	14 (14.6%)	3(3.13%)

Table 19: Amniocentesis Decision and Birth Country

Birthplace	Yes	No	Don't Know
Mexico	2	61	9
Honduras	0	5	0
El Salvador	3	5	0
USA	0	3	1
Other	2	4	0
Total	**7**	**78**	**10**

N=95/p=0.021

The seven women who chose to have an amniocentesis initially indicated the risk of miscarriage as low, very low, or failed to give a response. No women who initially thought the amniocentesis risk was average, high, or very high elected to have the procedure. While only half of the women in the study (50%) had heard of an amniocentesis, the majority of women (5/7) who had an amniocentesis had heard of it previously. No women under age 35 (n=6), no US citizens (n=8), and no one with a college education (n=7) had an amniocentesis. No one who used an interpreter chose to have an amniocentesis (n=12). All 7 women who had an amniocentesis had already had an ultrasound in the current pregnancy where no problems were identified. None of the women who had an amniocentesis had a household income of more than $1,500 a month (approximately $18,000 USD annually). There were two women in our study population who had a positive maternal serum screen indicating a risk of greater than 2% for a child with a chromosome abnormality and both of these women chose to have an amniocentesis.

There were two women who reported having a previous amniocentesis. One of these women perceived the risk of a miscarriage as very low before and after counseling, while the other thought the risk was low before and after counseling. Neither woman was able to quantify the risk prior to counseling, but both correctly quantified the risk afterwards. One of these two women chose to have a second amniocentesis, yet did not give an answer as to why she was having an amniocentesis. The other patient had a previous child with gastroschisis and a kidney abnormality and chose not to pursue the amniocentesis because she did not think that there was a problem with this pregnancy.

Trends

Although not statistically significant, a few trends emerged that are noteworthy. Prior to counseling, women who knew of their genetic counseling appointment, as well as women who knew why they had a genetic counseling appointment were more likely to indicate high or very high risks associated with the amniocentesis than those women who did not know why they had a genetic counseling appointment.

Of the 27 women who indicated a pre-counseling risk perception, two had had previous amniocenteses and indicated the risk to be very low or low. The other respondents (n=25) had not had an amniocentesis and felt the risk of an amniocenteses to be anywhere from very low to very high with no clear trend.

Some trends also emerged with the risk quantification responses after counseling. All United States born patients (n=4) were able to identify the risk of miscarriage associated with an amniocentesis to be 1% or less (p=0.373). Regardless of whether they chose to do an amniocentesis or not, more than half the women indicated that they did not know the risk of an amniocentesis after counseling.

The risk perception after counseling was associated with some variables. Protestants were most likely to indicate low risks (p=0.098). Women with one or zero miscarriages/abortions were more likely to indicate the risk as high or very high (p=0.832). No one who spoke English (n=11) indicated the risk of an amniocentesis as high or very high (p=0.249). Women who had an amniocentesis previously or who were undecided in the current pregnancy thought that the risk was very low to average (0.634). No one who chose to have an amniocentesis (n=7) viewed the risk as high or very high (p=0.391). No one counseled by a student (n=13) indicated the risk as high or very high (p value = 0.050).

No one who completed the survey in English (n=11) indicated the risk as high or very high. Only women born in Mexico or El Salvador viewed the risk of a miscarriage as high (n=9) or very high (n=5). No one with at least some college education (n=12) viewed the amniocentesis as high or very high. The genetic counselor indicated if she told the patient the risk of an amniocentesis in fraction form (1/300 or 1/200), by saying it is less than 1%, a combination of both, or another explanation. Individuals seemed more likely to choose a lower perception if the risk was given to them as a comparison (less than 1%) than as a fraction, although this was not significant (p=0.22).

Prior Experience with Amniocentesis and Decision Making

Four women indicated that they knew someone who found an abnormality by amniocentesis in a pregnancy. In the pre-counseling survey all four of these individuals said they did not know what the risk of an amniocentesis was. One felt the risk to be very low, two felt the risk to be low, and one found the risk to be average. After counseling, two of the four women indicated the risk of miscarriage was less than 1%, while two individuals still indicated that they did not know the risk. These four women all had different feelings about the risk of miscarriage after counseling and their responses ranged from very low to very high. In the end one of these four women chose to have an amniocentesis, one woman was unsure, and two women decided not to have an amniocentesis.

Similarly, two women indicated that they knew someone who had had complications (eg fever and miscarriage) related to an amniocentesis. Neither of these women knew the risk associated with amniocentesis prior to counseling. The individual who knew someone with a reported miscarriage thought the risk was low; while the individual who knew someone who had a fever after the amniocentesis left the response field blank for pre-counseling risk perception. After counseling both women again did not respond to the question asking about the miscarriage risk associated with amniocentesis and neither woman pursued an amniocentesis. The individual who initially felt the risk was low still thought the risk was low, while the other individual indicated that she felt the risk was average.

The locations of the counseling sessions were compared because some of the clinics have more referrals from private physicians than others. At the site that sees a higher percentage of private patients, women were significantly more likely to have the correct risk quantification than other sites ($p = 0.005$). We were unable to see if the patients sampled

were referred from a private physician or not. Other factors such as an individual's prior knowledge about genetics did not seem to be influenced by location.

Adverse events were lumped together and included previous history of miscarriages and/or abortions, knowledge of someone else with a genetic disease, or knowing a friend who had a problem identified by amniocentesis or who had a complication associated with the procedure. Forty-nine (51.0%) women had experienced some kind of adverse event. The number of adverse events that these women experienced is listed in Table 20. Both a woman's history of adverse events and the number of adverse events were compared to the pre-counseling risk perception and risk quantification, post-counseling risk perception and risk quantification, and the participants' amniocentesis decision. None of these comparisons were statistically significant.

Table 20: Number of Adverse Events per Participant

Adverse Events	**n (%)**
0	47 (49.0%)
1	38 (39.6%)
2	11 (11.5%)
Total	**96 (100%)**

Qualitative/Descriptive Data and Amniocentesis Decision

Although study participants were asked to select only one option regarding what factors they considered important when making their decision about amniocentesis, participants instead selected whatever options they felt like went into their decision making process, regardless of whether the option was classified as a "yes" reason, a "no" reason, or an "I'm not sure" reason. Individuals selected as many options as they wanted to and the choices are listed in Table 21. Some of the more common reasons cited included "the risk is too high" (n=13), "It doesn't matter if the baby has a problem" (n=24), "I don't think my baby has a problem" (n=23), and "I want to do an ultrasound first" (n=12).

Four of the seven women said they were proceeding with the amniocentesis because they needed to know if their baby had problems; 3 women did not give a reason. No other women selected this response. Two other comments were intended to correlate with having an amniocentesis as well: "the risk is low" and "I had one before and did not have any complications." However, the individuals who selected these responses did not indicate that they were planning on having an amniocentesis.

Table 21: Patient Reasons for Amniocentesis Decision

Amniocentesis Reason	**Frequency**
I need to know if my baby has problems	4
The risk is low	2
I had an amniocentesis before, no complications	1
The risk is too high	*13*
I don't like needles	8
It doesn't matter if the baby has a problem	*27*
I had a friend who had complications	3
I don't understand what an amniocentesis would show	2
Don't think the baby has problems	*24*
Husband says no	8
No – other	5
I need to speak to my husband	10
Need to speak with friends	1
I want to do an ultrasound first	*14*
Unsure – other	4

Genetic counselors were also asked to choose any number of reasons that they thought were influencing the patients' decisions (Table 22). The counselors most often said that they felt that it did not matter to their patient whether the baby had a problem or not. While the participants often chose the same response, the participant responses on a whole were more varied.

Table 22: Counselor Reasons for Amniocentesis Decision

Amniocentesis Reasons	**Frequency**
I need to know if my baby has problems	6
I had an amniocentesis before, no complications	1
The risk is too high	*15*
I don't like needles	3
It doesn't matter if the baby has a problem	*64*
I had a friend who had complications	1
Don't think the baby has problems	*17*
Husband says no	2
No – other	4
I need to speak to my husband	9
Need to speak with friends	1
I want to do an ultrasound first	3
Unsure – other	3

The counselors were then asked to list the single most influential factor in the session (Table 23). According to the counselors, the most influential factor affecting the respondents' amniocentesis decision making was that the information obtained from an amniocentesis would not affect their pregnancy management.

Table 23: Counselors' Opinion on Most Influential Factor in Decision Making

Most Influential	**Frequency**
Risk too high	*15*
Risk was low	2
Prior amniocentesis	1
Prior miscarriage or infertility	4
Information previously read	1
Would not affect pregnancy management	*55*
Religious conviction	4
Needles	1
Opinion friend	1
Opinion partner	1
Opinion family member	1
Opinion coworker	1
Opinion other	6

Both counselors and patients alike had an opportunity to write in comments or additional information. Counselors indicated that two women were adamantly against talking about the procedure, and not surprisingly, they did not pursue the amniocentesis. Neither woman recalled the actual risk of the procedure after counseling; one left the follow-up risk perception question blank while the other said it was "very high." Both women were Catholic. Another woman had a friend who reportedly had an amniocentesis and was told that the baby had Down syndrome, yet when the baby was born "it was fine." This is most likely misinformation, yet this participant did not want the amniocentesis even though she thought the risk of the procedure itself was low. Table 24 summarizes the open-ended responses.

Table 24: Additional Comments Made Throughout Survey Process

4 of the women were influenced by previous losses
5 of the women were of late gestational age
2 women were "adamantly" against discussing risks and/or the amniocentesis procedure
One women was convinced she had a friend who had an amniocentesis and was told the baby had Down syndrome; yet the baby was fine
One woman was very conflicted at the idea that she could obtain this information; but that we couldn't "fix" it
2 women were very emotional

DISCUSSION

An amniocentesis may be the most common invasive prenatal diagnostic test (Kupperman et al., 2006), but that does not mean that all populations are equally apt to pursue the procedure during their pregnancy. Such is the case with the Latina population, which has the lowest amniocentesis acceptance rate out of all ethnic groups (Cunningham, 1998; Saucier et al., 2005). There is an underlying risk associated with the procedure, which is typically quoted to the patient as somewhere between 1/200 and 1/1600 (Olney et al., 1995; Eddleman et al., 2006). However, decision making may be affected by previous experiences and risk perception, instead of the actual quoted risk. A previous study by Nuccio (2010) looked at the effects of anchoring within a heterogeneous group of pregnant women presenting for prenatal care in Houston, Texas. Nuccio did not identify significant factors that influenced anchoring. Instead, she found that individuals have unique heuristic frameworks that are used in decision making and that genetic counseling can help each individual in that decision making process. The current study aimed to examine the effects of anchoring and its role in the amniocentesis decision making process in a more homogenous Latina population in Houston, Texas. If anchoring affects amniocentesis uptake, we hypothesized that it would be more profound in this homogenous group.

Demographics

Multiple demographic markers were collected, both to determine the amount of heterogeneity in the group as well as to assess the degree of acculturation. Overall, our population was from a strikingly low socioeconomic status. The majority of the women in our study had less than a high school degree (54.1%), earned less than $1,800 a month

(75%), and very few spoke English as their primary language (11.5%). Many of the women were of the Catholic faith (78.1%), were from Mexico (75%), and had have been living in the United States for more than 10 years (50%). Given the maintenance of their native language and culture, as well as their lower socioeconomic status, it does not appear that this population has acculturated into the mainstream United States culture, making the population a relatively homogenous Latina sample.

There was a low uptake of amniocentesis, with only 7.3% of participants stating that they planned to proceed with the amniocentesis. This uptake rate is strikingly lower than what has been reported in previous studies (Saucier et al., 2005; Browner, 1999). Saucier suggested that Latina women with lower education and income levels would have higher amniocentesis refusal rates compared to other groups. As our group had a low educational attainment and low income level, it may be a reasonable claim that those variables affected the low uptake rate for amniocentesis. Additional factors pertaining to acculturation, opinions about healthcare and the etiology of disease, and personal experiences may also be confounding the lower acceptance rates. This sample is representative of a unique Latina population in Houston, Texas, predominantly ascertained at county and city clinics. Additional research among Latinas in other parts of the United States would be helpful with exploring what effects, if any regional beliefs and attitudes about prenatal testing have on their decision.

Pre-Counseling Risk Quantification and Risk Perception

Women in this study were largely unaware of the concept of prenatal testing and associated risks prior to coming to their genetic counseling appointment. Even though half

of the women had heard of the procedure (n=48, 50%), only one woman even attempted to quantify the risk of an amniocentesis. Some women may have been aware that there was a risk even though they were unable to quantify it, as 27 (28.1%) women were able to express how they felt about the risk. Patients may use their limited information on the subject of prenatal diagnostic testing to form attitudes and beliefs prior to the clinical appointment where the option of an amniocentesis is discussed.

On the other hand, many women had not heard of an amniocentesis before and could not qualify nor quantify the risk. The foreign concept of prenatal testing may catch women off-guard when they present for care and leave them unprepared to make an informed decision during their genetic counseling session (Browner, 1999). In our study, it is difficult to assess if women were averse to the procedure because it was a new concept, or if they had heard negative things about the procedure and its risks prior to counseling.

Women did not have statistically significant pre-counseling beliefs based on their experience with adverse events, such as knowledge of others with genetic disease, previous miscarriages and/or abortions, knowledge of someone who had an amniocentesis related complication, or someone who had a problem identified by amniocentesis. Therefore, adverse events did not appear to anchor women to a belief about amniocentesis.

Post-Counseling Risk Quantification and Risk Perception

After genetic counseling, many more women were able to indicate their risk perception (97.9%), than before counseling (28.1%). Additionally, significantly more women could quantify the risk (45.8%), correctly at 1% or less, compared to 1.0% prior to counseling. Given that almost all participants answered the perception question and only

half answered the quantification question it was evident that it was easier for women to describe how they felt about the risk on a Likert scale from very low to very high, rather than repeat the actual risk value. This could be due to difficulties in understanding the question, lack of comprehension during counseling, or difficulties understanding frequencies and probabilities. Research has shown that laypeople in general perceive frequencies better than probabilities (Keller and Siegriest, 2009; Miron-Shatz et al., 2009). Ginde et al. (2008) reported that the Latino population has significantly lower numeracy than other populations. Another study (Eichmeyer, Northrup, Assel, Goka, Johnston, Williams, 2005) explored the understanding of risks in a Latino population and found 71.5% failed to demonstrate risk comprehension, while only 7.8% of the Caucasian control population did.

After counseling, two of the women in our study indicated risks associated with amniocentesis that showed that they probably did not understand the question. Both women indicated very high risks, 98% and 99%. Other women said they did not remember (45.8%) and 2.1% left the question field blank. Therefore, the lack of answers to the quantification question in our study may be due to low numeracy. This lack of numerical comprehension followed a detailed counseling session where the risks were explained in multiple ways, counselors attempted to check for comprehension, and time was given for questions. Therefore new approaches to the information giving portion of a genetic counseling session may need to be developed for populations with low numeracy.

While risk perception was varied after counseling, the majority of women found the risk to be very low to average (79.2%). Also similar to the before counseling survey, many women who were unable to give a numeric risk value even after counseling were able to describe how the risk made them feel, as 90 women responded to the risk perception

question after counseling, but only 50 indicated a risk quantification after counseling. This could be additional evidence that while this population is unable to process the numeric values, they are still able to express how they feel about the risk. Additionally, patients had lower risk perceptions (p=0.22) when the risk was presented as a comparison, such as "less than 1%", rather than as a fraction. A comparison may be easier to understand than a small fraction and individuals may have greater ease in interpreting that risk because they are able to comprehend it.

Women who did not quantify the risk after counseling were more likely to identify the procedure-related risk as high or very high when compared to women who answered the risk quantification correctly (p = 0.027). Therefore, if women cannot quantify the risk they may be more likely to have an exaggerated risk perception. Otherwise, there were no significant patterns associated with a patient's risk perception and her risk quantification after counseling when looking at variables regarding her pregnancy history, history with genetic counseling and amniocentesis, and knowledge of prenatal diagnostic testing.

These findings suggest that a woman's perception of the miscarriage risk associated with an amniocentesis is likely dependent on factors other than the actual numeric risk of the procedure. In our study many of the counselors felt that, regardless of the risk, the information gained would not affect the woman's pregnancy management (n=55, 57.3%). When Stevens (2008) examined the effect the quoted risk of miscarriage had on a woman's choice to pursue an amniocentesis, 24% of the sample said they would only consider an amniocentesis if there was no risk involved. Therefore, the risk itself may not be influencing women as they may just be uninterested in the procedure because they feel that any risk to their pregnancy is unacceptable.

Twelve women said that they wanted to do an ultrasound first, prior to deciding about an amniocentesis. These women may be using a more complex, stepwise decision making process. This type of decision making process may be more difficult for less educated populations. However, the level of formal education of the individuals who wanted to do an ultrasound first was further examined, and varied widely. Two women had less than an 8th grade education, 2 women had some high school, 3 women had a high school degree or GED, 3 women had some college coursework, and 2 women had graduate degrees. Another possible explanation is that these women had high levels of confidence with the information an ultrasound could provide them and did not understand the need for an amniocentesis in the presence of a normal ultrasound.

Potentially Anchoring Effects

Some factors were identified as statistically significant when compared to risk perceptions and risk quantifications; however, none of them fully explained the participants' overall aversion to amniocentesis. Residency ($p=0.001$), use of an interpreter ($p=0.035$), gestational age ($p=0.028$), and previous ultrasound ($p=0.041$) were found to be significant predictors of the patients' ability to provide a correct risk quantification. Although these variables were found to be significant, there appeared to be no clear or explainable pattern to support these findings. The participants' inability to provide a risk quantification was most likely due to their low levels of numeracy. A larger sample size may negate the significance of these findings or elucidate other variables that may be impacting women's decisions. Therefore, additional studies with a larger population may be warranted.

Many women indicated that they did not believe that there was a problem with their pregnancy (n=23, 23.4%) on their post-counseling survey. Others indicated that it did not matter if the baby had a genetic condition or birth defect (n=24, 25.0%). Counselors involved in the sessions had correctly ascertained that an amniocentesis would not affect the patient's pregnancy management (n=64) and that women did not think there was a problem with their baby (n=17). A previous study determined that common reasons for Latinas to decline the amniocentesis included beliefs that the fetus was healthy and that they were able to bear a healthy child, and skepticism about the validity of the test (Browner et al., 1999). The fact that Latinas do not believe that there is a potential problem with their pregnancy could be due to cultural differences. As Latinas may have different opinions on the nature and cause of birth defects and genetic conditions, there may be an internal negation to the information presented during a genetic counseling session, which may suggest anchoring (Hunt & de Voogd, 2005; Griffiths & Kupperman, 2008). Research has suggested that Latinas' often have different beliefs about the etiology of birth defects, as well as the prevention and irreversibility of birth defects (Hunt & de Voogd, 2005; Griffiths & Kupperman, 2008). Furthermore, Latinas approach pregnancy with a different attitude than other populations, as they consider pregnancy to be a continuation of a healthy state of being (Callister, 2002; Conrad et al., 1998). Learning more about these opinions and previous beliefs will help health care providers understand Latinas' uneasiness about prenatal testing and different viewpoints regarding pregnancy.

No women that was born in the United States, had a college education, or made more than $1,500 a month chose to have an amniocentesis. This was unexpected and contrary to other studies, which have reported that more acculturated, wealthier, and higher educated

women are more likely to pursue an amniocentesis (Browner et al., 1999; Dormandy, Michie, Hooper, and Marteau, 2005). Our sample size of women in this demographic was small and therefore could be a biased finding, or it could be further evidence that each woman is unique and no set of variables can predict her decisions with any certainty. This is a similar finding to what Nuccio (2010) elucidated from her study of a more ethnically diverse population in Houston, Texas; each woman uses a unique set of opinions, experiences, and beliefs to reach a decision about amniocentesis.

Changes in Risk Quantification and Risk Perception

Since only one woman indicated a risk quantification before counseling we could not assess the change after counseling. Similarly it was hard to assess the change in risk perception since only 27 women reported a pre-counseling risk perception. The women who had previously skipped the risk perception question had a variety of feelings after counseling, with the majority ranking the risk from very low to average. However, more women that did not indicate a pre-counseling risk perception rated the risk as high or very high than women who did indicate a pre-counseling risk perception. This could be additional evidence that for women who were not familiar with the amniocentesis before counseling, the amniocentesis is a foreign and therefore potentially frightening concept.

Although not statistically significant, most women who had a previous risk perception had the same risk perception after counseling, and if they changed they were more likely to choose a less-risky response. This trend supports the importance of the genetic counseling session in providing accurate information and eliminating possible misconceptions about the amniocentesis procedure.

Strengths and Limitations

One of the strengths of the current study is the number of women we were able to recruit that met our inclusion criteria. Most women (87.3%) accepted the invitation to participate and completed the two portions of the questionnaire. Another strength is the fact that the majority of genetic counselors that were involved in the project were very familiar with the sample population, which gave us insight on how best to word the survey. We were able to assess participants' perception of risk both before and after counseling, and were also able to collect the counselor's thoughts regarding what women considered as they made their decision about accepting versus declining the amniocentesis. This study afforded valuable insight into a Latina population, and suggests there is more to learn on the best approach to take when describing risk figures and explaining their meaning during a genetic counseling session with this population.

The biggest limitation with our study was our population's apparent unfamiliarity with the use of study questionnaires. Many women struggled to fill out the questionnaire, and seemed to be unfamiliar with the concept of research obtained via a questionnaire. Even with individuals in other populations that may be more familiar with surveys, there can be difficulties in self-administered surveys due to a participant's personal interpretation of the questions. The previous study by Nuccio (2010) used a very similar version of the survey, which had a higher completion rate. Some research suggests that Latinos struggle with research questionnaires (Cortes, Drainoni, Henault, & Paasche-Orlow, 2010). Cortes found that Latina women have a lack of familiarity with research, consent forms, and surveys. These barriers are more significant than just issues with syntax and/or semantics on the forms themselves. In our study many women seemed confused about how to mark off their

answer choices, how to answer sequential questions, and about the actual purpose of the study. Therefore, future studies may wish to utilize face-to-face interviews or focus groups..

Some women commented that some of the words used on the questionnaire were not typically used in every day conversation. The survey was professionally translated and reviewed prior to distribution, but as many of our women were uneducated and/or from different countries it is entirely possible that the questionnaires were difficult for them to comprehend. In a study that examined participants understanding of folic acid during pregnancy, Latinas did not recognize or understand the words genetic or hereditary (Fisher, Hoagwood, Boyce, Duster, Frank, Grisso, et al., 2002). Some of the questions on our survey used these words in order to assess if a participant knew someone with a genetic disease or had had genetic counseling in the past. This may have created additional confusion for some women while trying to comprehend the survey questions.

Conclusions

Our results show that this sample of Latina women of low socioeconomic status and with little formal education were largely unaware of genetics and prenatal diagnostic testing. The sample size as a whole struggled with the idea of a paper questionnaire, and this proved to not be the most successful mode of data collection.

The vast majority of these women were not able to quantify the risk for amniocentesis pre-counseling and only slightly more than half of the women were able to quantify the risk post-counseling, suggesting low numeracy. Women were more likely to state how they felt about amniocentesis, especially after the counseling session. Women were more likely to indicate a lower risk perception when the risk was presented as a

comparison, rather than a fraction. Although not a significant finding, this could be a useful way for genetic counselors to describe risks to a highly innumerate population in a way that they understand.

Most women reported that they felt their babies were healthy and did not elect amniocentesis even if they felt that the risk of miscarriage was low or even very low. Therefore, it seems that Latinas have very different ideals, states of mind, and numeracy comprehension capabilities compared to other populations whose amniocentesis uptake rates have been analyzed. It appears that for this group of Latinas, neither the actual risk, nor their risk perception seem to influence amniocentesis uptake.

Women who have no interest in the amniocentesis nor the information gained from it, may not necessarily need to know all of the intricate details of diagnostic testing. Instead, we need to assess the individual woman's goals and tailor the session to meet those goals. The National Society of Genetic Counselors is currently defining and examining their existing service delivery models to try and determine how best to communicate genetic information to all populations (National Society of Genetic Counselors Strategic Plan 2010-2012). Our findings support the need for a customized genetic counseling model, potentially one that allows for more interplay with an individual's culture and numeracy. Genetic counselors are already educated about the importance of and need for cultural competency. The development of a counseling model that allows for more flexibility within a session, allowing genetic counselors to take into consideration each individual's needs and how their culture affects their needs, will allow us to provide the most beneficial care possible to our patients.

APPENDIX A

Unique Survey #

University of Texas-Health Science Center Houston/HCHD

Effect of Anchoring in Perceived Amniocentesis Related Miscarriage Risk within a Latina Population

Dear Ma'am,

You have a genetic counseling appointment today. The genetic counselor will talk to you about the chance your baby could have a problem like Down syndrome, as well as the different tests that are available to give you more information about your baby. All women coming to the clinic for genetic counseling are given a chance to fill out this survey. All of the information is kept confidential and not shared with anyone. It is not a test and your doctor will not see your answers. You can refuse to answer or stop taking the survey at any time. Your decision about participation in this study or answering questions will not change the care or services that you receive during your pregnancy. Participating in this study does not mean that you will be having an amniocentesis.

My name is Laura Panos and I am studying to be a genetic counselor at the University of Texas-Houston Health Science Center. My advisor, Sarah Noblin, and I are very interested in reasons why women choose to have or not to have an amniocentesis, specifically Latinas.

This research study involves taking an anonymous survey to look at factors that affect what people think about the risk of miscarriage that is associated with an amniocentesis. An amniocentesis, sometimes called the needle test, is a procedure used to tell if the baby has certain genetic conditions, such as Down syndrome. During an amniocentesis, the doctor uses a needle to remove a small amount of fluid from around the baby.

If you have any questions or would like more information, please contact Laura Panos or Sarah Noblin at (713) 566-5938. If you are willing to take part in our study please complete and return the survey to the front desk personnel or genetic counselor.

Thank you very much for your consideration.

Sincerely,

Laura Panos, BS
Genetic Counseling Intern II

Sarah Noblin, MS, CGC
Assistant Director, UT Genetic Counseling Program

APPENDIX B

University of Texas-Health Sciences Center Houston/HCHD

Effect of Anchoring in Perceived Amniocentesis Related Miscarriage Risk within a Latina Population

Section A - Demographics: In this section we would like to learn a little bit more about you. Please answer the following questions:

1. How old are you? _____years

2. What language do you speak at home?
   - ☐ English
   - ☐ Spanish
   - ☐ Both English and Spanish

3. Do you consider yourself Hispanic/Latina?
   - ☐ Yes
   - ☐ No

4. What country were you born in?
   - ☐ Mexico
   - ☐ Honduras
   - ☐ El Salvador
   - ☐ Guatemala
   - ☐ United States
   - ☐ Other:

     _____

5. How long have you lived in the US?
   - ☐ Less than 1 year
   - ☐ 1-5 years
   - ☐ 6-10 years
   - ☐ 11-15 years
   - ☐ More than 15 years
   - ☐ My whole life

6. What is the highest grade you have completed?
   - □ 8th grade or less
   - □ Some high school
   - □ High school or GED
   - □ Some college
   - □ College
   - □ Graduate degree

7. How much money does your family make each month?
   - □ <1,200
   - □ 1,200-1,500
   - □ 1,500-1,800
   - □ 1,800-2,100
   - □ >2,100

8. What is your religion?
   - □ Christian-protestant (for example: Methodist, Baptist, Lutheran)
   - □ Christian-Catholic
   - □ Jewish
   - □ Muslim
   - □ None
   - □ Other:_____

Section B – What is Genetic Counseling

1. Did you know you had a genetic counseling appointment today?
   - □ Yes
   - □ No

2. If yes, do you know why you have a genetic counseling appointment today?
   - □ Yes, if yes do you know why?
     - □ My age
     - □ The results of my blood test
     - □ Other:_____
   - □ No

Section C - Amniocentesis: An amniocentesis, sometimes called the needle test, is a procedure used to tell if the baby has certain genetic conditions, such as Down syndrome. During an amniocentesis, the doctor uses a needle to remove a small amount of fluid from around the baby.

1. Have you heard of an amniocentesis before?
   - ☐ Yes
   - ☐ No

2. Who have you spoken with about an amniocentesis?
   - ☐ No one
   - ☐ My doctor/other healthcare worker (such as a midwife or nurse)
   - ☐ My husband/partner/boyfriend
   - ☐ My mother
   - ☐ My sister
   - ☐ My friends
   - ☐ My co-workers
   - ☐ Other:_____

3. If you spoke with someone about an amniocentesis, did they suggest you have an amniocentesis?
   - ☐ Yes
   - ☐ No
   - ☐ They did not make a suggestion
   - ☐ I didn't speak with any one
   - ☐ I got conflicting information

4. Have you seen or read information about an amniocentesis?
   - ☐ Book (ex: *What to Expect When you are Expecting*)
   - ☐ Brochure or flyer
   - ☐ Internet website
   - ☐ No where
   - ☐ Other:_____

5. Have you ever had an amniocentesis in a previous pregnancy?
    - Yes, if yes how many
        - 1
        - More than 1
    - No
    - Don't know

---Please answer the next 2 questions ONLY if you have had an amniocentesis---

6. What did the amniocentesis results show?
    - No problem(s)
    - Down Syndrome (Trisomy 21)
    - Trisomy 18
    - Trisomy 13
    - Extra or missing sex chromosomes (Ex: Turner syndrome or Klinefelter syndrome)
    - Neural tube defect (spina bifida)
    - Don't know
    - Other:_____

7. Did you have any complications after the amniocentesis?
    - Yes (please indicate which complications)
        - Bleeding
        - Fluid Leakage
        - Fever
        - Miscarriage
        - Other:_____
    - No
    - Don't know

<u>Section D – Risks:</u> The following questions ask about the risk associated with an amniocentesis

1. What percentage of women who have an amniocentesis will have a miscarriage?
    - _____ % of women
    - Don't know

2. How would you rate the risk of miscarriage from amniocentesis?

Very Low	Low	Average	High	Very High
□	□	□	□	□

Section E – Genetics: The following questions ask you about what you know about genetics.

1. Have you ever had genetic counseling before?
   - □ Yes (Please indicate why you had genetic counseling)
     - □ My age, pregnant while over age 35
     - □ Positive blood test for Down syndrome or trisomy 18 (extra chromosome)
     - □ Positive blood test for problem with spine (neural tube defect/spina bifida)
     - □ Family history of a genetic condition
     - □ Other:_____
     - □ Don't know
   - □ No
   - □ Don't know

2. Have any of your children been diagnosed with a genetic disorder or birth defect? (Such as cystic fibrosis, sickle cell anemia, heart defect, cleft lip, Down syndrome)
   - □ Yes, they were diagnosed with:_____
   - □ No
   - □ Don't have children
   - □ Don't know

3. Do you know anyone who has a child with a genetic disorder or birth defect?
   - □ Yes
     - □ Friend
     - □ Mother
     - □ Sister
     - □ Another family member
     - □ Coworker
     - □ Other:_____
   - □ No
   - □ Don't know

4. If yes, what genetic disorder does that person have?
   _____

5. Do you know anyone who has had an amniocentesis?
   - ☐ Yes (please indicate who has had an amniocentesis)
     - ☐ Friend
     - ☐ Mother
     - ☐ Sister
     - ☐ Other family member
     - ☐ Coworker
     - ☐ Other:_____
   - ☐ No
   - ☐ Don't know

---Please answer the next 2 questions if someone you know has had an amniocentesis---

6. If you do know someone who has had an amniocentesis, did the amniocentesis show any problems with their baby?
   - ☐ Yes
   - ☐ No
   - ☐ Don't know

7. If you do know someone who has had an amniocentesis, did they have any complications?
   - ☐ Yes (please indicate which complications)
     - ☐ Bleeding
     - ☐ Fluid Leakage
     - ☐ Fever
     - ☐ Miscarriage
     - ☐ Other:_____
   - ☐ No
   - ☐ Don't know

Thank you for participating! Please return the survey to the front desk staff or genetic counselor.

APPENDIX C

University of Texas-Health Sciences Center Houston/HCHD

Effect of Anchoring in Perceived Amniocentesis Related Miscarriage Risk within a Latina Population

As you may recall, the genetic counselor discussed the amniocentesis with you. Please answer the following questions about that conversation.

1. What percentage of women who have an amniocentesis will have a miscarriage?
   - ☐ _____ % of women
   - ☐ Don't know

2. How would you rate the risk of miscarriage from amniocentesis?

☐	☐	☐	☐	☐
Very Low	Low	Average	High	Very High

3. Is the amniocentesis something you plan to do during this pregnancy?

   ☐ Yes (if yes, please check all that apply)
   - i. I need to know if the baby has a genetic condition or birth defect before birth
   - ii. I think the risk associated with amniocentesis is low
   - iii. I have had one before and had no complications
   - iv. Other:_____

   ☐ No (if no, please check all that apply)
   - i. The risk of miscarriage is too high
   - ii. I do not like needles
   - iii. It doesn't matter if my baby has a genetic condition
   - iv. I have a friend/relative who had problems after a miscarriage
   - v. I don't know what the amniocentesis will tell me about my baby
   - vi. I don't think my baby has a problem
   - vii. My husband/partner does not think I should have an amniocentesis
   - viii. Other:_____

   ☐ Unsure (If unsure, please check all that apply)
   - i. I need to speak with my husband or partner
   - ii. I need to speak with family or friends
   - iii. I want to wait for the ultrasound to see if there are any problems first
   - iv. Other:_____

Thank you for your participation!

APPENDIX D

University of Texas-Health Sciences Center Houston/HCHD

Effect of Anchoring in Perceived Amniocentesis Related Miscarriage Risk within a Latina Population

1. Risk of miscarriage from amniocentesis quoted to patient (check all that apply):
   - □ 1/200
   - □ 1/300
   - □ Less than 1%
   - □ Other:_____

2. What was the patient's indication?
   - □ Advanced maternal age
   - □ Positive serum screen, (Risk of _____for_____)
   - □ Advanced maternal age & positive serum screen
     (Risk of_____for _____)
   - □ Other_____

3. Is the patient having an amniocentesis? (check all that are applicable)
   - □ Yes (if yes, due to)
     - □ She wanted to know if the baby had a genetic condition before birth
     - □ She felt that the risk associated with amniocentesis was low
     - □ She has had an amniocentesis before
     - □ Other:_____
   - □ No (if no, due to)
     - □ The risk of miscarriage is too high
     - □ Does not like needles
     - □ It doesn't matter to the patient if the baby has a genetic condition
     - □ She had a friend/relative with amniocentesis related problems
     - □ She did not understand the information about amniocentesis
     - □ She did not believe there would be anything wrong with her baby
     - □ Her husband/partner was against the idea of an amniocentesis
     - □ Other:_____
   - □ Unsure (if unsure, due to)
     - □ She wanted to speak with her husband/partner
     - □ She wanted to speak with other family/friends

- She wanted to see if there were ultrasound anomalies first
- Other:_____

4. Which of the following most influenced the patient's decision regarding amniocentesis?
   - Risk of miscarriage was high
   - Risk of miscarriage was low
   - Prior amniocentesis
   - Prior miscarriage or infertility
   - Prior child with a birth defect/genetic condition
   - Information the patient read about amniocentesis
   - Would not affect pregnancy management
   - Religious conviction
   - Use of needles
   - Opinion of
     - Friend
     - Mother
     - The father of the baby
     - Sister
     - Other family member
     - Coworker
     - Physician/other health care provider (nurse, midwife, etc…)
     - Other_____
   - Other:_____

Pregnancy History

1. Patients gestational age today: _____weeks, _____days

2. Total number of pregnancies: G_____P_____ _____ _____ _____

3. Has the patient had an ultrasound during the pregnancy?
   - No
   - Yes, if yes were there any problems identified
     - No
     - Yes, please specify:_____

4. Has the patient already had an ultrasound TODAY?
   - □ Yes
   - □ No

5. Does the patient have a child with a genetic condition or birth defect?
   - □ No
   - □ Yes (please describe):_____

6. Counselor for the session:_____

7. Did the counselor perform the majority of the session?
   - □ Yes
   - □ No, if no who
     - □ First year genetic counseling student
     - □ Second year genetic counseling student

8. What is the patient's residency status?
   - □ US Resident
   - □ US Citizen
   - □ Other:_____

9. Were there any other factors that you felt influenced the session? If so, please comment:

   _____
   _____
   _____
   _____

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