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Prenatal Genetic Testing: Factors That Influence Uptake in Hispanic Women
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Purpose:

Pregnancy can signify a time of intense joy and anticipation for the expectant parents, particularly for Hispanics with traditional values who embrace motherhood and the importance of children and family (Page, 2004). Along with such anticipation can be uncertainty and anxiety regarding the health of both mother and baby throughout the pregnancy journey. As the pregnant couple prepares to become new parents, whether for the first time or again, they face many decisions and choices regarding their care. One such decision is whether to undergo PGT. PGT can offer the couple information on possible genetic abnormalities (aneuploidy) – such as Down syndrome, – and congenital malformations – such as heart, brain, and neural tube defects that can be caused by viruses such as Zika, in their baby. PGT can encompass both screening (maternal blood markers - including cell-free DNA - and ultrasound) and diagnostic (amniocentesis and chorionic villus sampling) tests.

The purpose of this study is to identify how perceptions and knowledge of prenatal genetic testing (PGT) influences uptake of PGT in a sample of hard-to-reach underrepresented Hispanic pregnant women in South Texas. Based on prior studies (Farrell, Hawkins, Barragan, Hudgins, & Taylor, 2015), our working hypothesis is that Hispanic women with lower health literacy will have lower uptake of PGT. We also expect that higher degrees of religiosity will be inversely related to PGT uptake. Furthermore, we hypothesize that women who understand themselves to be at higher risk (such as age > 35 years) for an infant with aneuploidy will have higher uptake of PGT (Taylor, Chock, & Hudgins, 2014).

Prior researchers offer support that increased knowledge of PGT increases uptake, or the decision to undergo testing (Farrell, Hawkins, Barragan, Hudgins, & Taylor, 2015). The results of PGT can offer the couple information about the baby and add clarity regarding possible risks their baby may face. Nonetheless, many couples - and Hispanics in particular - forego this testing. The decision not to test may be related to attitudes towards pregnancy termination, often influenced by religious beliefs, or lack of understanding regarding PGT (Farrell, Hawkins, Barragan, Hudgins, & Taylor, 2015). Hispanic women are underrepresented in medical research and few studies have explored Hispanic women and PGT. There is, therefore, a critical need to identify how perceptions and knowledge of PGT influence uptake in Hispanic women. Without such understanding, evidence-based and culturally sensitive educational interventions to improve informed decision-making in Hispanic women will remain ineffective.

Methods:

Thirty participants who self-identify as Hispanic are recruited from a convenience sample at a prenatal clinic in South Texas. Participants are given a paper and pen survey that includes four constructs: Acculturation, Religiosity/Spirituality, Familism, and Genetic Literacy.
Acculturation is measured using the Bidimensional Acculturation Scale for Hispanics (BAS) (Marin & Gamba, 1996). The BAS is validated for use with Mexican Americans. It measures 2 major cultural dimensions (Hispanic and non-Hispanic) encompassing 24 items total. The tool shows good internal reliabilities for Mexican Americans (0.93 and 0.97) and strong construct validity (Marin & Gamba, 1996).

Religiosity/Spirituality is measured using the Duke University Religion Index (DUREL) (Koenig & Büssing, 2010) which encompasses 5 items including public and private religious activities such as service attendance, prayer and meditation, and intrinsic religiosity such as experiencing God’s presence and the influence of religion in other aspects of one’s life. The DUREL has been widely used in hundreds of published studies and has been translated into almost a dozen different languages including Spanish. The Cronbach’s alpha for the DUREL ranges from 0.78-0.91.

Familism, or the importance of family as a means of social support, is measured using the Familism Scale (Steidel & Contreras, 2003). This 18-item scale was developed specifically for use with Latino populations. The tool assesses 4 domains of familial concepts: support, interconnectedness, honor, and subjugation of self for family. The Cronbach’s alpha for the scale is 0.83.

Genetic Literacy is measured using the aurally administered 63 item Rapid Assessment of Adult Literacy-Genetics ([REAL-G]; Erby, Roter, Larson & Cho, 2008) to assess pronunciation. The REAL-G represents a screening tool that can be used to quickly identify low literate patients in the clinical genetics context or to quantify context-specific literacy within a research setting. REAL-G scores identify readers at the sixth-grade level or below (95.4% sensitivity and 88.5% specificity). Scores are created by summing the number of words a participant pronounced correctly; words that a participant pronounced incorrectly or skipped are not counted. Higher scores indicate greater general health literacy and genetics-related health literacy, respectively.

Results:
Pending

Conclusion:
This study is significant because (1) it focuses on the leading cause of death for infants younger than one year in Texas; i.e., genetic abnormalities and congenital malformations which lead to devastating conditions for infants and families and an enormous cost for health-care systems and societies; (2) it provides data to identify patients with prenatal genetic literacy deficits and other factors influencing intention and completion of PGT in Hispanic pregnant women that will aid in the (3) planning and development of a focused evidence-based education intervention to increase PGT uptake among Hispanic pregnant women, an underserved Hispanic population in South Texas.

Title:
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Keywords:
genetic literacy, pregnant Hispanic women and prenatal genetic testing

References:

Bibliography

Abstract Summary:
This study explores factors related to uptake of prenatal genetic testing (PGT) in a hard-to-reach and underrepresented sample of Hispanic women. PGT can offer the couple information about their baby and allow them to prepare for possible risks their baby may face. Factors associated with PGT uptake are presented.

Content Outline:
1. **Introduction**

Based on prior studies, our working hypothesis is that Hispanic women with lower health literacy will have lower uptake of prenatal genetic testing (PGT).

2. We also expect that higher degrees of religiosity will be inversely related to PGT uptake.

3. Furthermore, we hypothesize that women who understand themselves to be at higher risk (such as age >35 years) for an infant with aneuploidy will have higher uptake of PGT.

2. **Body/Background**

1. Pregnancy can signify a time of intense joy and anticipation for the expectant parents, particularly for Hispanics with traditional values who embrace motherhood and the importance of children and family. Uncertainty and anxiety regarding the health of both mother and baby throughout pregnancy may also accompany this joyful time. The pregnant couple will face many decisions and choices regarding their care.

   1. One such decision is whether to undergo PGT. PGT can offer the couple information on possible genetic abnormalities (aneuploidy) – such as Down syndrome, – and congenital malformations – such as heart, brain, and neural tube defects in their baby.

   2. PGT can encompass both screening (maternal blood markers, including cell-free DNA (cfDNA) and ultrasound) and diagnostic (amniocentesis and chorionic villus sampling) tests.

   1. Prior researchers offer support that increased knowledge of PGT increases uptake, or the decision to undergo testing. The results of PGT can offer the couple information about the baby and add clarity regarding possible risks their baby may face. Nonetheless, many couples - and Hispanics in particular - forego this testing.

   3. The decision not to test may be related to attitudes towards pregnancy termination, often influenced by religious beliefs, or lack of understanding regarding PGT.

   4. Hispanic women are underrepresented in medical research and few studies have explored Hispanic women and PGT.

3. **Conclusion**

1. There is, therefore, a critical need to identify how perceptions and knowledge of PGT influence uptake in Hispanic women. Without such understanding, evidence-based and culturally sensitive educational interventions to improve informed decision-making in Hispanic women will remain ineffective.

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