Mexican-American Women & Decision-Making about Prenatal Testing

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A woman's pregnancy can simultaneously be one of the most exciting and uncertain periods during her life, and one key factor has changed women's pregnancy experiences in both positive and negative ways: the creation of and increase of reproductive technologies (Katz Rothman, 1986; Rapp, 2000). The overarching label "reproductive technologies" is an umbrella term for an array of prenatal screenings and testings including but not limited to ultrasounds, chorionic villus sampling, and amniocenteses. Prenatal testing is now a standard component of prenatal care in Western medicine, and the American College of Obstetrics and Gynecology (2007) recommends prenatal screening to all pregnant women, although it is emphasized more when women are 35 years of age or older (Browner et al., 2003; Griffiths & Kuppermann, 2008; Hunt et al., 2005). These diagnostic procedures are conducted to test the fetus for fetal risks, birth defects, and genetic or chromosomal anomalies (American College of Obstetricians and Gynecologists, 2014). The amniocentesis procedure, which is the focus of my dissertation, occurs when a physician inserts a large needle into a pregnant woman's amniotic sac through her belly button to extract amniotic fluid and cells for examination. The amniocentesis procedure has potential side effects such as fluid leakage and a 1 in 200 miscarriage rate, among others (Hunt, de Voogd, & Castaneda, 2005; Papantoniou et al., 2001). Moreover, if a pregnant woman's test results come back indicating Down syndrome or another anomaly, she is left with a few choices: termination of a pregnancy or a life with a child who might have a health issue. A woman's cultural backgrounds and beliefs can also complicate this process, particularly if she has certain value systems pertaining to life, health, and other factors.

This is where my dissertation (which I successfully defended this month, whoop!) enters the conversation. I am interested in how Mexican-American women envision and perceive the amniocentesis procedure, as well as their perceptions of their physicians' and family members' communication about the amniocentesis procedure. Given the Hispanic/Latino population's growth in this country over the last few decades, there is scant literature that explores this phenomenon. Plus, as a Mexican-American female, I am aware of all of the various Mexican cultural norms and dimensions that could potentially shape how Mexican-American women perceive prenatal testing. Thus, utilizing health communication and Chicana feminist lenses to situate my research questions, I obtained IRB approval and conducted semi-structured, face-to-face, in-depth interviews with 15 Mexican-American women in San Diego and 15 Mexican-American women in Houston. All participants were between the ages of 30 - 45. Participants were recruited via the snowball sample method, and during the hour-long interviews I asked participants about their ethnic identities (so that I could explore regional ethnicities), their perceptions of prenatal testing, their views on health and abortion, and their perceptions of their family members' and physicians' involvement in the process. I wanted to explore whether they engaged in shared decision-making with their physicians and the role of their family members in their decision-making processes.

To be honest, what I found shocked me. Much to my surprise, only *one* (yes, one) participant underwent the amniocentesis procedure. Only 4 out of 30 participants received blood test results that potentially indicated a chromosomal anomaly; even then, however, the

other 29 participants refused the amniocentesis because “it wouldn’t change the outcome” of their pregnancies, because they did not see the need for the amniocentesis-related test information, and because the amniocentesis was constructed by family members as a faulty and burdensome test that would result in miscarriages and other issues. Moreover, the most important source of health information for these participants was *not* books, pamphlets or their physician; rather, their family members emerged as the most important source of health-related information. Their family members’ fear narratives about their experiences with the amniocentesis oftentimes persuaded participants to reject the test. Lastly, in terms of physicians, most participants engaged in shared decision-making with physicians when they rejected the tests, and participants preferred physicians who communicated with them in caring, personalized, and supportive ways.

I conclude in my dissertation that the participants’ prenatal testing moments were undoubtedly situated within a complex web of ethnic, cultural, gendered, and familial factors. Moreover, although past research suggests that Mexican-American women generally accept the amniocentesis procedure at rates comparable to Caucasian women, this was not supported in my research. Rather, participants discussed at length reasons why they were so adamant to reject the amniocentesis, most particularly because they would not abort a pregnancy solely because of a chromosomal/genetic anomaly. As one participant mentioned, “As long as my baby is breathing and moving, she’s healthy. That’s all that matters.” The most important findings from my research are fivefold: (1) participants constructed their own interpretations of the amniocentesis procedure based upon a “homegrown understanding” of the procedure, which was shaped by personal interpretations of risk and family members’ fear narratives; (2) from a health information seeking perspective, participants’ family members emerged as the most important and influential source of health information (as opposed to books or websites), and family members’ stories were powerful sources of influence as participants weighed the advantages and disadvantages of the amniocentesis; (3) participants constructed various definitions of “healthy babies,” which varied significantly from certain biomedical constructions; (4) amniocentesis test information was perceived as a stressful burden that would have no bearing on the pregnancy outcome, as opposed to information that could help them plan their future; and (5) there was a disconnect between participants’ interpretations of how the blood screenings and amniocentesis procedure operate and what they test for versus medical definitions and understandings of how the diagnostic tests operate and they kinds of information the tests can provide. With this homegrown knowledge of the amniocentesis procedure, what it tests for, and what its false positive rates are, the participants operated from experiential knowledge bases as they evaluated the amniocentesis procedure and rejected it. Lastly, in terms of physicians, I found that less than one-third of the participants had physicians who were pushy about the test, and a few participants reported that their physicians did not recommend the amniocentesis at all, perhaps because their blood screenings tested negative for genetic and chromosomal anomalies. Participants spoke highly of physicians who took extra time to explain health-related information to them and who established relationships with them. I conclude that in future encounters, physicians should discuss the amniocentesis procedure with patients and then explicitly ask how their patients’ perceptions of the test are shaped by their family members.

References

American College of Obstetrics & Gynecology. (2007). Committee on Practice Bulletins. ACOG Practice Bulletin No. 77: Screening for fetal chromosomal abnormalities. *Obstetrics & Gynecology, 109*, 217-227.

American College of Obstetrics & Gynecology. (2014). *Frequently asked questions: Routine tests in pregnancy.* Retrieved from http://www.acog.org/~/media/For%20Patients/faq133.pdf?dmc=1&ts=20140220T1552062299.

Browner, C. H., Preloran, H. M., Casado, M. C., Bass, H. N., & Walker, A. P. (2003). Genetic counseling gone awry: Miscommunication between prenatal genetic service providers and Mexican-origin clients. *Social Science & Medicine, 56,* 1933-1946.

Griffiths, C., & Kuppermann, M. (2008). Perceptions of prenatal testing for birth defects among rural Latinas. *Maternal and Child Health Journal, 12*, 34-42.

Hunt, L. M., de Voogd, K. B., & Castaneda, H. (2005). The routine and the traumatic in prenatal genetic diagnosis: Does clinical information inform patient decision-making? *Patient Education and Counseling, 56*, 302-312.

Katz Rothman, B. (1986). *The tentative pregnancy: Amniocentesis and the sexual politics of motherhood.* London: Harper Collins Publishers.

Papantoniou, N. E., Daskalakis, G. J., Tziotis, J. G., Kitmirides, S. J., Mesogitis, S. A., & Antsaklis, A. J. (2001). Risk factors predisposing to fetal loss following a second trimester amniocentesis. *British Journal of Obstetrics & Gynecology, 108*, 1053-1056.

Rapp, R. (2000). *Testing women, testing the fetus: The social impact of amniocentesis in America*. New York, NY: Routledge.