

# **The Effect of Genetic Counseling on Prenatal Diagnosis Knowledge in Women of Advanced Maternal Age**

**Joanna S. Zeiger, MS**  
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**Genetic counseling strives to deliver important personal information in a non-directive manner to women concerning the risks of giving birth to a child with a birth defect. The better this information is delivered, the greater is the chance that at-risk women will make knowledgeable choices about their pregnancies. This thesis attempted to determine objectively just how well this information affects the knowledge of these women about their genetic risks. As you will see, we need to do better.**

**Background:** Prenatal testing to evaluate fetal chromosomes is considered routine care for women over 35 years of age. Chorionic villus sampling (CVS) and amniocentesis represent diagnostic tests that can directly assess fetal chromosomes. Measurements of maternal serum alpha-fetoprotein (MSAFP) concentration is a method of screening for risk for Down syndrome. Utilization of prenatal testing in women of advanced maternal age (women over 35 years old) ranges between 33% to 86%. An unresolved issue is, "What factors are incorporated into a woman's decision-making process when considering whether to undergo prenatal diagnosis?"

While individual circumstances greatly influence choices about having prenatal diagnosis, key elements of the decision-making process include knowledge about a test, attitudes toward a test, and perceived risk of having an abnormal child. It has been reported that women undergoing testing have more knowledge than those who do not. Consumer research has indicated that the processes used in making choices differ depending upon the knowledge structures present, levels of knowledge, and the timing of the decision-making process. Others have suggested that perceptions regarding prenatal testing and not lack of knowledge prevent women from undergoing procedures. It has been shown that the greater the perceived risk of having an abnormal child, the greater the choice to undergo prenatal diagnosis. Women with a negative attitude toward prenatal testing are less inclined to undergo a procedure. Attitudes towards amniocentesis differ among women who knew about amniocentesis before education and those who learned about amniocentesis for the first time during genetic counseling.

Most studies have focused on potential acceptance of prenatal testing by presenting women with hypothetical situations, by questioning women about their knowledge and attitudes toward prenatal testing after they have undertaken a procedure, or after the birth of a child. The present study attempts to measure women's knowledge and attitudes regarding prenatal diagnosis prior to a procedure. Women's knowledge and attitudes were explored before and after genetic counseling for advanced maternal age to measure whether genetic counseling changed their levels of knowledge and whether the changes affected their decision to undergo prenatal testing.

**Methods:** Forty-one women referred for genetic counseling because of advanced maternal age were studied to identify a priori knowledge and decisions regarding prenatal testing. A pre-counseling questionnaire was administered to obtain demographic information and baseline

knowledge regarding prenatal testing. The questionnaire also ascertained whether the women wished to undergo prenatal testing. Women then had genetic counseling to explain chorionic villus sampling (CVS) and/or amniocentesis as well as their age-related risk for having a baby with a chromosome abnormality. After the counseling session, women completed a second questionnaire to re-measure knowledge and whether counseling affected their decision to undergo prenatal testing. Knowledge scores were computed for each subject based on their answers to the questions.

**Results:** Before genetic counseling 83% of the women were prepared to have prenatal testing. After genetic counseling, the rate increased to 98%. Eighty-two percent first learned about amniocentesis through their physicians. In addition, 41% of the women also heard about the procedure through books and the media. Knowledge scores did not improve after compared to before genetic counseling. Only 32% of women knew their specific age-related risk for genetic disease in their offspring. Moreover, only 51% of the women believed they were at an increased risk for birth defects because of their age, despite all of them being at increased risk. Only 15% correctly answered what problems amniocentesis detects. The majority of the subjects over-estimated the ability of the procedure by stating that it can detect all chromosome abnormalities, any birth defect, or any genetic condition. Only 39% of the women knew that amniocentesis can also detect neural tube defects. Furthermore, women had difficulty differentiating between a screening procedure and a diagnostic procedure.

**Conclusions:** This study found that the goals of genetic counseling – to increase patient knowledge and understanding of their risks – were not met. Even though knowledge improved with genetic counseling, patients were unable to correctly answer their specific age-related risks, nor did they know the capabilities of prenatal diagnosis. Shortcomings of genetic counseling could be resolved by creating strategies for improving patient education. This process would entail several steps:

1. Using a validated questionnaire, measure prior knowledge about prenatal diagnosis.
2. Determine whether misunderstanding information is a general phenomenon by surveying populations in several different geographical settings.
3. Establish by surveying genetic counselors the important aspects of the counseling session for optimum patient comprehension.
4. Utilize focus groups of women from diverse educational and socioeconomic backgrounds to determine what aspects of prenatal testing patients wish to know.
5. Integrate the information sought by patients with genetic counselors.
6. Test different methods of counseling (e.g., face to face counseling, videos, interactive counseling with computers) to determine the most effective manner of conveying information.

It is hoped that genetic counselors will take these findings to heart and work hard to improve the educational approach of conveying genetic information to at-risk women.