How do distress levels affect women’s decision-making for invasive prenatal genetic testing?

Cassandra Heiselman DO, MPH; Lisa Pastore PhD; Gina Milone MD; Jay Davis MD; Cheryl Dinglas DO; Diana Garretto MD; Kimberly Herrera MD

1Renaissance School of Medicine Stony Brook University Obstetrics and Gynecology, South Nassau Communities Hospital - Maternal Fetal Medicine

**Background**
- Decision-making is a complex process with many influential factors, including a person’s emotional state.
- Even in ideal situations, the decision to pursue invasive prenatal genetic diagnostic testing (PGDT) can be emotionally and psychologically difficult.
- Little attention has been focused on the psychological aspects of such testing

**Objectives**
- Determine the levels of maternal decision-related distress, clarity of the pros and cons, and certainty when considering invasive prenatal genetic diagnostic testing (PGDT).
- Assess the relationship between these constructs

**Study Design**
- Cross-sectional design employing a voluntary, anonymous questionnaire (Q) assessing patient decision-making process in regards to PGDT (CVS or amniocentesis)
- Paper and online Qs were distributed from 2017-2019 to women referred for PGDT in a university academic practice
- Exclusion criteria:
  - Parous
  - Religion (n=44)
    - Catholic or Christian
    - Other
  - Race (n=42)
    - Caucasian
    - Black/African American
    - Other
  - Education (n=43)
    - College degree or more
    - Less than college degree
  - Marital status (n=44)
    - Married
    - Married

**How do distress levels affect women’s decision-making for invasive prenatal genetic testing?**

**Results**
- 44 female patients completed the questionnaire: 57% of whom had already made a testing decision
- Patients expressed low distress levels (mean 1.18, SD 0.80) and expressed high decisional certainty (mean 3.28, SD 0.76) and clarity (mean 3.30, SD 0.99) towards PGDT
  - Women still debating PGDT had greater distress scores (1.6 ±0.75 vs 1.1 ±0.78, p=0.05) and less decisional clarity (2.7 ±1.36 vs 3.5 ±0.64, p=0.07) than women who made a testing decision
  - Decisional certainty and clarity were positively correlated (r=0.47, p<0.01)
  - Distress was negatively correlated with decisional certainty (r=-0.81, p<0.0005) and decisional clarity (r= -0.49, p=0.007)

**Conclusion**
- Higher maternal distress summary scores were associated with lower decisional certainty and decisional clarity.
- Women in our study who are still in the process of making their decision had higher distress scores and were less certain and clear about PGDT.
- Instruments can be used to help to identify a patient-population that may benefit from decisional support to improve their decision making experience through:
  - Additional counseling
  - Closer or more frequent follow up
  - Strategies to reduce emotional distress

**References**