

The association between patient characteristics and psychological experiences when deciding about prenatal genetic diagnostic testing.

Gina Milone MD, Lisa Pastore PhD, Jay Davis MD, Cheryl Dinglas DO, Malini D. Persad MD MPH, Ayisha Buckley MD, Diana Garretto MD, Kimberly Herrera MD
Renaissance School of Medicine at Stony Brook University



Background

- Prenatal genetic diagnostic testing (PGDT) has evolved dramatically in the last several decades.
- While many advances have been made, little attention has been focused on the psychological aspects of testing.
- The decision to pursue PGDT can be psychologically challenging – influence from family and/or cultural constructs may also influence patients' thoughts about testing.
- Furthermore, no validated instrument exists to assess patients' decision-making process when considering PGDT.

Objectives

To determine if selected patient characteristics are associated with the degree of distress, certainty, and decisional clarity when considering PGDT.

Study Design

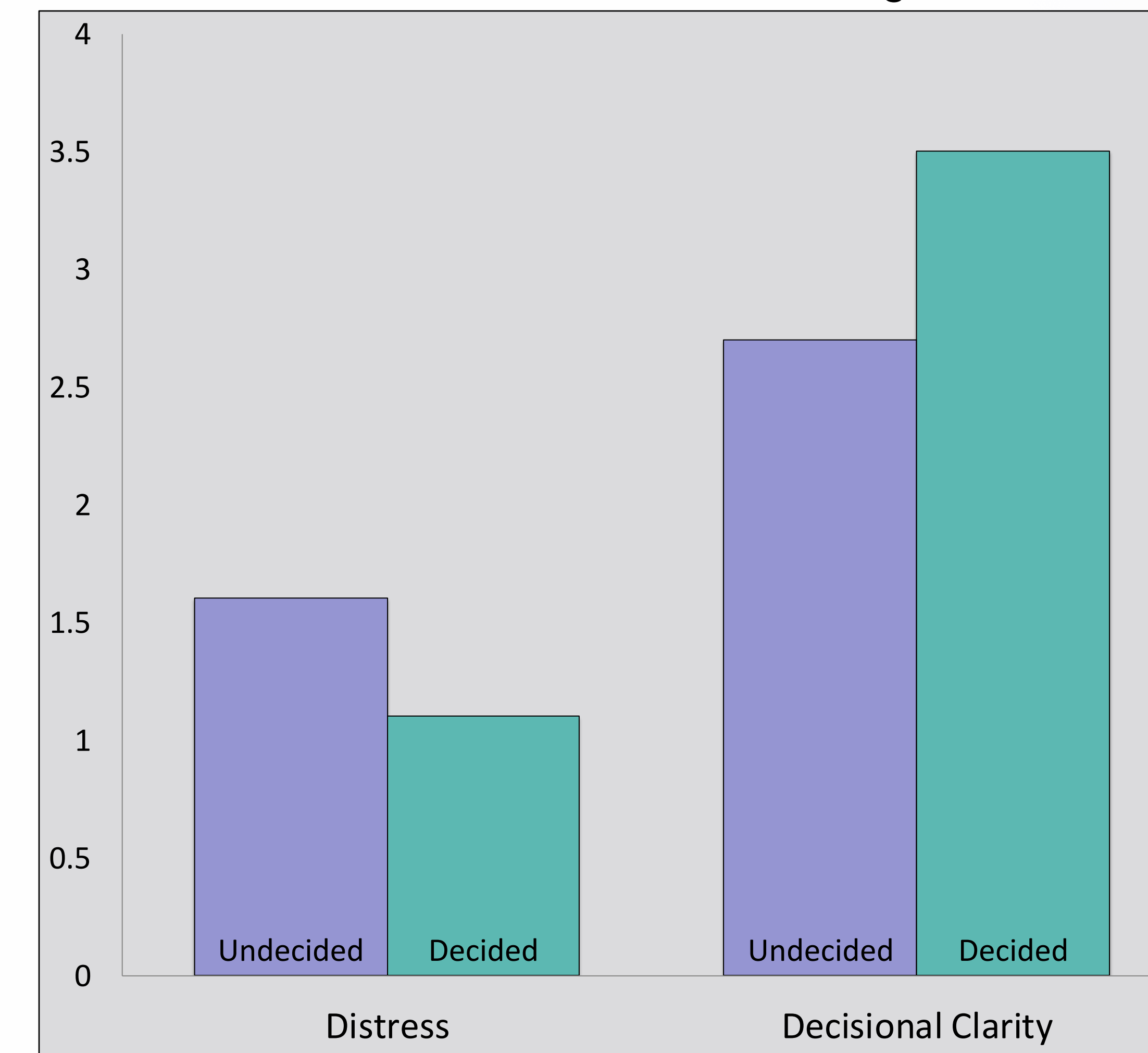
- Cross sectional design
- Patients were given a voluntary, anonymous questionnaire assessing the decision-making process in regards to invasive PGDT
- Invasive PGDT was defined as either chorionic villus sampling (CVS) or amniocentesis
- Questionnaires were distributed from 2017-2019 at outpatient Ob/Gyn office sites to those referred for genetic testing
- Exclusion criteria: English or Spanish illiterate
- The questionnaire had 44 total items that were structured to evaluate patient decisional certainty, distress, and clarity on the pros/cons of PGDT
- Questions were partially adapted from published validated questionnaires
- All questions were scored on a 5-point Likert scale with a range of 0-4
- Means, variances (SD), and ranges were tabulated.
- 3 variables were examined *a priori* for potential influence on the responses.

Results

Table 1. Maternal demographics.

Married	30 (68%)
Race	
White	34 (77%)
Asian	4 (9%)
Black or African American	3 (7%)
American-Indian or Alaskan Native	1 (2%)
Hispanic Heritage	7 (16%)
Religious Affiliation	
Catholic	20 (45%)
Protestant	1 (2%)
Jewish	3 (7%)
Muslim or Hindu	5 (11%)
None	10 (23%)
Other	5 (11%)
Education	
More than a college degree	18 (42%)
College degree	10 (23%)
Some college	8 (19%)
High school degree or less	7 (16%)
First Pregnancy	11 (25%)
Undecided Regarding PGDT	11 (25%)

Figure 1. Decisional distress and clarity among patients who had decided about PGDT vs. those remaining undecided.



- There was no significant difference in scores when comparing parity and religion.
- Greater distress (1.6 ± 0.75 v. 1.1 ± 0.78 , $p < 0.05$) and less decisional clarity (2.7 ± 1.36 v. 3.5 ± 0.64 , $p = 0.07$) were noted between those who were still deciding on PGDT testing as compared to those who had decided.
- There was no statistically significant difference in decisional certainty scores ($p = 0.17$).

Conclusion

- No demographic characteristics were identified that showed a greater degree of distress, less clarity, or less certainty when deciding about PGDT.
- Women who are in the midst of their decision reported greater distress and less clarity about pursuing PGDT.
- Additional provider counseling and closer follow up may benefit these patients and aid in their decision making process.
- Limitations: small sample size
- Future work: investigate if there are other, not studied, characteristics associated with decision making with use of a larger sample size.

References

1. Prenatal diagnostic testing for genetic disorders. Practice Bulletin No. 162. American College of Obstetricians and Gynecologists. Obstet Gynecol 2016;127:e108-22.
2. Hotun Sahin N, Gungor I. Congenital anomalies: patients' anxiety and women's concerns before prenatal testing and women's opinions towards the risk factors. Journal of Clinical Nursing, 2008 March;17(6):826-827.

