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

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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
  - Baseline maternal characteristics were collected.
  - Questions evaluated distress, decisional certainty and decisional clarity on a 5-point Likert scale
    - Range: 0=low/uncertain/unclear to 4=high/certain/clear
  - Exclusion criteria: English or Spanish illiterate
- Statistical analysis was performed using STATA (StataIC version 13)
  - Baseline Means, variances (SD), and ranges were tabulated.
  - Correlation statistics were run between scores with alpha < 0.05

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)

Table 1: Maternal Demographics

Factor	Mean (+/- SD) or n(%)
Age (years)	31.4 ± 5.9, range 19-43
Married	30 (68.2)
Education (n=43)	
Less than college degree	15 (34.9)
College degree or more	28 (65.2)
Race (n=42)	
Black/African American	3 (6.8)
Caucasian	34 (77.3)
Hispanic	7 (15.9)
Parous	33 (75.0)
Religion (n=44)	
Catholic or Christian	22 (50)
Other	12 (27.3)

Table 2: Decision Making Stage

	n(%)
Considering amniocentesis	7 (15.9)
Considering CVS	4 (9.1)
Have used (or will soon) amniocentesis	19 (43.2)
Have used (or will soon) CVS	6 (13.6)
Declined testing	7 (15.9)

Figure 1: Correlation between Distress score and Decisional Clarity Score

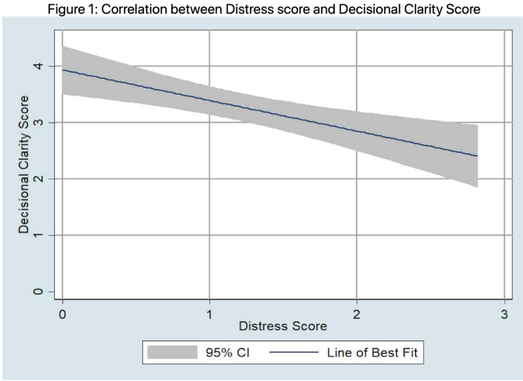
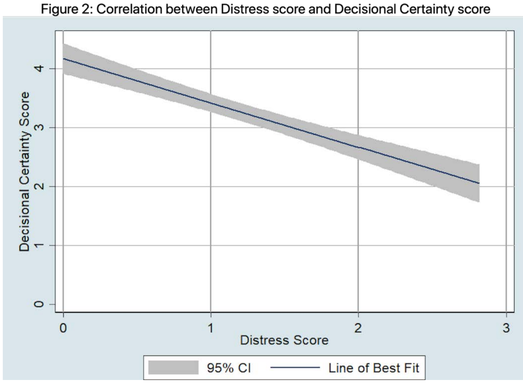


Figure 2: Correlation between Distress score and Decisional Certainty score



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

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