Provider Practices and Perceived Barriers towards Counseling on Reproductive Options for High-Risk Individuals

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National Human Genome Research Institute

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How did I get here?

- Time in grad school → interest in GC's role in non-genetics provider education
- Received flyer for ISCC-PEG scholars program
- Applied with a project on carrier screening awareness and education
- Matched with Barb!
- Together, Barb and I have brainstormed, shaped the project to where it is now, and added additional expertise along the way → high-risk reproductive options counseling

Outline

- Background
- Study Aims
- Study Design
- Planned Analysis
- Discussion

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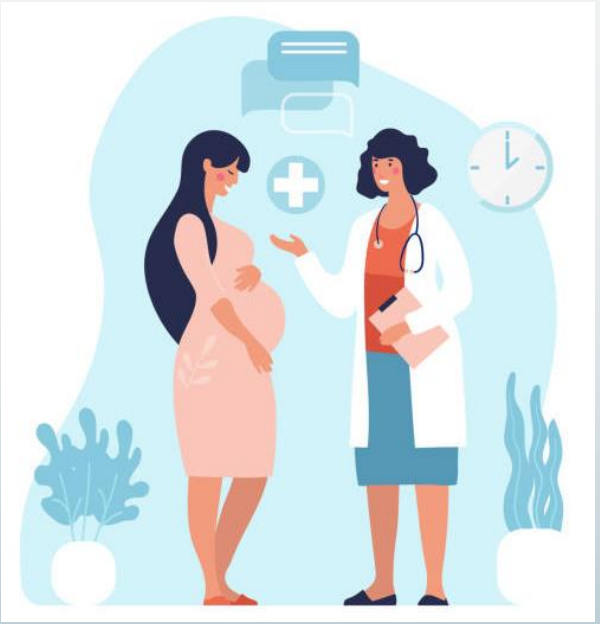
Background

- MFMs/prenatal GCs work with individuals whose future/current pregnancies are at risk for genetic conditions
- Reproductive options available:
  - **Pre-conception**: gamete donor, IVF + PGT, adoption, natural pregnancy +/- prenatal testing
  - **Current pregnancy**: termination, carrying to term + adoption, carrying to term + parenting, fetal therapy
- Timely counseling/referrals is imperative in many situations

Background



- Factors that influence access to options counseling:
  - Training of providers
  - Provider attitudes/beliefs
  - Patient experiences/attitudes/beliefs
  - Institutional/policy barriers
  - Health disparities
- Reproductive options counseling research has been largely in context of unintended pregnancies:
  - Only 26% PCPs engage in routine options counseling (Holt et al., 2017)
  - 48% of Colorado APCs were willing and able to counsel on all options (Coleman-Minahan, 2021)
  - There are racial disparities in access to comprehensive options counseling and appropriate referrals (Nobel et al., 2023)
- There is a current research gap on reproductive options counseling practices for high-risk/genetic situations

Study Aims

- Investigate/compare high-risk/genetic reproductive option counseling practices
  - Genetic vs non-genetic providers
  - Ohio vs Massachusetts
- Identify the barriers to comprehensive counseling

Study Design

- Study population: current prenatal genetic counselors (20) and MFM providers (60) in Ohio and Massachusetts
- Recruitment:
  - Professional connections/societies
  - NSGC ‘Find a Genetic Counselor’
  - Society for Maternal Fetal Medicine ‘Find a MFM Specialist’
  - Ohio Fetal Medicine Collaborative (OFMC)

National Society of Genetic Counselors

Society for Maternal•Fetal Medicine

Ohio Fetal Medicine Collaborative

Study Design

- REDCap survey:
  - Demographics: age range, gender, race, religious affiliation, provider type, years in practice, practice location/setting, pt population insurance coverage
  - General practices/attitudes
  - Abortion-restriction impact
  - 4 high-risk future/current pregnancy situations and counseling practices/barriers

Study Design

- Patient scenarios:
  - Two partners are carriers for Tay-Sachs (future)
  - Trisomy 18 (current)
  - Trisomy 21 (current)
  - Open spina bifida (current)

Study Design

Refer to this scenario (scenario 1 out of 4) to answer the following questions:

Two partners underwent carrier screening prior to conception and were both fou carriers of an autosomal recessive, severe/lethal condition like Tay-Sachs disea are disclosing the results to them.

How frequently do you provide information to patients in type of scenario regarding the following reproductive opti

	Never	Sometimes	About half the time	Most of the time	Always	I don't know/not applicable
Adoption	○	○	○	○	○	○ reset
Gamete donors (sperm/egg)	○	○	○	○	○	○ reset
In vitro fertilization (IVF) with preimplantation genetic testing (PGT)	○	○	○	○	○	○ reset
Natural pregnancy (knowing the 25% risk)	○	○	○	○	○	○ reset

Refer to this scenario (scenario 2 out of 4) to answer the following questions:

Following abnormal cell-free fetal DNA (cff-DNA) screening and the discovery of multiple fetal anomalies, a pregnant couple pursued diagnostic testing via amniocentesis. Chromosome analysis revealed trisomy 18. You are disclosing the results to them.

How frequently do you provide information to patients in this type of scenario regarding the following reproductive options:

	Never	Sometimes	About half the time	Most of the time	Always	I don't know/not applicable
Carrying the pregnancy to term and parenting with postnatal interventions/support	○	○	○	○	○	○ reset
Carrying the pregnancy to term and placing the child up for adoption	○	○	○	○	○	○ reset
Terminating the pregnancy	○	○	○	○	○	○ reset

Study Design

- [ ] I don't always have time to discuss this option
- [ ] Lack of personal understanding/knowledge of this option
- [ ] Concerns about insurance coverage and financial considerations
- [ ] There is no access to this option where I practice
- [ ] Uncomfortable discussing due to personal beliefs
- [ ] Other (please specify)

Planned Analysis

- **Descriptive**
  - Which reproductive options do providers feel comfortable counseling patients on?
  - What roles do providers feel they should play in supporting patients with reproductive decision making?
  - Which options are most and least often counseled on in each scenario?
  - What counseling barriers are being identified?
- **Inferential**
  - Are there any differences in frequency of counseling on certain options between cohorts?
  - Are there any differences in frequency of counseling on certain options between scenarios?
  - Are there any differences in reported barriers to counseling between cohorts?
- Thematic

Discussion

- Results → inform development of interventions to overcome identified barriers, improve counseling practices, ultimately improve patient care
- Future directions:
  - Implementation studies of barrier-specific interventions
  - Patient insights (quantitative and qualitative)
  - Qualitative provider insights
  - Chart review studies

To-do List

- ✓Committee creation
- ✓Protocol creation
- ✓Survey creation
- ✓IRB submission
- ❑IRB approval
- ❑Recruitment
- ❑Data analysis
- ❑Manuscript prep

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  - Barbara O'Brien, MD (mentor)
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- ISCC-PEG
  - Donna Messersmith, Ph.D.
  - Richard L. Haspel, M.D., Ph.D.
- Dawn Allain, MS, LGC
- Family/friends/colleagues

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