

Introduction

- Genetic counselor training and skill sets are highly valuable in clinical research activities including:
 - Introducing research options to patients
 - Providing education on complex topics and study design
 - Facilitating decision making to join a research study
- There may be areas where clinical and research areas overlap and create conflicts or tensions for the health care providers navigating between clinician and researcher roles
- Previous studies have examined the challenges faced by health care providers (physicians, nurses) who have dual clinician-researcher roles ^{2, 3, 4, 5, 6, 7} However, there has been no systematic study to identify challenges encountered by similarly situated genetic counselors.
- Genetic counselors who work in dual clinician-researcher positions may experience unique challenges compared to other clinician-researchers. Why?
 - NSGC Code of Ethics is based on an ethics of care model ^{8,9}
 - Importance of creating relationships with patients ¹⁰
 - Confidentiality and privacy of patients is emphasized

In this study, we focused on identifying common challenges encountered by clinical genetic counselors who conduct or perform research activities.

Methods

- Development of Interview Moderator Guide**
- Key domains identified from literature included: clinician-researcher roles for other healthcare providers, challenges faced by genetic counselors, and ethical guidelines such as the NSGC Code of Ethics
 - Questions were written to address the key domains
 - Guide was piloted with two genetic counselors

- Study Population and Recruitment**
- Recruited genetic counselors who: counsel patients in a clinical setting and are engaged in research
 - No limitations were made on based on : clinical area of practice, type of research activities, time spent in clinical versus research activities
 - Recruitment from NSGC listserv and selected NSGC Special Interest Groups (Cancer, Cardiovascular, Neurogenetics, and Research)

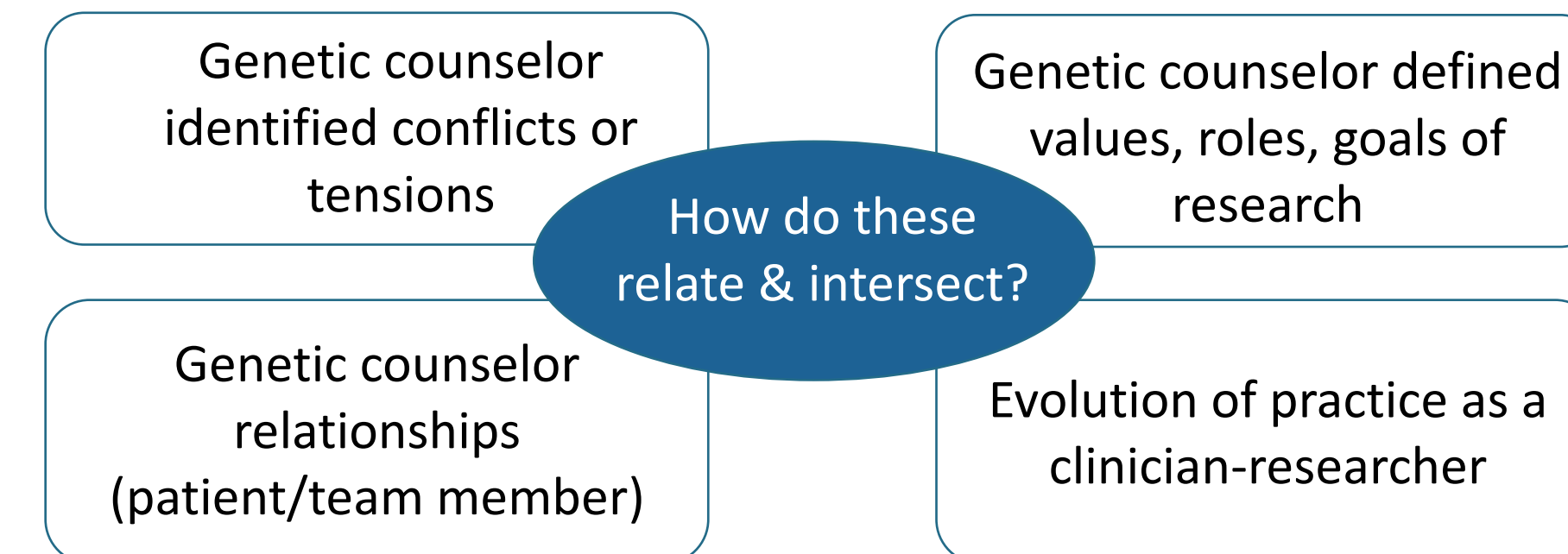
- Focus Groups and Interviews**
- Focus groups and one-on-one interviews were conducted in-person at the NSGC Annual Educational Conference or virtually.
 - Discussions were audio recorded and transcribed
 - Averaged 45-90 minutes in length
- | Discussion Type | Modality | Number of Participants |
|--------------------|-----------|------------------------|
| Focus group | In person | 2 |
| Focus group | In person | 2 |
| Interview | Virtual | 1 |
| Focus group | Virtual | 3 |
| Focus group | Virtual | 2 |
| Interview | Virtual | 1 |
| Interview | Virtual | 1 |
| Total participants | | 12 |
- Study participants reported areas of practice:
- Cancer
 - Cardiovascular
 - Neurogenetics
 - General genetics
 - Pediatrics
 - Prenatal

- Qualitative Data Analysis**
- Transcripts coded by two independent coders
 - Common themes pulled from the identified codes
 - Inductive qualitative analysis identified four higher order themes and 18 codes

Results

Themes Identified

Analysis of transcripts revealed four higher order themes which were divided into 18 codes:



First-Person Role Confusion

Definition: genetic counselor identified or described a tension or conflict related to separating their professional role as a researcher and a clinician

- What we found:**
- First-person role confusion was strongly tied to genetic counselor identity
 - Genetic counselors often prioritize the perceived clinical role and identity over the researcher role and identity.

"That's what a genetic counselor is supposed to do. If a patient has a question, you need to answer it... You can't just say, 'I'm not going to talk to you about [that]... my job is only to talk to you about [the research study] results... it's within my scope of practice."

-Genetic Counselor 141

- Genetic counselors reported the clinical identity remains even in research activities

"...I still have that clinical hat on, even when I'm talking to patients about the research... sometimes there are days when I come into work and I'm like, 'Oh my god. This patient would be perfect for my research.' I had to take a step back and be like, 'No, clinical first.'"

-Genetic counselor 210

Team-Based Conflicts

Definition: situations where the genetic counselor identifies a conflict with other healthcare providers (clinician and/or researcher)

- What we found:**
- Team-based conflicts related to the functional role the team member expected the genetic counselor to fulfill

"I was recruiting a patient from a clinic... [the physician] kind of asked me to just fill in as the clinical provider... We are only there to talk about the research. But sometimes they see you're a genetic counselor so you can... consent patients for the standard of care test."

-Genetic Counselor 165

Common Challenges

We identified five common challenges encountered by genetic counselors in a dual clinician-researcher position.

Here, we focus on the top three challenges:

- First-person role confusion
- Patient-related challenges
- Team-based conflicts

Two additional challenges were identified related to activities genetic counselors perform:

- Challenges related Informed consent
- Challenges of return of research results

Patient-Related Challenges

Definition: genetic counselor describes a challenge of tension created by their relationships with the patient/participant (either an established relationship or a lack of a relationship)

- What we found:**
- Genetic counselors reported conflicts when an established clinical relationship with a patient was perceived to influence the patient's decision making for research

"If I am the main genetic counselor and I am asking if my patient is interested in participating in this study, that they're more likely to want to participate to maintain their relationship."

-Genetic Counselor 112

- Genetic counselors also identified tensions between their roles as a clinician and researcher and supporting patient autonomy/goals

"They [the patient] may not want to know a whole lot of extra information. That's what I am going to support them, as a clinical genetic counselor. However, if I put on a research perspective, I might be very academically interested in this participant and want to send them for all these different studies."

-Genetic Counselor 112

- Other team-based conflicts related to the team member's expectation of the goals, process, or timeline of research not matching the genetic counselor's expectations.

"...the geneticists would be like, 'I highly encourage all of my patients to do this research.' ... 'Well, I mean, it's their choice. You're kind of influencing... And I kind of never felt comfortable telling people they should [join the research study]."

-Genetic Counselor 120

- Genetic counselors addressed team based conflicts by questioning or challenging the team member and/or clarifying expectations with patients

"The physician that I worked with was the Pl... He had a lot of ideas about what the lab could do... and that may or may not have been the case. That was something that I tried to clarify with patients about timelines and what was realistic."

-Genetic Counselor 109

Conclusions

- In this study, we identified five common challenges encountered by clinical genetic counselors who are engaged in research.
- As expected from previous literature on clinician-researcher roles, we found genetic counselors encountered role conflicts and patient-related challenges and these relate to their:
 - Professional values as a genetic counselor
 - Prioritized clinical identity
 - Emphasis on maintaining strong relationships with patients
 - Desire to promote noncoercive decision-making
- Team based conflicts were a novel challenge in genetic counseling compared to literature on other clinician-researcher healthcare providers

Guide future research

- Future work can address:
- Are these conflicts generalizable to the genetic counseling community?
 - How factors such as type of institution influence the conflicts encountered?

Facilitate discussion

- This work can guide discussions within the genetic counseling community:
- How do genetic counselors navigate these challenges and conflicts?
 - How should we define our roles as genetic counselors in clinical and/or research settings?

Code of Ethics

- This work suggests additional areas to be addressed with training and ethical guidelines for genetic counselors:
- NSGC Code of Ethics could better address team based conflicts and how to prioritize different roles as a clinician versus researcher in genetic counseling
 - Practice based competencies can address critical thinking skills needed to navigate areas of genetic counseling practice where the division between clinical care and clinical research is not well defined

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