# Preparedness and training of genetic counselors practicing in inpatient settings

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### Background

#### Genetic testing in inpatient settings

- Genetic disorders are prevalent in inpatient settings
- In neonatal intensive care units (NICU), as many as 71% of
- patients have a disorder with a significant genetic component • Rapid genomic sequencing allows for real-time results that can alter management during an inpatient stay

#### Genetic counselors in inpatient settings

- Recent studies describe:
  - Genetic counselors work varied inpatient specialties, such as pediatric, neonatal, cardiology
  - Challenges include demanding workflows, supporting patients in a time of crisis, collaborating with providers who do not understand the role of genetics, and lack of prearranged appointments
  - Non-genetics providers in inpatient settings desire the involvement of genetic counselors

#### Inpatient genetic counseling training

• 132 surveyed inpatient genetic counselors (2021), 50% reported no exposure to the inpatient setting in their graduate training and 87.3% reported receiving no training through their institution for their inpatient position

### **Objectives**

#### **Genetic Counselor Interviews**

- 1. Investigate how prepared genetic counselors felt when they started an inpatient position
- 2. Explore the type of inpatient training genetic counselors received in graduate school and at their job
- 3. Identify what training and resources would be beneficial to prepare genetic counselors for working in the inpatient settina

#### **Program Faculty Survey**

1. Evaluate current graduate training practices related to inpatient genetic counseling exposure

### **Methods**

#### **Genetic Counselor Interviews**

- . Developed semi-structured interview guide
- 2. Recruited participants through National Society of Genetic Counselors (NSGC) Inpatient Special Interest Group (SIG)
- 3. Interviewed **13 genetic counselors** working in varied inpatient specialties (by Zoom)
- 4. Transcribed interviews
- 5. Performed qualitative coding

#### **Program Faculty Survey**

- 1. Developed survey
- 2. Sent survey to the Association of Genetic Counseling
- Program Directors (AGCPD) email listserv
- **3. 28 respondents** (from different genetic counseling graduate programs)
- 4. Calculated frequencies

### **Results: Challenges and Preparedness**

#### **Genetic Counselor Interviews**

Interviewee Demographics

	N=13
Gender	
Female	13
Race//ethnic background	
White	12
Asian	1
Mean Age (SD, range)	29.5 (3.28, 24-35)
Specialty	
Participant selected 1 specialty Prenatal Adult cardiology Pediatric cardiology	2 2 1
Participant selected >1 specialty Most common: neurology Second most common: general pediatrics	8 6
Patients seen in inpatient setting/month	
<10	7
11-25	5
Year of genetic counseling program graduation	2018.5 (3.23, 2012-2021)

#### 4 categories of **unique aspects and challenges** of working in the inpatient setting

#### Roles of genetic counselors in inpatient settings

Participants felt prepared for roles in the inpatient setting that matched roles in the outpatient setting

• Psychosocial counseling, genetic test consenting, etc. Inpatient settings require education to be more tailored

"I feel like I do a different type of education in inpatient settings where I really need to distill down, what is the bottom line for this patient? Because they don't want to sit and listen to me for hours. And there's other providers who want to get in here and talk, and quite frankly, they would rather just sit in silence or be with their kid." (Participant #12)

#### 2. Inpatient environment and logistics Inpatient settings are fast-paced and unpredictable

"I didn't understand the culture of what does it mean to be on call? What does the NICU look like? I had no understanding [...] And some of that environmental stuff, **I just wasn't necessarily prepared for**." (Participant #12)

#### 3. Working with an inpatient team

Challenges with advocating for genetic counseling/testing to providers who did not understand the role of genetics

"But in the inpatient setting, I was much more aware of the power differential between me as a consultative service and the primary care team actively, consistently caring for the patient. And you know, how do I make that case and make myself heard and make myself respected?" (Participant #7)

#### 4. Navigating patient and genetic counselor emotions in the inpatient setting

Increased patient stress and emotions in inpatient settings Increased emotional impacts on genetic counselors

"I think the hardest part for me is that we are pretty much actively involved in the facilitation of the dying process [...] Sometimes I'm actually at the bedside when the parents are deciding to withdraw the care and just seeing the anguish on their faces is really hard. You don't see that in outpatient, like those kids are not in that world." (Participant #2)





## **Results:** Training

### **Genetic Counselor Interviews**

- Inpatient genetic counselor's graduate training experiences • 5 participants received no inpatient exposure in graduate
- school
- 4 participants participated in an inpatient clinical rotation in graduate school
- Participants who had inpatient exposure in graduate school felt more prepared for the hospital setting and fastpaced environment

"I got to do eight weeks of inpatient consults [in graduate school]. So, I felt like that prepared me for a little bit more of the on-the-fly aspect of inpatient consults. You know, you don't have a week to sit and prep if you want. You got maybe 20 minutes to read the patient's chart and go. I felt like I got good practice with that and just also practice with like, -being in an inpatient room is very different than an outpatient clinic [...] So sort of learning to navigate that and just seeing that experience and seeing it modeled in school was really nice because that is very different." (Participant #9)

#### Post-graduate training and resources

- Limited on-the-job training for an inpatient position
- Learning by trial and error
- Many participants described reaching out to colleagues and other inpatient genetic counselors in the field as a resource, often through the newly formed Inpatient SIG

### **Program Faculty Survey**

Program offers inpatient genetic counseling exposure/training	J N=28
Yes	23
No	5
(if YES) Type of Inpatient exposure/training	N=23
Clinical rotation experience	22
Lecture based instruction	11
Readings	5
Case Conference Presentations	16
Role Play Experiences	4
(If YES) Inpatient exposure/training is	N=23
Required for all students	11
Optional, but available to all students	1
Mix of optional/required	10
(If YES) Who provides inpatient education	N=23
Clinical genetic counselors	20
Physician	12
Clinical staff (RN, PA, MA, etc)	2
(If NO) Does program plan to offer inpatient exposure/training	N=5
Never	1
Not sure	2
Other	2
Additional areas of training provided	N=28
Crisis counseling training	20
Medical terminology	25
WGS/WES	27
Breaking bad news	26
Information about hospital specific resources (palliative care, etc)	24
Greif, death, and dying	27

# LEND

Leadership Education in Neurodevelopmental and related Disabilities

### Discussion

- Genetic counselors develop strong skills in graduate school which are transferrable to practice in the inpatient setting
- There are also unique aspects of working in an inpatient setting that many genetic counselors felt unprepared to navigate, particularly if they had limited to no previous inpatient exposure
- Recommendations for graduate training included increased awareness of the roles of inpatient genetic counselors and exposure to the inpatient setting
- Graduate training should reflect the unique aspects of the inpatient setting
  - Exposure to physical hospital setting
  - Practice with limited time for case prep • Multidisciplinary team training and practice
  - advocating for the role of genetics • Practice supporting patients in crisis and processing emotions
- Many genetic counseling programs are already providing students with some inpatient exposure in graduate school, such as inpatient clinical rotations and case conference presentations
  - Limited resources could be a barrier to providing inpatient exposure
- Inpatient genetic counselors benefit from professional and institutional resources
  - Inpatient SIG to foster connections Institutional peer support and mortality conferences to support provider grief processing

#### Conclusion

The results of our mixed-methods study suggest that genetic counselors' skills are transferrable to inpatient positions, but there are also unique challenges to working in an inpatient setting. Graduate exposure to the inpatient setting and professional support of inpatient genetic counselors is beneficial to support genetic counselors' preparedness to take on inpatient positions.

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