Examining Attitudes Towards the Measurement, Collection, Storage, and Use Data about Gender Identity in Children, Adolescents, and their Caregivers

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Project Overview

Driving Question

In what ways, does healthcare discriminate between cisgender and transgender and gender diverse (TGD) patients?

Literature Review Themes

Gender-Affirming Laws & Policies

Testosterone therapy and chest surgery are analogous in cisgender and TGD individuals, but are not provided to TGD patients in the same capacity as cisgender patients.



Literature Review Themes



Exploring The Transgender Individual's Experience With Healthcare Interactions: A Phenomenological Study

Amy P. Roach DNS, RN ®

Challenges with accessing health care

The theme most resounding among the nine participants was challenges with accessing health care. While participants were not directly asked about the issues they faced when receiving care, in all nine interviews, the conversation shifted to the challenges

they met when seeking health care. The main issues that were discussed included having to conduct their own research to find friendly providers, the use of or desire for a transgender-specific clinic and being denied care by either a healthcare staff member or provider.

Many participants identified the need to conduct their own research or receive recommendations from other transgender individuals when finding friendly providers. Social media was a prominent platform for the participants to use when identifying how they wanted their gender transition to look as well as where to find qualified providers.

Negative Physician -Patient Interactions

Most TGD patients seek out clinics that specialize in transgender/queer care due to the possibility of being turned away from a non specializing physician...

Literature Review Themes

Parental Consent for GDY care

In all 50 states, parental consent is mandated for gender-affirming care of Gender Diverse Youth (GDY). What happens if your parents are not supportive?



Literature Review Findings

Limitations

- Lack of racial and ethnic diversity in past studies
- 2. Lack of research on how to make non specializing clinics a safe and welcoming environment for TGD patients

Next Steps

Lays the foundation for the Sexual Orientation and Gender Identity Interview Guide.

Aims:

- #1: Develop and refine new gender screener items
- #2: Understand the attitudes about collecting and storing data about gender identity
- #3: Generate suggestions for collection, storage, and use of data on gender identity

Methods:

- Three part semi-structured interview
- Recruitment of Caregivers and TGNB adolescents (ages 13 to 21) from the CHOP Adolescent Specialty Clinic

Part #1:

- Reflective Interview with an Adolescent and/or Parent/Caregiver
- Questions about sexual orientation, gender identity, and sharing associated information

Question Examples:

- 1) In your opinion, what are your thoughts about clinics and hospitals collecting information about teenagers' gender identity?
- 2) Under what circumstances would you want to know if your adolescent's healthcare provider asked them about their sexual orientation and gender identity?
- 3) In what ways do you think healthcare providers can make it easier for patients to share their gender identity information?

Part #2:

- Video Elicitation with Six Scenes
- Scenes are embedded with topics of sexual orientation & gender identity
- Some scenes are curated to be welcoming, safe while others elicit uncomfortability
- Use participants' reactions to improve clinic visits and experiences

Part #3:

- Survey & Cognitive Interview Guide
- Operationalized in RedCap
- What type of wording and question framing make transgender and gender diverse
 (TGD) patients feel the most comfortable?

Please rank the question stems based on	your preference (p	ut the one yo	u like the best o	n the top, or in th	e #1 slot)
	1	2	3	4	5
What is your gender?	0	0	0	0	reset
What is your gender identity?	0	0	0	0	reset
What is your current gender?	0	0	0	0	reset
What is your current gender identity?	0	0	0	0	reset
Do you think of yourself as:	0	0	0	0	reset
The survey asked both about your sex assigned at birth as well as your gender identity. Which question would you prefer to be asked first?		○ Sex assign	ed at birth OG	ender identity	reset

Creating a ranked questionnaire in Redcap

	Very uncomfortable	Somewhat uncomfortable	Neither uncomfortable nor comfortable	Somewhat comfortable	Very comfortable
Scenario A: When responding to an electronic survey on a computer, phone, or tablet	0	0	0	0	0
					reset
Scenario B: When responding to a paper survey in the waiting room	0	0	0	0	0
Scenario C: When a healthcare provider is asking you directly (verbally) in the exam room in front of your parents/caregivers	0	0	0	0	reset
Scenario D: When a healthcare provider is asking you directly (verbally) in the exam room alone	0	0	0	0	reset
Scenario E: When an individual is asking you via video, web conferencing, or telehealth?	0	0	0	0	reset

Utilizing scenarios rather than direct questions to better understand an individual's comfort level

Key Takeaways

Pesearch takes a lot of little steps.
All your questions will probably not be answered through one project.

─ Finding work-life balance.

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Questions?

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