

Transition or Transplantation: A Qualitative Study of Transgender Experiences with Kidney Transplantation

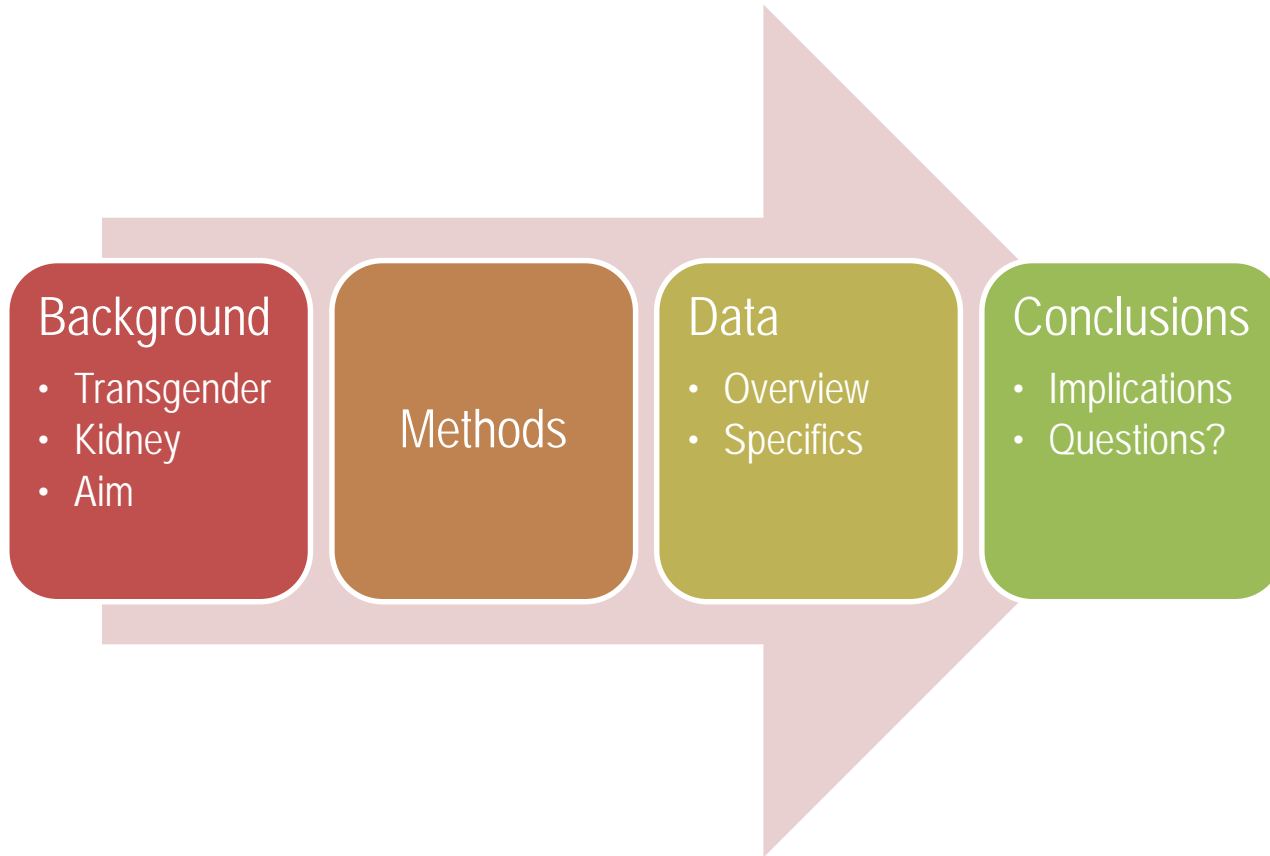
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Our Time Together



Background

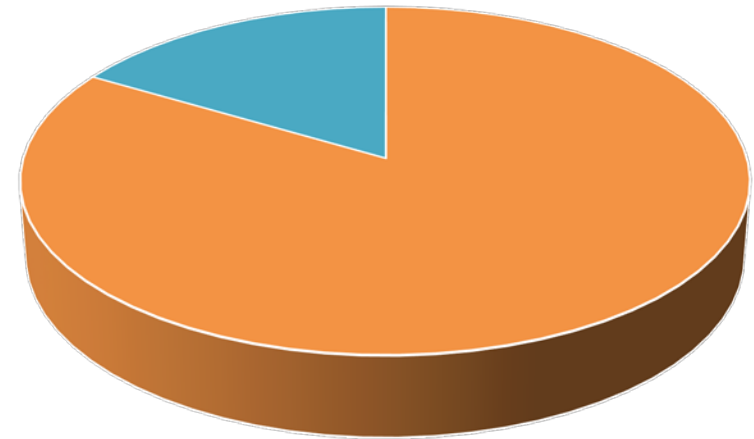
- We're all assigned a sex and assumed gender at birth
- Transgender gender non-binary is an umbrella term
 - Refers more generally to people whose perceived gender identity differs from their assumed gender at birth
 - May or may not undergo medical transitioning¹
 - NOT required to identify as transgender
- My limits as a researcher
- Language, like identities, are evolving and fluid



Background

- 83% of the approx. 114,000 people currently on the U.S. transplant waitlist are in need of a transplantable kidney²
- Estimated 1.4 million Americans identify as TGNB³
- Despite known disparities across the lifecycle for TGNB persons AND inequities in kidney transplant experience → no formal effort detailing experiences

Current U.S. Waitling List



■ Kidney ■ Other Organs

Based on OPTN data as of March 25, 2019

The Aim

Assess health care providers' experience with and knowledge of kidney transplantation among TGNB persons

To elucidate

Challenges and pitfalls

Assess TGNB persons' kidney transplant experiences along spectrum of transplant care



Methods

- Scoping Literature Review⁴
- Purposeful sample
 - Nephrologist, transgender-care social worker, & community engagement specialist
 - Transgender women (N=4) ; Transgender women who've had kidney transplant (n=2)
- Narrative Interviews
 - 7 total: 3 w/ providers & 4 w/ transgender women
 - Moderator's guide developed → guided approx. 60- 90 min discussion
 - Audio-recorded, transcribed
- Qualitative Analysis
 - Content Analyzed for emergent themes
 - MaxQDA 12
- IRB approval, written consent

Transgender Participant Characteristics (N=3)*

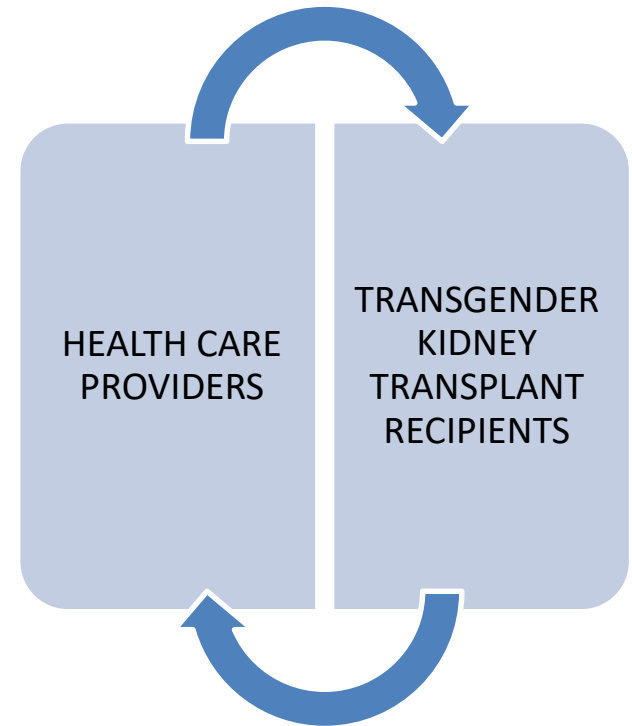
Characteristics	Total Sample (N=3)*
Age, years, mean (SD)	39 (15)
Race, n (%)	
Black	2 (66.33)
White	1 (33.33)
Educational Attainment, n (%)	
High School/GED	1 (33.33)
Some college, no degree	1 (33.33)
Associates Degree	1 (33.33)
Income, n (%)	
<\$5,000	1 (33.33)
\$10,000-\$19,999	1 (33.33)
\$30,000-\$39,999	1 (33.33)
Insurance Status, n **	
Public Insurance	3
Employer based	1
Experienced Homelessness in past 6 months, n (%)	
Yes	1 (33.33)
No	2 (66.33)

*Note: Demographic information was unable to be collected from one interview participant

** N>3 because some participants reported multiple forms of insurance

Findings: Health Care Providers

- Close management
- Coordination of transgender health care and transplant care team
- Bolstered social support services
- Strengthened mental health services
- TGNB persons should not be denied from the process of transplant evaluation outright, but, there may be specific medical considerations providers should be cognizant of



Overview

- Ultimatum at sudden KD onset
- Lacking
 - Support
 - Patient-provider communication
- Response to stress
 - Avoidance
 - Substance use
 - “Acting out”
- Worsening kidney health

“Me taking a long time to get some type of help actually damaged my kidney even further because the next time I got any help wasn’t until I went into the emergency room” TW 2

“I really thought I was gonna die and unfortunately, I started using drugs and stuff like that to ease the pain.” TW 3

“I couldn’t afford to skip treatment so what I did was just started acting out.” TW 3

Findings: Ultimatum

Say they were a transgender individual who had no medical comorbidities but developed IgA nephropathy and their kidneys stopped working but they got a kidney transplant and are now in a perfect state of health, their risk for transplant is minimal, but then you know it's kind of a quality of life thing and I try to steer people away from anything, but I would not put my foot down in that setting if they really wanted to get some sort of, as you said, gender affirmation surgery.

Nephrologist

They didn't really focus on my kidney transplant. They was focused on my transition.

TW 3

TW 3

It was a very hard decision [to halt HRT]. It was a very hard decision because I felt incomplete and I had to put my transition on hold to get the necessary treatment and health care that I need to get the transplant done.

TW 2

It is not about me being trans I just need medical care like this is my kidney and you're worried about me being trans as opposed to just giving me medical care.

Findings: Social Support

I think having a strong support system is uniquely important for trans folks.

**Trans-care
social worker**

If I had a friend or some type of social support at the time when I was going through that [dialysis] at the beginning stages it probably would have been different because they would have understood the trans part.

TW 2

I feel like my trans support system at that time was just low.

TW 2

They should hire a special team of maybe doctors maybe patients that could help volunteer for people whose going through the same thing that I went through and build their self-esteem up and keep them confined and keep them happy you know just hang around with them.

TW 3

Findings: Communication

Establish a good communication with the rest of their provider team and contact team and stuff like that

Nephrologist

You feel like they are telling you no you can't be here, you can't live life as her and I feel like if I wanted to get treatment I would have to subject to getting treated like somebody I wasn't.

TW 2

If someone has an experience that didn't feel like affirming like talking about how you can best advocate- I mean I usually end up just switching providers just so they don't have to do that work

**Trans-care
social
worker**

Mentally I was f***ed up because I didn't know if I was gonna die, are my kidneys gonna fail more, or if this is gonna work, what the hell is going on.

TW 1

Findings: Transphobia

My family came and they said they had my robe open and I was just over with my breast and d**K and s**t out laying on the stretcher thing, they said there was all these doctors coming and looking at me and stuff so to me they was not transfriendly.

TW 1

It was apparent that I was trans at the time, because my name wasn't changed, but then I came in dressed as a woman, cause that is how I felt, and the doctor was scared to touch me to diagnose it and to check my breathing and everything.

TW 2

I told him [the nephrologist] we'll I don't feel comfortable keep going to this clinic because its very you can tell its very transphobic. So he made the recommendation that I stay at home and receive my treatment.

TW 3

He would say Mr. so and so. I said well I identify as Mrs. So and so and so he said well it says in your record that you're male. So I said so you have no respect for my identity. He said well I to refer to you as your assigned birth.

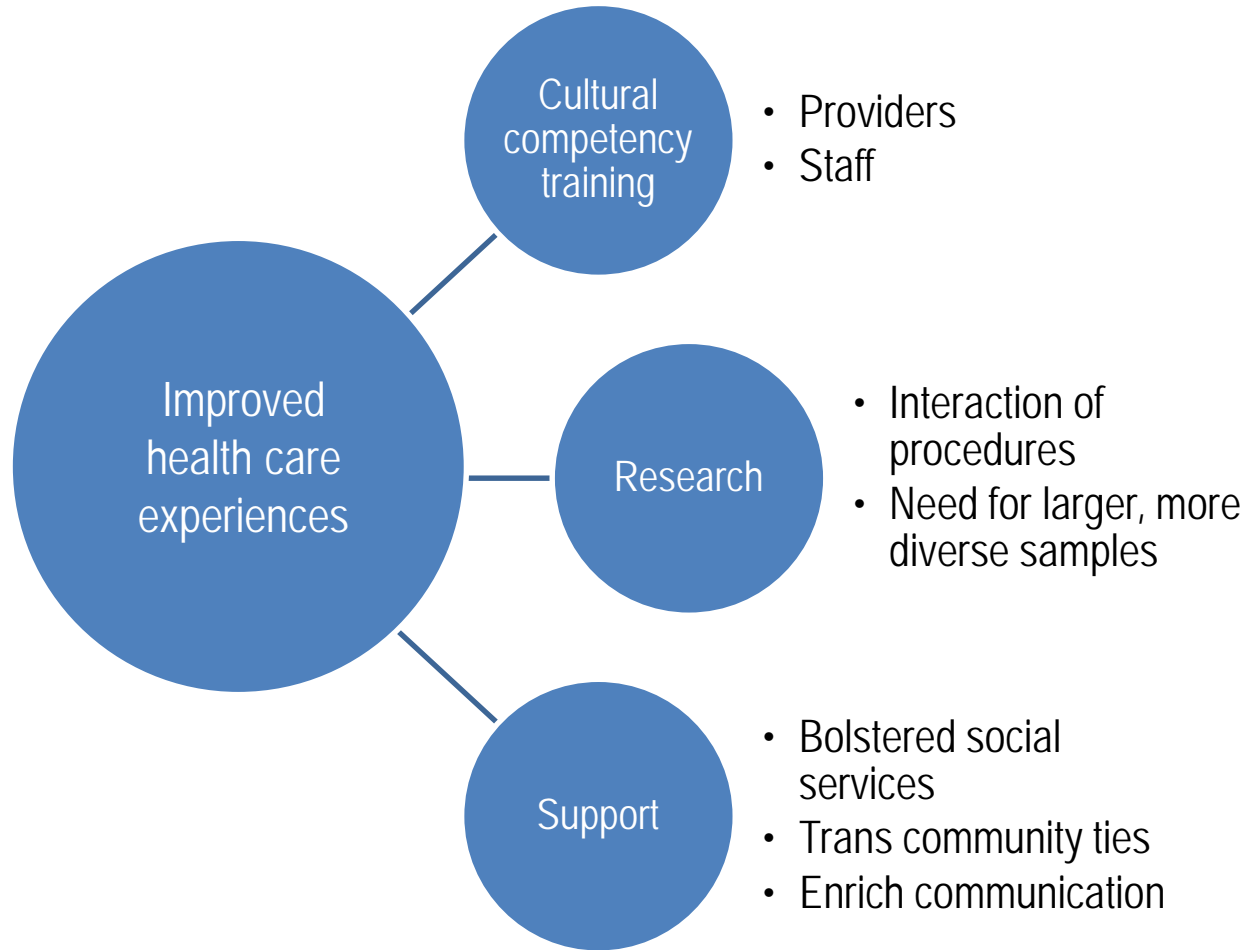
TW 3

Conclusions

- Sub-optimal experiences along the transplantation process were reported
- Participants reported deciding between transplant or transitioning
 - Provider practices, sociocultural and institutional barriers
- Transphobia undergirded neg experiences



Implications for Research and Practice



Study Limitations and Strengths

- Limitations
 - Findings are not generalizable
 - Wasn't our intent. Formative work.
 - Sample homogeneity
 - Dependent on medicalization of trans identity
- Strengths
 - Formative work
 - Natural emergence of ideas, concepts



Acknowledgements

Research Team

Patrick J Kelly, MPH Candidate, Principal Researcher
Heather Gardiner, PhD, MPH, Faculty Mentor

Partnering Individuals

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Thank you!

Questions?

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