



ADVANCING EXCELLENCE IN TRANSGENDER HEALTH

Detransition, Retransition: What Providers Need to Know

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Continuing Medical Education Disclosure

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Agenda

- Introductory remarks
- How I learned about this topic
- Contextualizing detransition and regret
- Definitions, language and frames
- What people say they need
- Q and A



Complexity

- Listen to this talk in its entirety—
 - Don't cherry pick
 - Clinical talk
 - My interest is helping you do a better job than I did with my first detransitioning patient
- We need to tolerate increasing complexity as people experience a new landscape—one where surgeries are paid for, where there is a little bit more openness to exploration
- Lack data we will have in the future, learning as we go



Harriet



Controversial

- It is a fact that some people will die or have a terrible quality of life if they do not access every possible medical procedure to decrease their gender dysphoria. They experience pain and suffering from lack of access and poorly educated provider care. Improve QoL.
- It is also a fact that a small number of people regret transitioning and detransition. They too experience pain and suffering from lack of access and poorly educated provider care.



Detransition and transition occur within a sociocultural context



Cultural context



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Trump Health Officials Prepare to Promote Anti-Trans Discrimination

by Harper Jean Tobin



Trump administration rolls back protections for transgender students

Trump expected to roll back LGBT protections in Obama Care

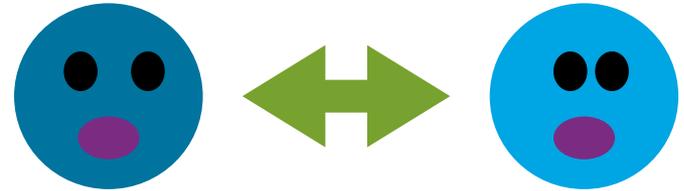
Trump orders Pentagon to reverse transgender policy



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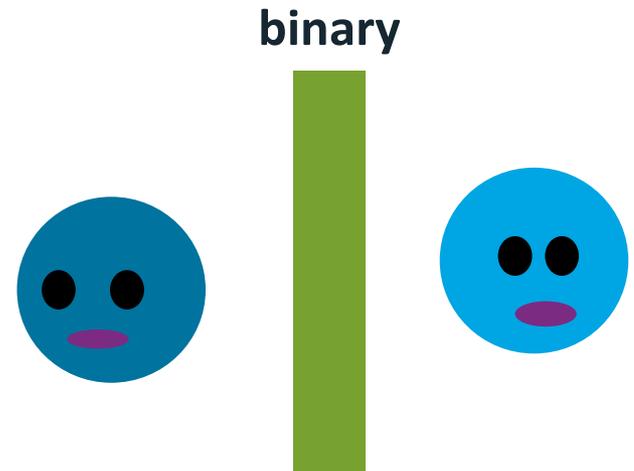
Reactivity





**Everybody gets
informed care
regardless**

One person's need to
detransition means
nothing about
whether access to
gender confirmation
medical care should
be provided for
others.



No one size fits all

- Who has a client who has socially, hormonally and surgical transitioned?
- Who has a client who has only socially and hormonally transitioned? Doesn't want surgery.
- A client who has only hormonally transitioned but not socially transitioned?
- A client who wanted a flat chest but no hormones?
- A Eunuch?
- Transition is not monolithic, it's not prescribed, and we talk about it like it is—even though we all know better. It's part of the problem.



We are maturing as a field

- If you've seen one person, you've seen one person
- Simplistic ideas in the past
 - A person used to have to prove they were a stereotype to have surgery
 - People had to follow the same path, social, hormonal and then surgery
 - It supported the gender binary—expect to see more and more gnb; gnc people
- One size fits all has always been mythical



Complexity is a good thing

- We are expanding our definitions; the field expanding and changing
- pendulum, gatekeeping, paternalism versus now
 - I've never seen a detransitioner so they don't exist
- It means we are growing up as a field
 - move away from polarity; binary, simple ideas
- It makes us return to patient centered care
- It's reality—transition doesn't fit or is a miss for some



Language you might hear

- Detransition
- Just what I am doing now-no big label attached
- Gender Journey; Gender Path— professionals say this
- Retransition
- Disidentification/Reidentification
- Regret (talk about later)
 - Don't try to change people's language-meaning in it; empowering for them or not; not hear



Many reasons people stop a medical transition process

Four major groups

- People who got what they needed and do not regret their choices—unforced choice—“gender journey”
- People who are forced to detransition by external forces
- People who regret they transitioned medically but there was no other way to know it wasn't the right choice—may also be gender journey folks
- People who regret they transitioned medically and regret their choice. Many feelings.



Who here has seen a detransitioner from ...

1. People who got what they needed and do not regret their choices—internal choice—“gender journey”
2. People who are forced to detransition by external forces
3. People who regret the impact of their medical transition, but there was no other way to know it wasn't the right choice—may also be gender journey folks— and detransition.
4. People who regret they transitioned and regret their choice and detransition.



What it's not

- Detransitioning is not people developmentally exploring who may start and stop use of hormones or social transition



When detransition is about the "gender journey"

- Gender fluid-may return -this moment versus the next
- Old SOC — Path was social transition to hormones to surgery—forced more physical change than needed/wanted
 - Clinicians who wondered why trans men started on hormones and then stopped coming in for them. They later realized that these guys got what they needed and didn't return.
 - Reductionist and unresponsive to people's actual needs NB
 - We've forced people to work around us



People who got what they needed and do not regret their choices—internal choice

- Stop taking hormones because they achieved their goal
- They determined it didn't work and they have no regret.
- Shifting identities—this was or seemed true now it's not
- People who go on and off hormones, are gender fluid, people who are non-binary, mixed expression, etc.
- We want to make it safe for people to tell us what they *really* want and who they really are and that they do not have to work the system to get what they need.



Detransition when it's forced, coerced or out of desperation

- Incarceration
- Other institution related issues—situation out of one's control. Don't want to, but feel they have to. Aging
- Family—need to go home and care for someone. Putting self first is a arguably an American concept. The frame on identity is as well.
- Can't tolerate the rejection from previous supports (family, church, etc.)
- Can't financially support themselves—life or death



People who regret the experience of their previous transition-forecasting

- Shifting identity-worked and then didn't
- Some people can not know something until they do it. People who have difficulty with forecasting. How will it be for you to live as a typical woman now? How will your friends feel? Your parents? Your work?
 - How would I know until I do it?
 - I'm happy about it so everyone else will be too.
 - neurodiversity



Clear that it's coerced

May return when situation changes

- If the person wasn't facing transphobic discrimination or external inability to live as one's self in all aspects of their life they would NOT have returned to presenting as male or female or gone off medically necessary care.



Older people: 2 groups

- detransition because they fear that they will not be cared for appropriately as they age and must rely on systems to care for them
- detransition because they feel finished with this developmental period of their life. They do not regret living as female, they choose to live as male now.



All groups share:

- Need for Standards of Care regarding detransition
 - We have SOC to transition
 - We should have them to detransition
- People need medical information and care—how to safely go off hormones; how to reverse effects of procedures, how to care for a body with a sex atypical presentation
- Some people need mental health information or care
- Need for individualized patient-centered care and to be seen as themselves



Concerns

- Need transition related care (going off on hormones, perhaps starting on other hormones, hair removal, continuing gender dysphoria, psychosocial support, adjustment disorders, possible surgery, etc. Decision making about new transition)
- People feel that their life story has become weaponized for use by others, politics-trust issue
- Distrust-People may have felt harmed or neglected by previous providers
- Distrust-people may have encountered providers, friends, family who did not believe them
- Shame



Understand with them

- What have they discovered that demonstrated that transitioning isn't the right choice?
 - How they feel about that. What support they have. Who understands.
- What was going on in their lives they believed that transitioning would address?
- What does this mean in their everyday life?



Appear with typical male/female secondary sex characteristics

- Yet they are women/men
 - How do they feel about this?
 - What, if anything, do they need to do regarding this?
 - What are their fears



What are their medical concerns

- Long-term impact of hormones
- Reproductive issues
- Will they look like the gender they feel they are
 - fear of being stuck in between
 - being a freak
- More surgeries
 - Don't want to mess with body anymore-wrong before



Mental health

- grieving
- deciding on procedures to change or not change body
- changes they and other see
- brain changes or fear of harms
- loss of community
- shame



Are they still “trans”

- Is that how they see themselves?
- Is it your need to call people that or not see people in that way



Support services

- Peers
- Online and some in person support groups
- Coping with dysphoria groups



“Welcome to Gender Identity Dropouts, an ftm detransition support group. We are women who have stopped our ftm transition, at any stage. You are welcome here regardless of what transition milestones you experienced or didn't experience. We are here to witness for each other, support each other, and share the tools that help us cope and heal. Sometimes we may hear a lot that we recognize in each other's stories and sometimes we may not. Both are okay. We do not all have to be the same to belong here and to deserve support. We do not have to make the same meaning of our experiences. We are here to support and honor everyone here in making meaning of her own experience, however that looks for her. Being here does not require adherence to any particular beliefs or practices, but it does require a commitment to complete confidentiality for what we all share.”

Gender Identity Dropouts—



How do you treat their dysphoria

- Who has a client who CANNOT take hormones?
- Can't surgically transition because of health or religious reasons?
- Who has a client who has transitioned and still experiences dysphoria—at least some of the time?
- Need skills to treat dysphoria that are not medical in nature



Regret



Tell me how I can differentiate between people who
may regret and people who won't

**I'll disappoint you if you are looking
for easy answers**



Difference between what provider thinks is a good decision and the decision a well-informed patient might make

Also a good decision at the time can still later be regretted



Regret happens

- Regret is inevitable in life; Regret is tied to decision making
- The belief that life would have been better had we made a different choice
- Regret is a complex phenomena
- Regrets tied to outcomes—a good outcome a patient might be happy with, however with the bad outcome from the same surgery they regret the surgery.
- Regret is negative so people experiencing it feel negatively about the choice they made and that lens is present-subjectivity



Mental health issue

- trauma
- grief
- autism spectrum
- belongingness and attachment (peer group)



Regret

- 28% of US women who have had tubal sterilization report regret. Shreffler, K. M. et al (2016).
- 4.9% breast cancer treatment experienced decision regret. Martinez KA, et al 2015
- 95% of women report abortion was the right choice for them after 3 years. Rocca, C.H. 2015
- 23% men expressed regret with treatment decision for metastatic prostate cancer



Regret is not disappointment

regret≠/≠detransition

- People who are disappointed in the outcome of their surgery do not necessarily regret their surgery
- People may be disappointed in surgical outcomes, but do not necessarily regret the procedure, they regret the outcome. Very Different.
- There are people who regret their medical transition who do not detransition—they make peace with the choices they have made



Statistics and information

- Gender dysphoria is rare (small n)
- Detransitioning is rare
- Intentional misinformation or using data incorrectly
- Low quality statistics—too small sample sizes, no rigorous research, anecdotal
- Can't do a double blind randomized control compare treated to untreated, not ethical to deny care
- Follow up hard (people who live as m or f not as trans, move away after surgery)
- Definitions for regret vary, when they do they study, how long after surgery, etc.



What should you be looking for?

- The people I've spoken with were certain that medically transitioning was the correct choice at the time they made it and there was nothing anyone could have said.
- In fact, they would have felt that it was gatekeeping if anyone had intervened to slow them down
- Doesn't mean they don't wish, in hindsight, that someone had slowed them down.



Ideas from past

- heterosexuals
- social isolation
- psychological instability
- poor surgical results
- less attractive physical appearance
- lack of familial support
- transsexualism secondary to transvestitism
- poor differential dx
- later onset of gender dysphoria
- Later requests for treatment



No single explanation

- Wrong treatment of the problem they faced-didn't achieve expected results.
- Worked and now doesn't. Didn't give people what they needed.
- People felt misled by providers



Problems with general medical informed consent

- Schenker, Y., Fernandez, A., Sudore, R., & Schillinger, D. (2011). Interventions to Improve Patient Comprehension in Informed Consent for Medical and Surgical Procedures. *Medical Decision Making*, 31(1), 151-173.



Better job with IC

- Informed consent is a process and not an event
- Bodies changes, health conditions change, learn more about ourselves, learn more about transition process
- Informed consent as practiced in the general population has a long way to go before people would say it's successful for most people.



Can't ask the patient, either

- glaucoma patients acknowledged they received sufficient information yet few could objectively recall the information given to them
- 91% of the doctors felt that had taken enough time 9%
- 68% of patients felt they had enough time 32%
- only 17.8% were able to demonstrate a good understanding of their glaucoma surgery 83.2%



Sweden

- 2.2% applications for reversal of legal gender status (regret rate) for both sexes Dhjene (Binary) from 1960-2010
- Improvements is cultural context, increasing out, improvements in surgery



80% satisfied

- Murad MH, Elamin MB, Garcia MZ, Mullan RJ, Murad A, et al. (2010) Hormonal therapy and sex reassignment: a systematic review and meta-analysis of quality of life and psychosocial outcomes. Clin Endocrinol (Oxf) 72: 214–231.



Other ideas

- Gender queer, gender non-binary
- Misdiagnosis (patient self-diagnosis)
- Fantasy; Disappointment; Unrealistic expectations
- Poor outcomes from surgery make people regret the surgery at time not necessarily transitioning.
- Trauma
- Grief
- Misogyny, gender straight jackets



Citations

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