ADVANCING EXCELLENCE IN TRANSGENDER HEALTH

Detransition, Retransition: What Providers Need to Know

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Gender Health SF

We exist to improve quality of life

- Surgery is an important treatment
  - Good outcomes
  - Wrap around care based on actual situation
  - Don’t want to punish people for having dysphoria and we know that outcomes can be improved
  - Mitigate and address modifiable risks
  - We want to get you what you need and base it in reality

Gender Health SF

- Patient navigation
  - accompaniment throughout, education and preparation—the information that should be in an informed consent-one area IC models can fail
- Peer model-- distrust of providers-learn from people they trust and can hear
- Vaginoplasty by community member who has had a vaginoplasty
- Aftercare groups

Agenda

- My intention is to help you do a better job than I did with the first detransitioning patient I saw
- Introductory remarks
- How I learned about this topic
- Contextualizing detransition and regret
- Definitions, language and frames
- What people say they need
- Problems with Informed Consent models if time
- Q and A

Detransition
is a charged and triggering topic

self care and self awareness of your response

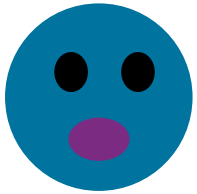
Who here has seen a detransitioner?

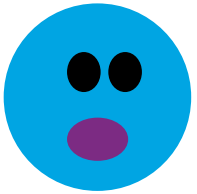
A person with regret?

A person with regret who doesn't detransition?

FACTS

- 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 providers.
- It is also a fact that a small number of people regret transitioning and/or that some people detransition. They too experience pain and suffering from lack of access and poorly educated providers.





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

One person's dissatisfaction with their choice to have a knee arthroscopy is not a comment on your need for the procedure

Trans 101

- Everybody gets informed care, gets good clinical care
- regardless of whether we agree with them, regardless of our personal beliefs
- (I train reluctant providers)

Detransition and transition occur within a sociocultural context

Cultural context

National Center for Transgender Equality Follow

We're the nation's leading social justice advocacy organization winning life-saving change for tran...

Aug 17 · 5 min read

Trump Health Officials Prepare to Promote Anti-Trans Discrimination

by Harper Jean Tobin

Trump administration rolls back protections for transgender students

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Trump orders Pentagon to reverse transgender policy

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Philadelphia Trans Health Conference

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RESPONSE TO THE CANCELLATION OF WORKSHOPS.

Treated as toxic, dangerous, do not belong under trans umbrella

OUR SUPPORTERS

August 29, 2017

6 4

Workshop content for the Philadelphia Trans Health Conference is a community-led effort, and while the community agrees on many workshop topics for the conference, there is occasionally a difference of opinion on others.

The mission of the Philadelphia Trans Health Conference is to educate and empower trans and gender non-conforming/non-binary (GNC/NB) community individuals on issues of health and well-being; educate and inform allies and health service providers; and facilitate networking, community-building, and systemic change. We strive to create an accessible and respectful environment that is inclusive of diverse gender-identities and expressions as well as inclusive of diverse opinions and

We have to be able to talk about this and to provide relevant care

- People are uncomfortable talking about ambivalence because they fear it will be used against them
- If you aren't 100% certain…
- Providers don't want to have their certainty rocked out here on the frontier
- People who detransition are dumped on and blamed and harmed by being used against the trans community

Newsweek

HEALTH

TRANSGENDER SURGERY: REGRET RATES HIGHEST IN MALE-TO-FEMALE REASSIGNMENT OPERATIONS

BY LIZETTE BORRELI ON 10/3/17 AT 1:30 PM

SHARE

7-8 in

HEALTH | WOMEN'S HEALTH | SEXUALITY | PSYCHOLOGY AND BEHAVIOR

Gender-confirmation surgeries—the name given to procedures that change the physical appearance and function of sexual characteristics—increased by 20 percent from 2015 to 2016 in the U.S., with more than 3,000 such operations performed last year. Rates are also increasing worldwide. Now, at least one surgeon is reporting a trend of regret.

Urologist Miroslav Djordjevic, who specializes in gender reassignment surgery, has seen an increase

It is a fact that he's done these surgeries—that's all. Weaponized. Discussion doesn't help detransitioners.

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
- 50% arthroscopic knee dissatisfied

Nuance and conflicting models

- We need to embrace increasing complexity
  - technology outpaced social conversation
  - everything has changed because access has improved
- We are expanding our definitions; the field is changing
  - GNB didn't exist for me as a youth; language we used in past is now offensive
- Stable identity
  - We want certainty-
  - our need is unreasonable and conflicts with a developmental model-gender across the lifespan

This is because we are maturing, growing up as a field

- Pendulum swing
  - Gatekeeping, paternalism, activism
  - Good patient-centered clinicians managing our own countertransference
- Move away from polarity; binary, simple ideas
- Complexity is a good thing
- Hard for insurance to code

New Frames

- Reactivity and non-science
  - I've never seen a detransitioner therefore they don't exist
    Greenland I'm pretty sure it exists
- A binary world
  - Cis or trans
  - For us against us
  - Transition or suicide
  - Trans or mentally ill
    - Stigmatize trauma survivor; stigmatize mental illness in an attempt to depathologize ourselves
  - The only treatment is medical-
    - No one size fits all so why do we act like it should?

Ideas from past--transition regret

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

Harriet

My counter transference

- It must be internalized oppression
  - Wasn't listening, it was the frame, the lens I had at that time
- This is going to hurt the movement
- I disagree with her
  - Transgender people ARE real!
    - My identity (I am real!)
    - My work
- I have no answers to your questions
  - Hormones lasting effect on brain
  - How to find community

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—coerced or forced
- People who regret they transitioned medically but there was no other way to know it wasn't the right choice—concrete thinkers-may also be gender journey folks
- People who regret they transitioned medically and regret their choice. Many feelings.

When detransition is about the "gender journey”

- Old SOC — Path was social transition to hormones to surgery—forced more physical change than needed/wanted.
- Reductionist and unresponsive to people’s actual needs
- NB

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 an 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

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.

People who regret the experience of their previous transition-forecasting

- Some people can not know something until they do it. People who have difficulty with forecasting. Concrete thinkers. Neurodiversity.
- 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.

People who regret they transitioned medically and regret their choice.

- It was the wrong choice
- I feel mis-treated or misled
- I want redress, I want my life back, I want justice

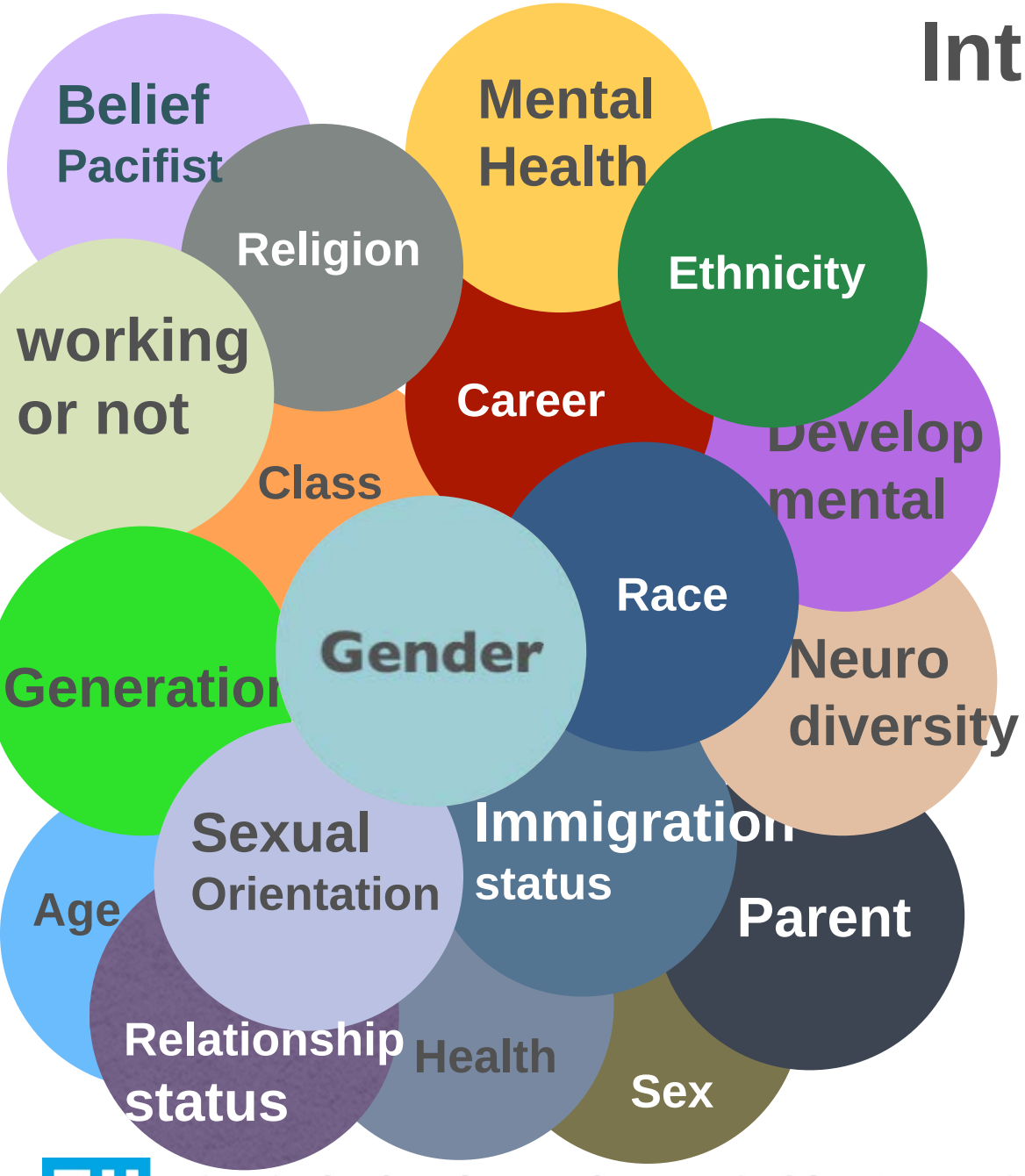
All groups share:

- 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

Problems for therapists

We used to only see pathology and not gender

Intersectionality



Simultaneous effects of multiple identities

Patient Centered Care- whole person

- People struggling with detransitioning can trigger providers
  - Inexperienced providers with just a gender lens
  - Their exploration may upset us, their views
    - People should not be allowed to transition, it's not a brain issue
- Whatever patient brings to you is ok
  - Judgment on our parts
  - Frames we are bringing
    - They don't exist; This is a phase
    - They threaten the movement

Whole person client centered care

Transition back is hard-need support

- Social Isolation
- Relationships matter-need support
- Trans Community-some want to stay
- Rejection; banned online
- Existence is triggering to others
  - Lose support they found after transitioning the first time
- If not trans community, who is community now?

You're unwelcome and dangerous

- No place to talk about feelings or concerns
  - Peers and providers are uncomfortable with you
  - Unwelcome in online communities—get banned
- You are a failure
  - tx didn't work-triggering to people who need the treatment
- Your story is dangerous-- PTHC
- Your existence harms a community
  - Given the message you are dangerous (or mentally ill as if that's a bad thing)

Concerns

- Decision making about new transition, road map
  - Need the same kinds of care people in transition need
- Going off hormones, perhaps starting on other hormones, hair removal, possible surgery, etc.
- Treatment of continuing gender dysphoria, psychosocial support, adjustment disorders

Shame

- Treatment failures
- Pariahs
- Parents, friend, church was right
- No one to help
- Coping with changes they and other people see
- Grief and loss
  - Their original body and original brain
  - They are hopeless—tx failed
  - Let themselves and others down, perhaps therapist

Distrust

- People feel that their life story has become weaponized for use by others, politics-trust issue
- Distrust of providers-People may have felt harmed or neglected by previous providers, inadequate informed consent models
- Have no idea if you “believe” them or are going to explain them (what’s really going on is…)
- Distrust-people may have encountered providers, friends, family who did not believe them

What are their medical concerns

- How to go off hormones safely
- Long-term impact of hormones
- How has it changed my brain
- Concerns about autoimmune disorders
- Reproductive issues
- Physical presentation

Appear with typical male/female secondary sex characteristics

- Will they look like the gender they feel they are
- Yet they are women/men
  - fear of being stuck in between
  - being a freak
  - How do they feel about this?
  - What, if anything, do they need to do regarding this?
    - More surgeries? Mistake before.
  - How will they cope in this binary world with a mixed presentation?

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
  - Find each other on the internet now
- 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 (DBT, mindfulness)

Regret

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

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

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.

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

Mental health issue

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

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

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

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 change, 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.

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? How are they dealing with that now?
- What does this mean in their everyday life?
  - If not trans, MUST be mentally ill or worse

Citations

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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.