

THE EXPERIENCES OF GENDER DIVERSE AND TRANS CHILDREN AND YOUTH ATTENDING SPECIALTY CLINICS: THE STORIES OF GENDER-AFFIRMING CARE PROJECT

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On behalf of the *Stories of Gender-Affirming Care* team



Background literature

- Children who are affirmed in their gender identities experience positive mental health outcomes equivalent to those of their cisgender peers (Durwood et al., 2017; Olson et al., 2016).
- Access to puberty blockers, cross-sex hormones and surgery, as needed, improves medium- and long-term health outcomes into adulthood (Chew et al., 2018; Cohen-Kettenis et al., 2011; De Vries et al., 2014; Olson-Kennedy et al., 2018).
- Very little data on experiences of care from the perspective of children and youth (Gridley et al. 2016; Steensma et al., 2011; Corliss et al., 2007).
- Experience seeking gender affirming (GA) care: Delayed or limited access to trained gender-affirming health-care providers and medication; inconsistent protocol application; use of incorrect names and pronouns; lack of coordinated care. (Gridley et. al 2016)

Aim of the Project

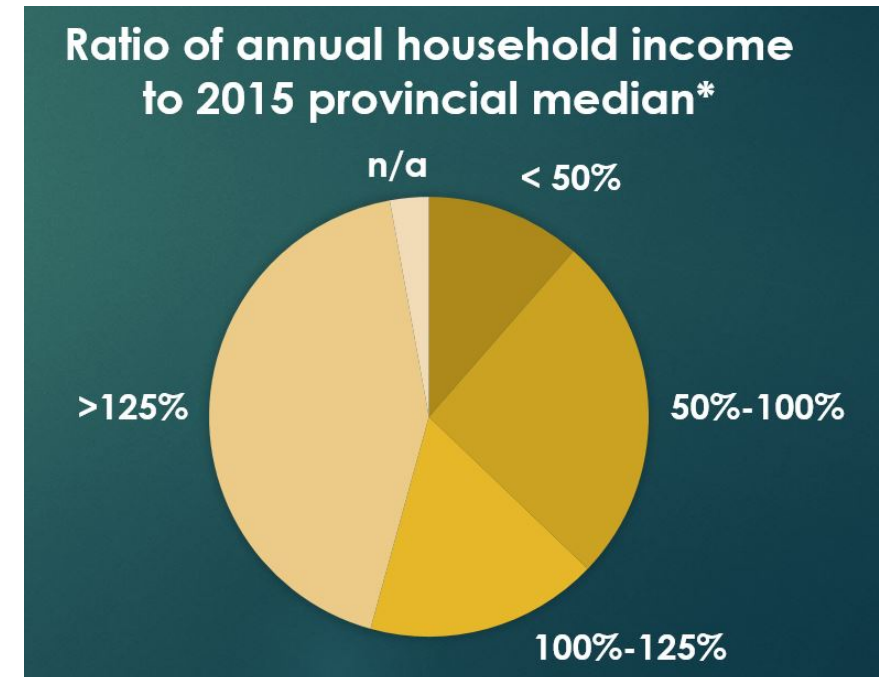
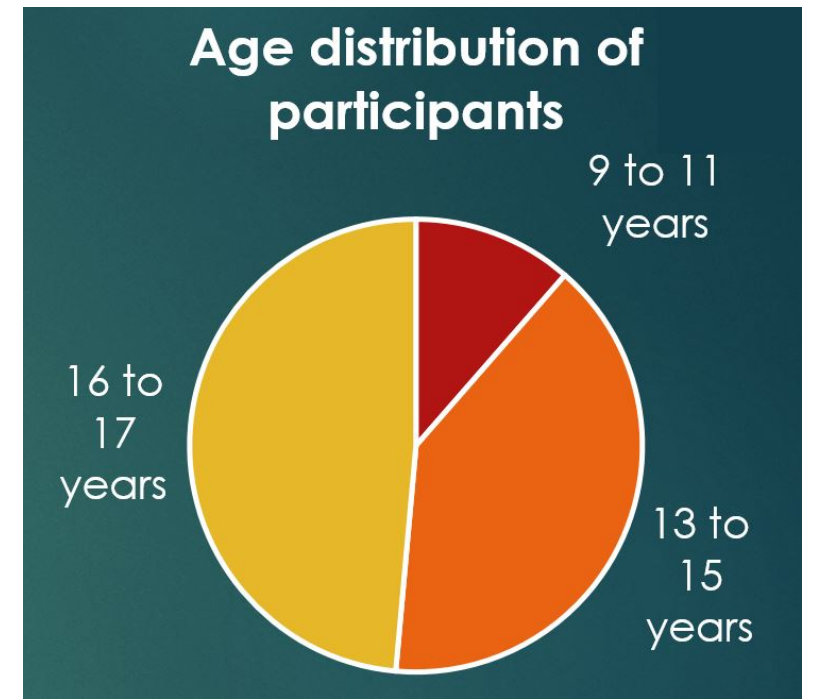
- To explore the experiences of trans children/youth and their families accessing GA care during the prepubertal, pubertal and post-pubertal stages of development, specifically:
 - motivations and pathways
 - strategies to express and/or address dysphoria /navigate social and family situations;
 - what contributes to their psychosocial well-being and quality of life;
 - their experiences of GA care and medical interventions.
- This presentation focuses on **trans and gender diverse children and youth*** and their **experiences accessing specialty clinics and medical interventions.**

Methodology

- Grounded Theory methodology (2016-2019)
- Social determinants of health framework as sensitizing concept
- Data collected at three specialty clinics providing GA care to trans and gender-diverse youth and children in Canada: Meraki Centre in Montreal, Children's Hospital of Eastern Ontario (CHEO) in Ottawa, and the Health Sciences Centre in Winnipeg.
- 72 semi-structured interviews with 36 child-parent dyads (12 per clinic):
 - **36 prepubertal trans children & pubertal/postpubertal trans youth**
 - **36 parents or caregivers** (interview + socio-demographic questionnaire)
- Data analysis via MAXQDA, line by line coding, then axial and selective coding

Diversity Sampling

- 35 youth (9-17 years old)
- 14 transfeminine (TF) & 21 transmasculine (TM)
- 7 interviews in French / 28 in English
- 15 had changed their legal gender marker (3 more were in process)
- The majority of youth were white (N=30). 5 were Asian or Indigenous; 4 of these were living with Caucasian adoptive- or foster-parents.
- 29 were covered by private health insurance
- Household income tended towards higher values compared to provincial census data.



*Based on 2016 Canadian census data: \$59.8K (QC), \$68.1K (MB), \$74.2K (ON)

Reasons for Seeking GA Care

- To help with youth's gender dysphoria.
- Close to $\frac{3}{4}$ of youth had experienced suicide ideation in the past.
- The idea of seeking gender-affirming care was first raised by a parent or a professional (ex: medical doctor, school counsellor) after discussions about gender identity or expression.

To be honest, I forget how [I started at the GD clinic], but I remember my mom and I talking about next steps. At this point, I was still very unsure, and so my mom had the idea that I could talk to someone. I talked to many different people who had more knowledge than me. Maybe so they could help me, guide me in the track that I'm trying to get. And so she found the place here, and so I came here and I met with [GD clinic intake nurse]. That was awesome. (Adrian, TM, 14 yo)*

* The gender specialty clinic

Reasons for Seeking GA Care

- Some participants, (all TM), said they first brought up the idea of seeking gender-affirming care with their parents:

*I went, and I talked to my mom. I was like, "I want to start hormone therapy." She was like, "Okay, we'll find out more about it. We'll research it."
(Randy, TM, 16 yo)*

- It took several months to years from the moment they first told parent about their gender identity until their first appointment with a physician at the clinic. By then, many had a clear idea what interventions they wanted:

Well, I think we like came here [GD Clinic] pretty much to get the blockers and then get the hormones. [...] So I probably talked about like the first time we even met. (Yannick, TF, 16 yo)

Hurdles to Overcome Before Seeking Care

- Coming out to parents and getting support described as a necessary hurdle to overcome before accessing care:

Of course, if I'd [talked to my mom], say, before my puberty hit, or when I was 10 years old, yeah, I would have done it, yeah, I would have told her. Everything would have happened, I would have had my real puberty as a girl. It would have been easier. But I don't regret my life right now, I'm really happy with my life. But if I could have told her sooner, I would have done it. (Eloise, TF, 14 yo)

The time it took my mom to get used to the idea for herself, she didn't want things to move forward too fast and for me to start changing [my body] before she'd taken the time to get used to it before sending me to a psychologist. So it took longer. (Jim, TM, 14 yo)

Desired Medical Interventions & Outcomes – Youth under 12 (N=4)

- No interventions undergone (4/4)
- Most had specific ideas what effects they wanted, but a vague idea of which interventions would achieve these.

I'm kind of interested [in taking blockers], just to change my voice, because when I'm older, and change my, um. Just mostly male like... (Kevin, TM, 10 yo)

- Two youth had a marked fear of needles, posing a potential obstacle to blockers:

Interviewer: *So I know today you're here to talk to [Endocrinologist]. Right? So what did you guys decide [about taking blockers]? Are you going to...*

Youth: *No needles.*

Interviewer: *No needles. Okay. So is that what you want eventually, or?*

Youth: *No needles. I don't like needles. [...] Yeah, I don't like the needles, but I have to do the needles if I want to have the blockers and to continue all that (Elisa, TF, 10 yo)*

Desired Medical Interventions & Outcomes – Youth over 12 (N=31)

- Clear idea of desired interventions
- Desired outcomes from blockers: Stop puberty, menses

I [was] really scared. I was like "We have to get there [GD clinic] as soon as we can to stop this [puberty]". [...] Just like a complete stop of everything. Because, like I said, I'm not uncomfortable with my body but I'm more uncomfortable how other people see my body. So I didn't want it to fully develop (Oliver, TM, 16 yo)

- Desired outcomes from hormone therapy:
 - TM youth: to change their voice, face or body shape, grow facial hair
 - TF youth: to change their body shape, develop curves

I [said] to [GD clinic nurse], "I can't wait til I have boobs. When can we start the estrogen now? I'm down with the blockers, but like, estrogen!" A couple more years. (Juliette, TF, 13 yo)

- Surgery: TM youth were more likely to want top surgery; TF youth were more likely to want bottom surgery.

Positive Outcomes

- Feeling of happiness about physical effects from the medical interventions
- Just knowing they were beginning GA care or medication alleviated anxiety :

I realized that I accepted myself much more, and that it felt much less bad looking at myself in a mirror after taking blockers. (Jeff, TM, 15 yo)

[Since I was around 7], I would hit my arm against walls and stuff because I was just really unhappy and it's better now that I'm on testosterone because I'm kind of feeling content, like things are going to get better. So it hasn't been bad for quite a while. (Joseph, TM, 16 yo)

Right now, just having the [prescription] to start hormones, just knowing that I'll be starting soon, already makes me happier, because it's a big step in my life that's going to bring me towards physical changes and it's going to bring me towards being who I really want to be. (Eloise, TF, 14 yo)

Experiences at the GA Clinic

-- Positive experiences

- All participants said staff always used correct pronouns
- Many said staff were helpful (giving them access to medical interventions; helping them understand their gender)
- Participants felt heard, welcome, validated, cared for:

It was helpful because talking to someone who knew a lot about that stuff, more than Google could give you is helpful. [...] And they really make you feel good about your decisions and help you realize what you really want. So it's nice. (Jake, TM, 16 yo)

Experiences at the GA clinic (continued)

-- Frustrations

- Long waiting time (waiting list or protocol restrictions)
- Discomfort about some questions asked
- Youth sometimes felt they had to convince staff they are trans
- Some staff have limited understanding of non-binary youth; need to expand the care options available to them.

Concerns & Reservations

- Unwanted side effects
 - Injection site pain
 - Hot flashes, issues with mood, increased acne, or weight gain from blockers or hormones.
 - More serious side-effects (4 participants) youth linked to blockers: vomiting due to hot flashes, strong fever after the injection, a suicide attempt, and stress fractures:

[After starting blockers] I had a serious suicide attempt where I went to the hospital. That was one of my darker periods of my life. Even though I was beginning my medical transition, estrogen blockers are known for being a little bit wacky on your emotions. I was already in a pretty not-that-great place mentally [since 2 years] at that point. So it was a rollercoaster of everything going on. Simulated menopause was not the best thing at that time. (Jason, TM, 17 yo)

Second Thoughts or Regrets

- Even youth who had more serious side-effects felt that medical transition was the right choice for them, though some had questioned the decision in the past:

[The time of my suicide attempt] was one of my most strongest parts where I was like, "Okay. What if I'm lesbian, you know, and this all a mistake?" But then eventually, everything stabilized, and I was like, "But I'm so much happier, come on". It wouldn't make sense. [...] I feel like it would be difficult [if I changed my mind], because I've come so far. [...] But honestly, I personally don't think it'll happen. In the hypothetical case, I would definitely say something if I would be repeatedly think[ing] about it, if hormones would be actively making me miserable or some stuff. Because I have read about people who de-transitioned, that's perfectly fine. (Jason, TM, 17 yo)

Second Thoughts or Regrets (continued)

- A majority had never questioned their decision, and those who said they had past doubts said these had been fleeting:

I've had little moments where I'm like, "What-- what am I doing? This is something serious," but then I look in the mirror and I listen to my [deeper] voice and I'm like "This is what I want to do." (Brandon, TM, 17 yo)

Discussion and Conclusions

- The vast majority of youth described their experience of accessing medical interventions and GA care at the clinics in positive terms.
- Many youth also described improved well-being since they came out and started accessing GA care.
- Frustrations most frequently evoked by youth concerned delays in accessing GA care and interventions.
- Though unwanted side-effects were evoked by several youth, none expressed regrets about any of the GA medical interventions undergone.
- Results are coherent with data from the limited existing literature, with one marked exception: all youth said GD clinic staff always used their preferred names and pronouns.

Study Limitations

- Youths' narratives of their medical and social transitions are often intertwined, making it difficult to separate the role of each in improved well-being or reflections on second thoughts.
- The sample might benefit from a greater diversity of participants.
- The study design and recruitment documents were such that only youth whose parent(s) were fairly supportive of their gender identity participated.
- The sample of prepubescent youth is small.

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Winnipeg Health Sciences Centre



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(CHEO)

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- Please get in touch for further information and news on the *Stories of Gender-Affirming Care* study: Annie Pullen Sansfaçon a.pullen.sansfacon@umontreal.ca

