

THE EXPERIENCES OF PARENTS/CAREGIVERS ACCOMPANYING 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



Our Objective

- As we strive clinically to respond to the increased numbers of children and youth seeking Gender Affirming (GA) care, we wanted to learn about the experiences of youth and families:
 - The motivations and pathways leading youth & families to seek GA care;
 - Strategies used to express and/or address dysphoria and to navigate social and family situations;
 - Aspects that contribute to psychosocial well-being and quality of life.
- This presentation describes the parents' perspective accompanying their children and accessing care.

Literature Review

- Parents/care givers have been observed to react both positively and negatively to their child's assertion of gender diversity (Clark et al., 2018; Riggs & Barthomeaus, 2018; Sansfaçon et al, 2018)
- Lack of parent/caregiver support, family-based rejection, as well as stigma and discrimination significantly increases adverse health and well-being outcomes for youth (Pullen Sansfaçon et al., 2018; Veale et al., 2015; Travers et al., 2012)
- Youth who experience family acceptance and affirmation of their gender identities experience greater overall quality of life. (Aramburu Alegria, 2018; Katz-Wise et al., 2018; Travers, 2018; Durwood et al., 2017; Olson et al., 2015; Veale et al., 2015)

Literature Gap

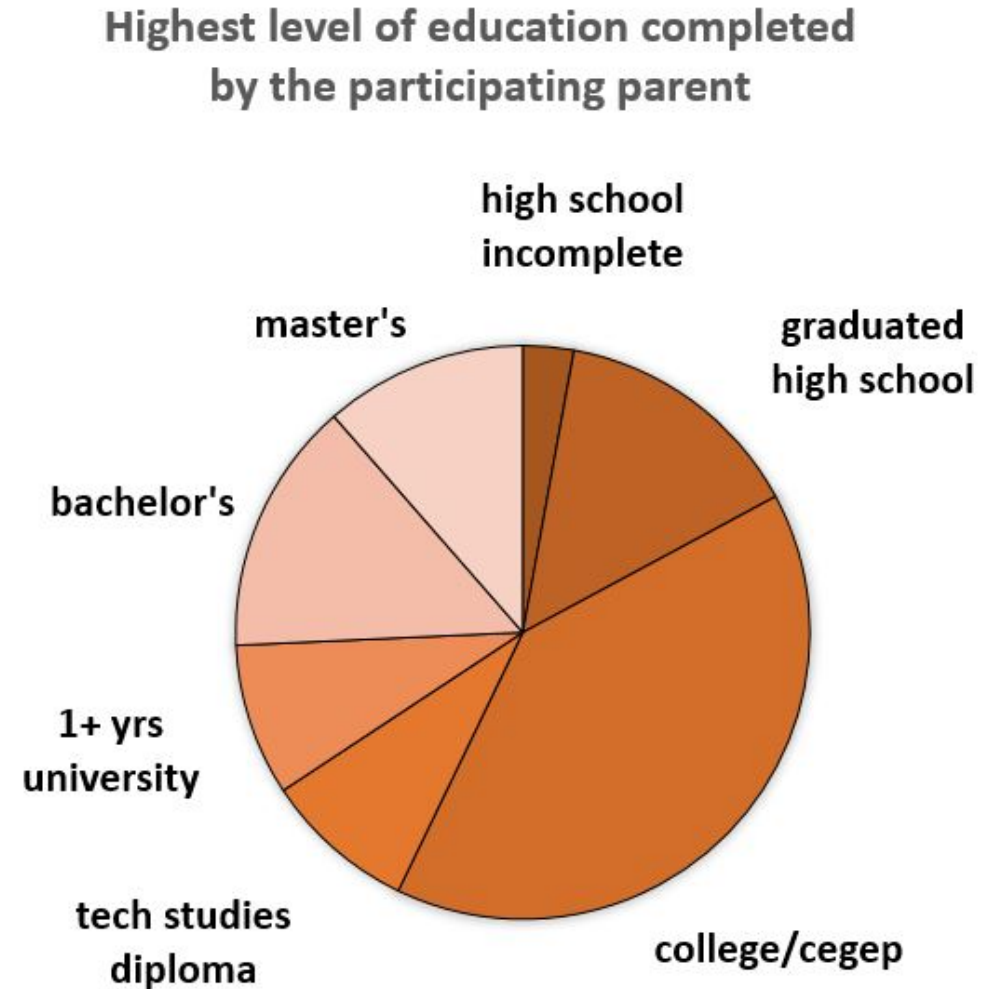
- Parent/caregiver perspective on accessing GA medical care is limited:
 - Parents concerns about accessing care relate to issues of safety and acceptance after transition (Lawliss et al., 2017)
 - A gender affirming, trans competent clinical environment can foster improved parent/child relationships, increased self-esteem and reduced stress for parents (Gridley et al. 2016)

Methodology

- Grounded Theory with case study methodology (2016-2019)
- Guided by a social determinants of health framework
- Data collected at three specialty clinics providing GA care 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 + socio-demographic questionnaire with 36 child-parent dyads (12 per clinic).
- Data analysis: interviews are transcribed, coded line by line then axial and selective coding

Participant Sample

- N=35 from 3 clinics
- Diversity sampling for the children cohort.
- Household income tends towards higher values compared to provincial census data.
- Relation with the youth: 4 fathers and 32 mothers, 2 of whom described themselves as a foster parent or guardian*
- 29 families were covered by private health insurance



* Both parents participated in one interview at their request, hence 36 participants for 35 interviews.

Results: Reactions to Coming Out

This important moment for parents initiates the process of acceptance and eventually the seeking of GA care

Main reactions to coming out:

1. Resistance and denial:

It's like how do we deal with this, where do we go, we've had so many mental health issues prior to this with your ADHD, your behavioral disorder and [...] impulsivity, and now we've got another, I hate to say it "label" to add to it, and we're just more scared for her at that point (Francine, parent of 17 year old Lisa)

Of course my reaction [...] wasn't a good one, it was like, "No, this is how you were supposed to be born, and like, just because you like girl things doesn't mean you're a girl, it's okay to like both things" and [...] I didn't know what to do, I was just in a panic, right? (Kylie, parent 11 year-old Katie)

Reactions to Coming Out (continued)

2. Surprise :

I didn't see it coming.. you know.. [dead name] always dressed like a little girl, always had, until recently, long hair” (Jackie, parent of 15 year-old Jeff)

3. Supportive : Positive feelings and reactions such as **pride, openness,** and **feeling that everything was making sense** or falling into place (more than ½ the sample):

When I learned that, I was like “Phew!”, we just realized what it was, why things haven't been working over the past year and half. (Lydia, parent of 14 year-old Jim)

I looked, and I said to [youth] “I am proud that you are my child.. I am proud of the courage you had to express and to say what you were feeling and I am proud of the courage you display to move forward in all of this” (Jacky, parent of 15 year-old Jeff)

Acceptance was slow for most parents:

Experience of Grief:

I had a tough time dealing with the fact that I had a daughter but I didn't have those five years of my daughter. Like I have no baby pictures of my daughter as herself. I have her as who I thought she was. So there's a mourning. [...] The things you didn't get to do because you didn't know. And also, it's the loss of the identity of my son.

(Maria, parent of 9 year-old Debbie)

A small number of participants also spoke about **denial** – may be part of the grieving process

Lacking knowledge and information about trans identities:

We didn't understand because we had nothing to do with transgender anything, I mean I might have heard the word but I didn't know anything about it.

(Brenda, parent of 16 year-old Josh)

Other Barriers and Struggles

- **Co-parenting struggles** - these might have affected a parent's capacity to support their child.

I wish [husband] would talk about things, because I want [youth] to feel more supported, but I think, I just end up doing the best I can for [youth] and hoping that he knows, that I'm there. And I've always said to him "I'm here behind you 100%, you know." (Rose, parent of 14 year-old Adrian)

- **Issues with using the right name and pronouns:**

I've been using male pronouns for 16 years, that she's a boy, and now, she's asking everyone to start saying "she" and call her [youth] overnight. When we slip, she gets angry. [...] She had to learn that, we're human beings, and that we need to get used to her new state. (Franca, parent of 16 year-old Eloise)

Aspects Facilitating Acceptance of their Child

- **Education**

I found a couple of books that were helpful that kind of give you an idea of what things are like. You know, “No it's not a phase,” that sort of thing, that parents want to know for sure. (Meghan, parent of 14 year-old Annie)

- **Allowing oneself to take time to integrate the new reality**

Not to say that it was easy, because by no means, there's lots that takes a long time to wrap your head around and change your perspective on things.

(Amal, parent of 17 year-old Brandon)

- **Receiving support from other parents**

But it was good to have, and I always went to meetings, I always went. Tried to get everything I could out of it, but I could still see way ahead. And I still used it as a [reference point]. I always had that to refer to. And the group evolved over the years and I evolved. (Mona, parent of 16 year-old Anika)

- **Receiving support from professionals**

Parents' Experience with Clinic Staff

- All the experiences reported by parents were generally described as very positive.
- Overall:
 - Staff were helpful, access to the clinic was fairly rapid, access to services within the clinic after intake was rapid;
 - Staff were knowledgeable and parents didn't feel pressured but rather felt guided towards informed decisions;
 - Parents felt supported, at ease, that they were not being judged by staff.

Negative Experiences and Critiques

- **Wait times to access care (one site):**

It has been a good experience once we could see them. I think it's unacceptable that you have to wait over a year, and part of the problem with that is also initially, your child is super happy to be out in the open and it's freeing, but there are other issues involved once you are out that immediately come out, and you have to face in society because you're trying to be yourself. (Jessie, parent of 15 year-old Gary)

- **Delay related to protocol restrictions linked to age:**

[The clinic] still rejected him, and [the staff member] was still like, "Well, I guess you'll have to wait," and I'm like, "Are you guys insane?" Talking about, you read any of the documentation, you don't fucking wait. [...] And, at times of times of extreme frustration, probably closer to rage, I often think "Do I send the funeral bills to [clinic]?" (Sophia, parent of 13 year-old Danni)

- **Lack of mental health services for their child**

- Other complaints raised by a handful of parents related to language barriers, lack of resources to support parents, or feeling that some of their concerns or needs were belittled by staff.

Parents' Unmet Needs

- Parents said **care for parents' mental health** was a fundamental need that was not being met.
- Given their crucial role in ensuring the well-being of their child, support for themselves as parents was identified as important :

[I would like to see more] therapeutic help [for myself]. One-to-one – not just in groups. Groups are fun, but for kids. (Romy, parent of 17 year-old Clare)

We were in the circle where we had to say our names or whatever, and who your child is. I just remember when it got to me, and, this was my first ever experience and I just burst into tears. I couldn't get the words out. It was a hot mess. So, (laugh), I was just, "Whoa!" (laugh). I didn't go back (laugh) after that. (Kylie, parent of 11 year-old Katie)

Discussion

- Many parents struggle for a long time with fully accepting their child's gender identity, including those who access GA care with their child.
- Four main pillars of acceptance emerge:
 - Education;
 - Allowing oneself time to integrate a new reality;
 - Support from other parents;
 - Support from professionals.
- Though they felt supported in the clinical setting, they also said that their personal needs as parents were not well met.
- Considering that parental support and acceptance are crucial to youth well-being, a more systemic, family approach to care in the clinics would be desirable.

Conclusion

- This study sheds much needed light on the experiences of parents accessing speciality clinics with their trans and gender-diverse children.
- Parents in this study described the importance of getting support for themselves so that they could effectively support their child, and they recounted different issues they encountered in seeking that support.
- Themes emerging in this study echo those found in earlier studies of parents' more general experiences, suggesting that some parental needs remain unmet.
- Increased support and education for parents might be achieved through closer collaboration between clinics and community organizations and groups, supplemented by additional resources.

Study Limitations

- The sample would have benefited from a greater diversity of participants.
- The study design and recruitment documents were such that only parents who were fairly supportive of their child's gender identity participated.
- Much of the interviews focussed more generally on the child needs than on the parents' needs.

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