



# The experiences of gender diverse and trans children and youth considering and initiating medical interventions in Canadian gender-affirming speciality clinics

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### **ABSTRACT**

Background: Canadian specialty clinics offering gender-affirming care to trans and gender diverse children and youth have observed a significant increase in referrals in recent years, but there is a lack of information about the experiences of young people receiving care. Furthermore, treatment protocols governing access to gender-affirming medical interventions remain a topic of debate.

Aims: This qualitative research aims to develop a deeper understanding of experiences of trans youth seeking and receiving gender-affirming care at Canadian specialty clinics, including their goals in accessing care, feelings about care and medical interventions they have undergone, and whether they have any regrets about these interventions.

Methods: The study uses an adapted Grounded Theory methodology from social determinants of health perspective. Thirty-five trans and gender diverse young people aged 9 to 17 years were recruited to participate in semi-structured interviews through the specialty clinics where they had received or were waiting for gender-affirming medical interventions such as puberty blockers, hormone therapy, and surgery.

Results: Young people felt positively overall about the care they had received and the medical interventions they had undergone, with many recounting an improvement in their wellbeing since starting care. Most commonly shared frustrations concerned delays in accessing interventions due to clinic waiting lists or treatment protocols. Some youth described unwanted medication side-effects and others said they had questioned their transition trajectory at certain moments in the past, but none regretted their choice to undergo the interventions.

Discussion: The results suggest that trans youth and gender diverse children are benefiting from medical gender-affirming care they receive at specialty clinics, providing valuable insight into their decision-making processes in seeking care and specific interventions. Providers might consider adjusting aspects of treatment protocols (such as age restrictions, puberty stage, or mental health assessments) or applying them on a more flexible, case-bycase basis to reduce barriers to access.

#### **KEYWORDS**

Childhood gender dysphoria; hormone therapy; pubertysuppression medication; qualitative study; regrets; treatment outcome

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### Introduction

Across Canada over the past 5 years, we have observed an increase in the number of referrals of young people to specialty clinics offering gender-affirming care, mirroring trends in other countries. Transitions, whether they be social, medical or legal, can help alleviate gender dysphoria and decrease suicide ideations and attempts and are supported by gender-affirming models of care. Conversely, barriers to accessing transition related care can lead to increased anxiety, suicidal ideation, and to the disaffirmation of a person's gender identity.

In Canada, there exist just under a dozen specialty clinics offering gender-affirming medical care to trans youth. Previous qualitative research has explored barriers to accessing gender-affirming clinical care, but there are little data on youth's experiences of receiving care at such clinics. The Stories of Gender-Affirming Care project traces the experiences of prepubertal, pubertal and post-pubertal trans youth and their parents/ caregivers who have been referred to three specialty clinics in Canada. It seeks to learn more about their well-being, their concerns, experiences with and reasons for seeking care. This paper specifically focuses on the trans youth's experiences considering and initiating medical interventions.

### Literature review

We define gender diverse and trans children and youth as young people under the age of 18 whose gender identity differs from their sex assigned at birth (Ontario Human Rights Commission, 2014). In this article, we will refer to them as "trans youth." Research, clinical, and media attention on medical care for trans youth has increased rapidly in recent years. A review of research on trans youth seeking medical care reveals several reviews of care models and practices (Edwards-Leeper & Spack, 2012; Khatchadourian, Amed, & Metzger, 2014; Olson, Forbes, & Belzer, 2011), clinical studies of a variety of mental and physical health characteristics of trans youth seeking care (Olson-Kennedy, Okonta, Clark, & Belzer, 2018), mental and physical health outcomes of hormone therapy (De Vries et al., 2014), examinations of health care providers' perspectives and concerns about offering trans youth care (Knight, Shoveller, Carson, & Contreras-Whitney, 2014; Vance, Halpern-Felsher, & Rosenthal, 2015), ethical approaches to the care of transgender youth (Clark, 2017), barriers to care for trans (Breland et al., 2016; Gridley et al., 2016; Temple Newhook, Benson, Bridger, Crowther, & Sinnott, 2018a) and non-binary (Clark, Veale, Townsend, Frohard-Dourlent, & Saewyc, 2018) youth, and a community-based study of the future perspectives of trans youth and caregivers (Katz-Wise et al., 2017). An emergent body of research also focuses on the experiences of pre-pubescent gender diverse and trans children (Durwood, McLaughlin, & Olson, 2017; Olson, Durwood, DeMeules, & McLaughlin, 2016; Olson & Gülgöz, 2018; Temple Newhook et al., 2018b).

Throughout North America, the majority of gender clinics practice an affirmative approach to care for trans youth (Ehrensaft, 2016; Temple Newhook et al., 2018b), although not all providers adhere to this approach. Canadian and international associations of pediatricians and other health care providers have released policy statements and resources endorsing affirmative care for trans youth (Canadian Association of Social Workers & Canadian Association for Social Work Education, 2015; Canadian Pediatric Society, 2018; Canadian Professional Association Transgender Health, 2015; Canadian Psychological Association, 2015; Rafferty et al., 2018; Temple Newhook et al., 2018b). Affirmative care for trans and gender diverse youth includes the following principles: gender variations are healthy differences and not disorders; gender presentations vary across cultures; gender involves a web of nature, nurture, and culture; gender can be binary, non-binary, or fluid; and gender distress primarily stems from marginalization and negative reactions from society (Hidalgo et al., 2013). In this model, gender health is defined as a young person's "opportunity to live in the gender that feels most real or comfortable to that child and to express that gender with freedom from restriction, aspersion, or rejection" (Hidalgo et al., 2013, p. 287).

On a population basis, trans youth experience significantly poorer health outcomes than the general population, including increased risk of depression, anxiety, suicidality, and self-harm (Becerra-Culqui et al., 2018; Eisenberg et al., 2017; Rider, McMorris, Gower, Coleman, & Eisenberg, 2018; Veale, Watson, Peter, & Saewyc, 2017). This increased risk of poor mental health has also been documented in trans youth seeking medical care, with Reisner et al. (2015) noting that, compared to their cisgender peers, trans youth experience "a twofold to threefold increased risk of depression, anxiety disorder, suicidal ideation, suicide attempt, self-harm without lethal intent, and both inpatient and outpatient mental health treatment" (p. 274). Among trans youth, the most at risk of suicidal behavior (planning or attempting suicide) are trans boys and nonbinary youth (Toomey, Syvertsen, & Shramko, 2019). It is clear however that negative mental health outcomes are not inevitable for trans youth (Shumer, 2018). Emerging research indicates that youth 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). Research from the United States and the Netherlands demonstrates that access to hormone blockers, hormone replacement therapy, and surgery, as needed, improves medium- and longterm health outcomes for transgender youth into adulthood (Chew, Anderson, Williams, May, & Pang, 2018; Cohen-Kettenis, Schagen, Steensma, de Vries, & Delemarre-van de Waal, 2011; De Vries et al., 2014; Olson-Kennedy et al., 2018).

There exists, however, a significant gap in the literature exploring trans youth's own perspectives and experiences in seeking medical care. This gap is particularly pressing given the importance of centering trans voices in trans health research (Thompson, Karnik, & Garofalo, 2016). In view of the rapidly evolving context of trans rights and trans health care, existing studies in the literature dating back several years may have limited relevance for today's context & Wilson, (Corliss, Belzer, Forbes, Steensma, McGuire, Kreukels, Beekman, Cohen-Kettenis, 2013). We were able to locate just a few recent studies on the perspectives of trans youth accessing gender-affirming health care. The US Based study of Gridley and colleagues (2016) identified six barriers to care that include: a lack of accessible trained, genderaffirming healthcare providers for children and youth; inconsistent protocol use; use of incorrect names and pronouns; lack of coordinated care; delayed and limited access to pubertal blocking medications and hormones; and exclusion from health insurance policies. Clark, Townsend, et al. (2018), on the other hand, explored the impact of care on mental health and well-being of youth and found that increasing competence in gender-affirming care can improve health of young people.

### Method

The data presented in this article are part of a larger study of trans youth and their parents that is still under way. The objectives of the study are to explore the experiences of trans youth and their families who access care during prepubertal, pubertal and post-pubertal stages of development, to understand the motivations and pathways that lead them and their families to seek care, the issues affecting them, and the strategies they use to express and/or address dysphoria with the help of the gender clinics and in larger social contexts.

### Methodological approach

The study was designed according to Grounded Theory (GT) methodology (Dey, 1999; Strauss & Corbin, 1998) to ensure that data was "grounded" in participants' experiences, and to build a theory rooted in the participants' accounts (Strauss & Corbin, 1998). However, in order to meet differing requirements of ethics boards at each clinical site, in response to delays associated with ethics approval, research staff recruitment and training, and to accommodate the perspectives of a multidisciplinary team composed of qualitative and quantitative researchers from the social and medical fields, the study's methodology was adapted to integrate Thematic Analysis (TA) (Braun & Clark, 2006). GT was originally used for its inductive approach, relying on sensitizing concept rather than a fully developed theoretical framework and by including varied data collection contexts and experiences to achieve maximum diversity. That said, because of the time constraints and the research context, it would have been impossible to adapt the tools as the data and the theory emerged. Hence, we followed GT for data collection, but then used thematic analysis for data analysis, resulting in inductive, parfindings. ticipant-driven Combining methodology with TA is helpful to produce a multidimensional understanding of medical experiences (Floersch, Longofer, Kranke, & Townsend, 2010) and offers a "systematic approach to the analysis of qualitative interview data in the healthcare setting" (Chapman, Hadfield, & Chapman, 2015, p. 204). The flexible nature of TA means that it could be coherently applied to the project as it developed (Braun & Clark, 2006).

### Theoretical framework

The perspective of social determinants of health (Mikkonen & Raphael, 2010) was used as a sensitizing concept (Bowden, 2006) to guide the study design and recruitment by paying attention to the social location of participants. All aspects of the social determinants of heath as defined by the Canadian health services (Public Health Agency of Canada & Health Canada, 2019) were explored qualitatively in the research, either through the socio- demographic questionnaire or the interview questions. The work environment was discussed more largely by parents who discussed their peer network, but no explicit questions were asked about this.

## Settings

The complete data set (parents and youth) was collected at three Canadian clinics offering gender-affirming care to trans youth: Meraki Health Center in Montréal, Québec, the Children's Hospital of Eastern Ontario (CHEO) in Ottawa, Ontario, and the GDAAY clinic of the Health Sciences Center, in Winnipeg, Manitoba. All three participating clinics operate from a genderaffirming care perspective, in that they aim to provide the youth with "the opportunity [...] to

live in the gender that feels most real and/or comfortable for the child and the ability for children to express gender without experiencing restriction, criticism, or ostracism" (Keo-Meier & Ehrensaft, 2018, p. 13). While clinics differ in terms of staff, resources and protocols for accessing appointments and medical interventions, they all seek to validate the child/youth's experience with respect and sensitivity. Examples of affirmative practices integrated in these clinics include gender inclusive forms, displaying trans-positive literature and posters, providing support groups for youth and their families, and inquiring about and using preferred names and pronouns.

### Recruitment

Recruitment began with each clinic generating a list of patients that varied in age, gender identity, stage of puberty and medical interventions received. Each clinic aimed to recruit 12 youth of different genders with their parents: 4 prepubertal children and 8 adolescents on blockers or hormones, ideally a few from each treatment option. A letter of invitation was sent to each youth/parent on the list. The letters described the project and asked the parent or the youth to contact the research assistant hired for the site if they were interested in participating. These were sent either by email or lettermail, depending on local REB requirements. Both French and English versions were available, and the research assistant sent the letter in the language of the potential participant. The site research assistant collected basic demographic information from each individual who responded to the invitation in order to build a diversity sample and invited participants for an interview. Both the parent and the youth had to agree to participate to be eligible for the study. If no new interest was received from the first batch of letters sent, another batch of the same letters was sent to other potential participants. Those participants were again selected according to diversity principles (age, stages of puberty, gender identity and medical interventions received) in order to build a varied sample of youth. This process stopped when the clinic reached a total of 12 dyads of participants, with one of the clinics unable to recruit the final pair. Only families who

self-selected for the study by contacting the research assistant were included in the study. In total, thirtyfive dyads (trans youth and their parents) were interviewed. In this article, we discuss the data from the youth sample only (12 young people at each of two clinics and 11 at a third clinic).

### **Data collection**

Data was collected from November 2017 to August 2018. Participants could choose to interview in French or in English: seven youth chose to interview in French. Semi-structured qualitative interviews were conducted with trans youth aged 9 to 17 and their parents/guardians, who were interviewed separately, and a short socio-demographic questionnaire (gender identity of the child, educational level of the parent, cultural identity, ethnicity and citizenship status of both child and parent, and family income and access to health insurance) was completed by the parent in order to gather information related to the social determinants of health. Different interview guides were used for parents and for youth, but all youth were interviewed with the same interview guide. This guide focused on understanding the young person's life situation (family, school, friendship, sports, other activities), the challenges they faced and how they responded to them, and resiliency-related factors such as activities and self-care that make the child/ youth feel healthy and good about themself. In addition, we explored their hopes and expectations for medical and other services. For youth undergoing endocrine treatment, we also inquired about starting and using blockers and hormones and accessing surgery. The interview with youth lasted from 24 to 104 minutes (average 61 minutes). Interviews were tape-recorded and then transcribed verbatim but with any potentially identifying information removed. Participants were given a pseudonym. Interview transcripts were complemented by detailed memo notes, including analytical insights that had been written by the research assistant who had conducted the interview.

### **Analysis**

All youth transcripts were analyzed by the same research assistant who is fully bilingual and

trans-identified, under the supervision of the lead researcher. First, we immersed ourselves in the data by rereading the interview scripts in conjunction with the audiotapes, to check for errors in transcription. We also read the analytical memos produced by the research assistants who conducted the interviews. Next, initial codes were generated at a semantic level (Braun & Clark, 2016) by reading each line of the interviews, after which they were analyzed and categorized into themes. Because of the original Grounded Theory methodology design, we conducted an inductive Thematic Analysis, rather than one based on a fully developed theoretical framework. We went beyond simply describing the interview material by comparing study material between individual youth and between groups of youth by age, stage of puberty and insurance status, between clinics and protocols, etc. and reviewing the themes as analysis progressed. MAXQDA data analysis software was used to facilitate data sorting and cod-The process of theme development continued as we began to write articles, an integral part of Thematic Analysis, helping us to "define and refine" write the "story" around those themes (Braun & Clark, 2006). This article focuses on the themes that were developed around the experiences of trans youth and their pathways and access to care.

### **Ethics**

The project was approved by the ethics boards responsible for each clinical site (Meraki Health Center and McGill University; Children Hospital of Eastern Ontario (CHEO); the University of Manitoba and Health Sciences Center Winnipeg, as well as by University ethics boards responsible for the principal investigator and co-researchers who may access raw data.

Before beginning the interviews, the research assistant obtained informed consent from the parent/caregiver and the youth. The age of consent was determined by the provincial requirements of the individual site that is between 14 and 18 years old. Youth assent with parental consent was obtained from those too young to provide formal consent. Interviews were conducted by four trained interviewers, including two who

are trans-identified, and all of whom endorsed trans-affirming principles (using correct name and pronoun, posing the questions so as to respect the youth's identity). To preserve anonymity of the participants, the site's research assistant generated an anonymous code for each parent-child dyad. Participants were informed that clinicians might be made aware that they had participated in the study (interviews occurred on the same premises as the clinic), but that clinicians would not view transcripts from the clinic and would only have access to data extracted from interviews in which it was not possible to identify participants.

A list of support and mental health support services was provided to all participants, and referrals to appropriate resources were provided to those participants who manifested a need for greater support. An emergency protocol was developed for each site to ensure the safety of young people who might be at risk of suicide or child abuse.

# Youth sample<sup>1</sup>

Of the thirty-five participants, four were aged from 9 to 11 years,<sup>2</sup> fourteen were aged from 13 to 15 years and seventeen were 16 and 17 years old. 14 youth were transfeminine (TF), i.e. had been assigned male at birth, and 22 where transmasculine (TM), i.e. had been assigned female at birth. All youth described their identity in binary terms, either as male/female, boy/girl, or trans boy or trans girl, except for three transmasculine youth who described themselves differently from the gender binary. Only one of these youth situated his identity as more firmly non-binary, saying that he would probably situate himself 3 "in the middle." The other two identified as trans male with some experiences of gender fluidity. Regarding their ethnicity, the sample is mainly constituted of youth who were described by their caregiver, in the open-ended question of the sociodemographic questionnaire, as "white," "Anglo-Saxon," "Caucasian," "Irish,' "Canadian," or "Québécois," with only four identified as nonwhite or Indigenous. Seven parents preferred not to answer this question or left it blank. Twentynine youth were covered by a private health insurance plan.<sup>4</sup> In comparison with recent Census data, the median of annual household income reported by participating caregivers was roughly equivalent to the local provincial median for one clinic, 1.15 times the provincial median at the second clinic and 1.5 times the provincial median at the third clinic (Statistics Canada, 2017). At the time of their interview, youth had been receiving care at the clinic for a period ranging from one month to 6 years, including nine participants who had been attending the clinic for more than two years.

### Results

Four recurring themes were identified around youth access and experiences of medical intervention: path to access care, desired medical interventions and expectations, outcomes of the medical interventions, and overall experiences with clinical care and service received.

# A long, winding, and complicated path to access care

The narratives of the youth suggested that they sought care at the clinic with their family because of their experiences of gender dysphoria. Among those already in puberty, there was a clear goal of accessing medical interventions to stop puberty, to develop secondary sex characteristics that aligned with their gender experience, and in some cases to get counseling and support. However, the process leading to accessing care was very long, often complicated by many factors, including the necessary hurdle of coming out to parents and the fear of negative reactions from them.

Youth waited from several months to more than a year to get their first appointment after initial referral to the specialty clinic. This waiting time was also preceded by a period often extending to years of reflection and waiting as they explored and came to accept their own gender and then worked up the courage to come out to their parents.

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, 16 yo<sup>5</sup>)

Coming out to parents was identified as a necessary and sometimes intimidating hurdle that young people had to overcome before they could seek gender-affirming care. Fear or uncertainty about possible reactions, or shame about their gender identity, were the main reasons for delayed coming out to parents.

After coming out, some told their parents that they needed gender-affirming medical care immediately, while others recounted waiting a further period of time before asking for medical care. Yannick explains delaying asking for medical interventions for fear of bothering his parents:

Well at first I like, you know, I wanted blockers and I wanted hormones, and I like never talked about it. Like, I wouldn't avoid it if it came up, but I would never start a conversation about it. So, you know, I think I probably, you know, I could've have gotten them like sooner. But at that I was so shy, and I was like, "No, I don't want to like bother them or anything." So I like never talked about it. (Yannick, TM, 16 yo)

This theme related to reluctance to bother or to cause parents to worry recurred in other narratives regarding coming out or seeking or changing services related to gender identity.

While most youth we interviewed feared negative reactions to their requests for care, very few experienced major struggles with their parents. Those parents who expressed fear about genderaffirming medical care were mainly concerned about health risks, future regrets or loss of fertility.

Participants felt they needed medical care mainly for gender dysphoria. With the exception of children who had not yet started puberty, participants all mentioned elements of their body that they disliked, though not everyone described an urgent need to change their body. It also emerged from the narratives of the young people that they experienced periods of depression or "feeling down" linked with their dysphoria. Several had also had thoughts of suicide, and many had engaged in self-harm, self-induced vomiting or food restriction.

For most youth, the idea of coming to the clinic was first suggested by their parents or a professional (e.g. medical doctor or a school counselor) after parents became aware of issues with their child's gender identity or expression. Some youth reported that seeking professional care was motivated by the youth's expressed desire to transition medically or stop puberty, to find professional assistance or support, or because the youth required assistance in coping with their dysphoria.

I remember my mom and I talking about what, next steps. At this point, I was still very unsure, and so my mom had the idea that I could talk to someone. [...] Maybe so they could help me, guide me in the track that I'm trying to get. And so she found the [specialty clinic] here, and so I came here and I met with [intake nurse]. That was awesome. (Adrian, TM, 14 yo)

The sometimes difficult and protracted personal and family processes youth underwent before or while accessing gender-affirming care provide insight into the sense of determination and at times extreme urgency many youth expressed in their quest for medical interventions. Overall, accessing the clinic for the participant was the culmination of a number of prerequisite steps, including coming out and sometimes convincing parents of their need for care.

# Desired medical interventions and expectations

Medical interventions provided at the clinics include hormone suppression therapy/blockers, hormone therapy (HT) in the form of estrogen or testosterone, and for some older youth, surgery. The medical interventions that participants sought and/or received, as well as the effects they expected or hoped for, varied considerably from one youth to another. However, thematic analysis allowed us to identify several patterns in the data.

Talking about their bodies and the changes they sought was often not easy, especially for the younger participants. Some had specific ideas about what effects or changes they wanted but had only a vague idea of what interventions would achieve these and what puberty entailed.

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)

One young girl expressed a strong desire to avoid male puberty and change her body to be read as a girl, while also wishing to preserve certain aspects associated with her sex assigned at birth.

[It makes me happy to] be accepted, to accept myself as transgender. To use my girl name, to forget my boy name from before. [...] But what I don't like, I don't want to have breasts, I don't want to have a vagina. And, yeah, and no hairs, here, here (pointing below and to her face). I want to keep my penis, but be in the body of a girl. [...] I'd really like to look like a girl and not [...] like a boy. (Debbie, TF, 9 yo)

More specifically, all younger kids were having conversations with their parents and doctors at the time of the interview to decide if blockers were the right course of action for them. Participants who expected to take blockers or were already taking them said they wanted to use them to stop puberty changes, or to allow them more time to figure out whether hormone therapy would be the right choice.

I actually think I started [blockers] [2.5 years ago]. 'Cause I was just about to start puberty. 'Cause I didn't want to be a male, but I also didn't want to be a female. So having the boy puberty stop was a good thing. [...] [At that time] I played with dolls, I wore leggings, I wore a top like this. [...] But I didn't know for sure what gender I was. If I could go back to that day I would definitely say "Okay, I want to be a girl. (Rebecca, TF, 14 yo)

Stopping pubertal progression was important for all youth who participated in the interviews, even those who defined themselves outside the binary spectrum. For example, one youth discussed how long he could stay on blockers.

If I could, I would have wanted to stay on blockers my whole life. Because I feel some balance between masculinity and femininity (stumble on the word). But yeah. (Oliver, TM with fluid aspects, 16 yo)

Fear of medical interventions also emerged as a theme. Marked fear of needles was a concern, especially for the prepubertal youth, although some older youth also expressed past fears related to needles, injections or blood tests, or regarding undesirable side effects such as losing bone density or developing cancer.

Hormone therapy was desired by nearly all pubescent and post-pubescent participants, transmasculine and transfeminine alike, so as to align their body more closely with their gender identity.

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

Participants were hopeful that hormone therapy would reduce feelings of dysphoria and that it would increase the likelihood of being read or "passing" in their gender identity, which would therefore enhance their social interactions:

I stay away [from the boys' bathroom] until I feel like I pass better— I mean, I know I pass already— I mean my voice and everything once I start T. (Josh, TM, 16 yo)

While it was clear that hormone therapy was very important for most youth, non-binary youth were often unsure whether or how it would help them achieve the body changes they needed to feel affirmed in their gender.

[Blockers is] a maximum two years. And then I have to choose if I want to go on estrogen or testosterone. And that's again where I feel I'm more middle. I'm not, I don't want to choose one. I just want to stay at my body, which is not completely done. It's stopped. (Scott, TM non-binary, 16 yo)

The only binary-identified youth who did not want hormones explained that this was because of health concerns (heart palpitations) and possible undesired body changes that could come with testosterone, such as clitoris growth and body hair. That said, for the most part, young people we interviewed had a strong desire for hormone therapy and anticipated positive outcomes.

Most participants were still years away from the minimum age restriction for most surgical programs. Some participants were not interested in surgery, while others considered it a crucial step to alleviate gender dysphoria.

Some days I hate myself and I just really want to rip my breasts off with a knife, I'm not necessarily a danger to myself, it's something that passes. I really don't like my breasts. (Jeff, TM, 15 yo)

It appears that participants who wanted to access surgery were among those describing most

acute experiences of gender dysphoria, which could take the form of feeling distressed with body parts, either in private or public situations. While transmasculine participants expressed less interest in undergoing bottom surgery, many expressed a desire for top surgery to alleviate the dysphoria triggered by their chest and thereby achieve a better quality of life. A lack of access to surgery was identified as an important source of distress and reduced well-being.

I feel if I'm, like twenty-five and I haven't had bottom surgery at all, then I feel that could really put me into a depression. (Lisa, TF, 17 yo)

Most participants were not eligible to access surgery at the time of the interview because of age/protocol restrictions, and not all participants expressed a need for surgery or hormones. Overall, however, all three categories of medical intervention (puberty suppression, hormone therapy and surgery) were considered important methods to help youth align their body more closely with their gender identity.

### **Outcomes of medical interventions**

Participants who had accessed medication or surgery generally felt positively about the interventions they had received. They recounted how medical interventions had improved their well-being and outlook on the future, in general or specific ways. For example, those who had had suicidal thoughts and/or engaged in self-harm in the past recounted decreased incidence of these thoughts or actions since starting medical intervention. For some, such improvements coincided with coming out to and being supported by their parents. For others it was after they began the overall process of transition, while the rest specifically credited medical interventions with a definite improvement in their mental health and general well-being.

[Self-harm] has kind of been a thing that's been happening for a long time, since like grade 2 or 3 [...] I was just really unhappy and it's better now that I'm on testosterone because I'm kind of feeling like content, like things are going to get better. (Joseph, TM, 16 yo)

Puberty blockers were specifically said to alleviate their experience of dysphoria by stopping pubertal changes such as the development of curves, genitals, Adam's apple, or facial or body hair, as well as unwanted erections. Even for those who did not perceive any changes in their body, taking blockers was said to improve their well-being because it represented a step forward in their transition. Overwhelmingly, accessing blockers was described as providing a sense of relief and greater optimism, positively impacting the mental health of participants:

Well, mental health-wise, yes. In the sense that I can stop asking myself all these questions. I won't be worried any more about how my body's going to change. (Tia, TF, 14 yo, on receiving her blocker prescription)

With regard to hormone therapy, participants who were already taking hormones spoke positively of its effects. Most said it made them happier, less anxious or less dysphoric, and described positive body changes from the medication. For example, transfeminine youth mainly spoke of fat redistribution or softer skin, though most tended to describe the changes as very slight or slow or almost invisible. Transmasculine youth, on the other hand, were more likely to describe visible effects from testosterone, most frequently their voice getting lower, facial and body hair growth, and in several cases, the changing shape of their face, neck or shoulders. This made them feel like they were being read as male more often or more convincingly.

While a few were awaiting approval for top surgery, only one participant had had top surgery at the time of the interview. He reported that it had had the most significantly positive impact on his well-being of all the interventions he had undergone.

[Top surgery] definitely [made me feel] more comfortable. All of them [medical interventions] have made me feel more comfortable about my body. Probably the one that made the biggest difference was top surgery. (Steve, TM, 17 years old)

Though young people largely described the experiences of medical intervention as positive, some did mention some unwanted side effects. Most unwanted side effects were linked to puberty blockers, such as hot flashes and mood swings. Other unwanted effects reported by a



handful of participants and identified as possibly being caused by blockers, included headaches, knee pain, and drinking more water because they were hot.

One participant reported a situation that he linked to more serious unwanted side effects from the blockers. He described experiencing stress fractures:

I guess the only side effects that I've had is that just a couple of weeks ago I guess I found out that my stress fractures were related to the Lupron and I wouldn't go back and change it because I needed to be on Lupron but I mean it was frustrating just not knowing for a while why I had four stress fractures. I was doing less activities but I guess I found out that actually, having done a lot of activity and then getting injured and going on Lupron not doing much activity, actually contributed then to getting the stress fractures. That's the only downside I've had from Lupron. (Steve, TM, 14 years old)

Another youth reported having made a suicide attempt while on blockers. However, in discussing the situation, the youth explained that many factors were at play and that he was already in a "dark place' when he got to the clinic:

But I think it's important to mention that in 2017 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 [started in December 2016], estrogen blockers are known for being a little bit wacky on your emotions. I was already in a pretty, not that great place mentally for the past since 2015 at that point. So it was kind of just like a, thank you, a rollercoaster of everything going on. Simulated menopause was not the best thing at that time [...] High school was a big jumbled mess, it was a bit of a weird time. I don't know. I was going through some stuff with my friends as well, and my grades are slipping, and everything was slipping. I was sleeping 16 hours, so excessive napping. It was a really big, a really big depressive episode, I'd say. (Jason, TM NB, 17 yo)

This young person described his gender as "I don't really label it, it's just kind of in the air" and identified as a nonbinary transmasculine person who uses masculine pronouns but doesn't mind being called "she." He recounted that the mood swings and the suicide attempt occurred at a time when he was also deeply questioning his gender identity. While it was not possible to identify the exact causes of his suicide attempt from his narrative and our research, he also stated clearly in the interview that accessing medical interventions was very positive: "Eventually I got over, like everything stabilized, and I was like, 'But I'm so much happier, like come on" (Jason, TM NB, 17 yo)

Receiving medical care improving the wellbeing of young people is an important theme that emerged from the data, even for those who had side effects linked to medication.

I get sick randomly now, I just start throwing up, cause of the hot flashes, so I' m like "This is fantastic." [...] Never in a million years would I consider stopping [blockers], this is better for me. (Lyndon, TM, 15 yo)

My life was magically better [after starting hormone] like I was still the same person. It's just that I had more drive to study, more drive to pay attention in class. I wouldn't be plagued by like, "Oh my god. I want to die." (Jason, TM NB, on the positive effect of taking hormones)

When asked, none of the participants expressed regrets or doubts regarding the medical interventions they had undergone so far. However, it is important to note that moments of questioning aspects of their medical transition was part of the journey for some youth.

I've had little like 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 voice and I'm like, "This is what I want to do." (Brandon, TM, 17 yo)

And honestly, I've never regretted, since I've never... Honestly, I don't even really know how I was a boy before. Because like, I'm like I must have been really unhappy, because I'm super happy like being a girl, and like just being a girl. (Stephanie, TG, 14 yo)

Overall, medical interventions, whether in the form of hormone blockers, hormone therapy or surgery appear to be very positive in the lives of trans youth who participated in our study, even for those who reported side effects. They experienced improved general happiness or well-being and reported feeling that their body was better aligned with their gender identity.

# Overall experiences with clinic care and services received

Participants were also asked about how they felt about their experiences at the clinic. All

participants were asked what advice they would give to parents, doctors and other youth about care of trans youth, what was the best and what was the hardest part of coming to this clinic, and whether or not they would recommend this clinic to other gender-nonconforming kids. Clinics were generally described by youth as a place where they could openly discuss some of the difficulties they experienced and get the support they needed. However, youth also shared some concerns and reservations about their experiences, mainly related to waiting times and possibilities available for medical interventions, and cost of the medication.

The length of time youth waited to access desired medical interventions varied depending on their developmental stage and the clinic they went to. Though many youth said they were satisfied with the speed at which they accessed care, some expressed frustration, and many said they felt delays were unnecessarily long. They recounted delays due to what they considered to be long wait times for first and subsequent appointments, limited resources, clinic policies including extended assessment processes before being offered blockers and/or HT, lack of consensus between themselves, the provider and their parent, or a combination thereof. The sense of urgency and frustration many youth shared about delays was likely amplified by the often protracted internal and family processes that they had lived through even before they sought care, as described earlier.

[The process was] way too long. "Cause I feel like I've been waiting for this transition since I was 6 years old." (Steve, TM, 17 yo)

Youth also mentioned concerns about having to return to the clinic repeatedly for evaluations and blood tests before they could finally start blockers or HT, and the time this took away from school and other parts of their life. Other aspects that could be considered negative elements of their clinical care experience include feeling discomfort or reluctance discussing certain topics with staff such as suicidality, depression and side effects of medical interventions they feared or experienced.

Some non-binary participants voiced frustration about the limited medical intervention options available to them. While youth said staff tried to help identify possible options, non-binary participants felt that their identity was sometimes not well understood or that medical interventions were not available to answer their needs.

Finally, another theme was the cost of medication, blockers in particular. While most of the participants were covered by private insurance, affordability was a concern for some, regardless of their parents' income.

[I worried about not being able to take the medication], at first, but, like between my mom's coverage and my dad's, it's, the cost has gone down quite a bit, and we don't pay very much, and so, I feel pretty good that, you know, my parents will do what they have to do to, to get the, get it for me. [...] And hopefully, you know, when I get a job, hopefully I can take that off their backs, and I can do that for myself. (Jake, TM, 16 yo)

All youth reported that staff at the clinic had always asked for and used their chosen or preferred pronouns and name when speaking to them. In some situations where their legal name was not changed yet, some experiences of misgendering were reported in other areas of the hospital, such as at the Emergency Room. Some also reported administrative mistakes having an impact on services received, discomfort in the waiting room or about being seen there, difficulty finding parking, or being dependent on their parents to reach the clinic because they lived far away. Finally, it is important to note that several youth described barriers to accessing mental health counseling including cost, limited services provided free-of-cost, and difficulty getting insurance approval. Several also evoked concerns about the cost of surgeries not covered by provincial health insurance.

### **Discussion**

To our knowledge, this study is the first qualitative project to specifically investigate the perspectives of youth on their experiences accessing specialty clinics offering gender-affirming medical care. Accessing gender-affirming healthcare was a positive experience for youth overall, however our research highlighted that youth experience a number of barriers in accessing this care, both before their first appointment and while receiving care.

A first set of barriers is centered around delays in access to care. Our findings have shown that coming out to a parent was seen as a necessary hurdle to overcome before accessing care. Some youth experienced additional concerns even after coming out, including fear of burdening their parents, or feeling that parents required additional processing time before they would be ready for their child to transition medically. The fact that some position their need for medical care as a "burden" for their parents is important for all caregivers of trans youth to be aware of, particularly when providing counseling for a gender diverse young person.

During care, youth also described barriers including what they considered to be unnecessary delays, protocol or clinic restrictions and lack of non-binary care options. Older and non-binary patients tended to voice concern that some of the clinic's protocols were too rigidly applied and sometimes too restrictive. These perspectives could have an impact on the willingness of nonbinary youth to seek clinical care, and is particularly concerning given that well-being is influenced by access to services (Clark, Veale, Greyson, & Saewyc, 2018).

Due to universal health care coverage in Canada, participants in our study did not encounter health insurance policies restricting access to basic medical care. However, some youth recounted not having access to needed mental health services or full coverage for certain prescriptions, and this may have affected youth in their choices and options for medical care. Our findings concur with Gridley et al. (2016) in the different context of the United States, who also found that price of medication was a concern for youth.

All of the participants reported that specialty clinic staff used correct pronouns and names, a finding that contrasts with those of Heard et al. (2018), who found in a 2015 study of one of the same clinics that a small percentage of participants had reported issues with staff respecting their name and pronouns. This suggests that practices may have improved. However, our findings also show that gender-affirming practices

need to be extended to departments located outside speciality clinics, as barriers continue to exist.

In accordance with Clark, Veale, Townsend, et al. (2018)'s findings, the youth's narratives highlighted how having access to medical intervention has improved their overall well-being, including feelings of greater happiness overall, better mental health, or better functioning at school. Though youth described some unwanted side effects, none expressed regrets about the medical interventions they had undergone. Furthermore, the youth's narratives showed a remarkable level of conviction and assuredness, as well as a capacity to think independently, voice their needs, and make their own choices freely while engaging in the process of receiving care.

For clinics, these findings support the importance of embedding gender-affirming principles in ethos and training staff accordingly (Hidalgo et al., 2013; Keo-Meier & Ehrensaft, 2018) so that youth may feel better supported and understood. Such practices are also associated with lower depression and suicidal behavior youth (Russell, Pollit, trans Li, Grossman, 2018).

### Implications for practice

Given that participants often waited lengthy periods of time before coming out to their parents and then had to wait further to access care, they expressed a considerable sense of urgency in obtaining care. In order to address this urgency, professionals could seek strategies that mitigate delays, including discussions with other providers who have knowledge of the youth. For example, increasing dialog with the young person about their experience and how they feel about waiting times to obtain a prescription could be helpful in emphasizing that the assessment process is intended to achieve greater understanding of the youth's experience. This could help to ensure that young people are sufficiently informed to make decisions about the best care for them. It is also very important to explain to the young people that delays or clinic policies are not intended to question or challenge their gender identity (Hidalgo et al., 2013).

By identifying barriers and voicing their needs, young participants also illustrated the importance of examining and improving the structure of care and medical interventions, as well as further recognizing young people's capacity and agency in asserting and assessing their own needs and experiences. This finding suggests that care for young gender diverse people could be improved by applying protocols more flexibly as young people mature, and by increasing the opportunities for young people to take greater agency in decisionmaking around their own care.

In the case of non-binary youth, it is possible that some clinical protocols may need to be adjusted and used more flexibly in order meet their specific needs. To achieve this, it may be necessary for professionals to think further outside the binary model. Non-binary youth may experience specific difficulties that differ from binary-identified youth, as exemplified by Jason and Scott, who situated themselves as trans males but on the non-binary spectrum. Furthermore, it is important for providers to be aware that some non-binary-identified trans youth may declare themselves as binary to health care professionals if they perceive that this strategy will ease their access to care. While medical research must continue to provide professionals with safe intervention levels and intervention must continue to be based on evidence, the results of our study show that it may also be necessary to examine further options for medical transition for non-binary young people whose needs are not currently well met by the clinics.

For both binary-identified and non-binary identified youth, our findings point to the importance of gender-affirming models (Keo-Meier & Ehrensaft, 2018) that take a nuanced, individualized approach to medical interventions. For example, Debbie talked about wishing to avoid some of the secondary sex characteristics estrogen or testosterone would cause and also described being content with her penis. It is thus key for providers to avoid assumptions about how young people experience their bodies or which elements of medical transition they may need (Temple Newhook et al., 2018b).

In addition, considering that the clinics in our study are located in metropolitan areas, we

recognize that youth living outside of urban centers, particularly in rural and isolated areas and on reserves, face further challenges in accessing care. Systematic training of all health care providers in gender-affirming care so that gender diverse youth would be able to access care from providers in their own communities would help alleviate barriers to care including waiting times. This could also help improve the experiences of youth who have had negative experience when interacting with other medical departments within hospitals where clinics are located.<sup>6</sup> We expect that these themes will emerge more strongly in the parents' interviews and we will continue to analyze them as the research progresses.

Finally, in recounting concerns about accessing needed medication, youth demonstrated their ability to identify and assert needs such as prompt access to services and medication. They clearly delineate the substantial benefits they draw from the care they receive when it is timely and responsive. Gender-affirming care provides an opportunity for reflection and careful exploration of gender at each step of their journey, from the initial process of coming out to parents to decisions regarding medical care. The results from this study emphasize the importance for all professionals providing care to trans and gender diverse youth to maintain a gender-affirming approach to care that is experienced as inclusive, validating and safe.

### Limitations

Because of the nature of the research, the results cannot be generalized to the broader population of trans and gender diverse youth. It was difficult to recruit a very diverse sample of young people as originally planned, and thus age and gender identity were the main basis upon which participants were chosen. Furthermore, youth were selected in clinics located in eastern and central Canada. Therefore the sample excludes participants who live on the eastern and western coasts. The sampling method also resulted in generating a data set where none of the participants under 12 had started puberty whereas all the older participants had, which could mistakenly give the

impression that puberty starts at 13, when it can in fact, begin much earlier. In addition, in coherence with qualitative research and in order to allow participants greater leeway to describe themselves, the research team chose to ask about ethnicity, race and national identity through open-ended questions. This generated some difficulties in categorizing the ethnicity of youth and their families, complicating analysis in light of certain social determinants of health.

Almost all participants identified as white, so the perspectives of the youth in this study will not directly address barriers to care experienced by youth who are nonwhite and Indigenous. In addition, we can posit that youth recruited to the study all benefited from relatively strong parental support given that study participation of a parent or caregiver was required. However, even within this sample we see differing levels of well-being that might in part be explained, or amplified, by specific experiences of support and speed of access to gender-affirming care. The interaction of these factors and their contribution to wellbeing are limited in this study.

Finally, this study does not present the views and experience of young people who may be unwilling to talk to researchers, who do not have parental support, or who are unable to access the clinics. Given that the interviews were conducted within the clinics where they received care, it is possible that this biased how they assessed the care they received there.

### **Conclusion**

These data show that trans youth's feelings and experiences related to accessing gender-affirming medical interventions are complex and multifaceted. Our results expand on perceived barriers to care and highlight the importance of prompt access and the significant and positive effects that care has on young trans people. These results allow a deeper understanding of the ways in which gender-affirming care improved youth's well-being. By reinforcing the gender-affirming model of care, clinics will be better equipped to meet the needs of young people who seek medical interventions. The observed impact of the various protocols on youth's experiences suggests

that youth would benefit from a more flexible protocol application adapted to the individual reality of each youth, including their ability to consent, the level of parental support, and local legislation. Further research should also specifically examine how medical care can be optimized for non-binary youth.

### **Notes**

- 1. The information presented in the sample section comes from the youth's interview except for the data on insurance and socioeconomic status, ethnicity that were taken from the sociodemographic questionnaires filled by the parent participants. Some information about the timeline for accessing care was extracted from parent interviews as well.
- No 12 years old participated in the study.
- We asked each participant what pronoun and name they use at the beginning of the interview. We have respected these pronouns throughout the text. This participant non-binary says masculine pronouns.
- All Canadian residents are covered by a publicly funded health care system, which covers medically necessary hospital and physician services, but whose specifics vary by province or territory. Private health insurance plans are often provided by employers and may cover items such as medication or mental health services that are not covered by the public plan.
- All citation are identified by a pseudonym followed by gender identity: TF (transfeminine), (transmasculine), NB (non-binary), and age. When the participant described their gender identity outside the gender binary, we have indicated it.
- There also exist some online Canadian trans health guides available to support providers who may have to work, outside speciality clinics, in trans health care. See for example the document from the Endocrine Society Clinical Practice Guidelines for Endocrine Treatment of Gender-Dysphoric/Gender-Incongruent Persons-JCEM 2017.

### **Disclosure statement**

The authors declare that they have no conflict of interest.

### **Ethics**

The study was approved by the research ethics boards at Université de Montréal, McGill University, the Children's Hospital of Eastern Ontario, the University of Manitoba, the Winnipeg Health Sciences Center, Memorial University, and the University of Victoria. All procedures performed in studies involving human participants were in accordance



with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

### Informed consent

Informed consent was obtained from all individual participants included in the study.

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