Article

Experiences of Puberty and Puberty Blockers: Insights From Trans Children, Trans Adolescents, and Their Parents Journal of Adolescent Research I-27 © The Author(s) 2022



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Abstract

This research explored experiences of transgender children and their families approaching and into adolescence, understanding experiences relating to puberty and puberty blocking medication. Data were drawn from 30 parents of 30 trans children and adolescents who at time of interview, were an average age of 11 years old. Parental interviewees were 90% white, 93% female, 100% cis, 60% heterosexual. Additional data were drawn from 10 trans children and adolescents, average age 12 years old. Interviews were held remotely, with families from across the UK. Rich qualitative interviews, averaging 2 hours for parents, and 25 minutes for children, covered aspects of family life, healthcare, and education. This article examined a sub-set of data on trans children and adolescents' experiences of puberty, and of accessing, or trying to access, puberty blockers. Research received ethical approval from the author's university. Data were analyzed through inductive reflexive thematic analysis. Three major themes are presented, relating to pre-pubertal anxiety; difficulties accessing blockers; and, for a minority who were on blockers, experiences of relief and frustration. The research has significant relevance for families, for healthcare professionals

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and policymakers, and for all seeking to protect trans adolescent mental health and well-being.

Keywords

transgender, adolescents, puberty, parents, well-being, mental health

Introduction

Over the past decade, a diverse body of research has enhanced understanding of effective approaches to enabling wellbeing in transgender children (Turban & Ehrensaft, 2018). Affirmation including family support, use of preferred name and pronoun and support for social transition are all associated with positive mental health and low levels of depression or anxiety (Olson et al., 2016; Pollitt et al., 2021; Russell et al., 2018). A number of quantitative clinical studies have shown the benefits of affirmative healthcare including access to GnRH agonists, colloquially known as 'puberty blockers' (Achille et al., 2020; Cohen-Kettenis et al., 2011; de Vries et al., 2014; Khatchadourian et al., 2014; van der Miesen et al., 2020). Global and national healthcare bodies endorse 'affirmative healthcare', wherein puberty blockers are accessible at the onset of puberty (Hembree et al., 2017; Murchison et al., 2016; Telfer et al., 2018). However, at the same time as increasing medical consensus, politicized and ideologically driven attacks on trans adolescent healthcare have led to political and legal interference in, or restrictions on, access to puberty blockers (Abreu et al., 2021; Leibowitz et al., 2020).

Across the existing literature on puberty blockers the voices of trans children and their families are rarely heard, with research dominated by clinician perspectives (Rew et al., 2021). Only two studies, both from the Netherlands, focused on the perspectives of trans adolescents and their parents (Vrouenraets et al., 2016, 2021). These studies primarily captured the experiences of older adolescents, with a median age of 17-years-old (range 14–27 years-old) (Vrouenraets et al., 2016, 2021). The Dutch research emphasized the importance of puberty blockers in reducing suffering related to the development of secondary sex characteristics, in providing time for decision-making on gender affirming treatment, or as a first step toward gender affirming treatment (Vrouenraets et al., 2016, 2021). This present study brings a unique and important addition to the literature, focusing on perspectives and experiences pre-puberty and in early adolescence from a younger cohort of trans children and their parents, in a sample of families with socially transitioned trans children at average age 11 years-old (range

6–16 years). It includes a focus on parents' and children's experiences leading up to puberty, their experiences whilst trying to access or deciding on puberty blockers, and for a subset of the sample it includes their experiences whilst being prescribed puberty blockers.

Research Questions

The existing literature on puberty blockers is almost entirely absent the voices of trans children and adolescents or their families, missing out on experience-based insights. This research aimed to address this gap in the literature, guided by the following questions:

- 1. What are parents' experiences of navigating puberty, including experiences accessing or attempting to access puberty blockers with a socially transitioned trans child?
- 2. What are trans children and adolescents' perspectives on navigating puberty, including experiences accessing or attempting to access puberty blockers?
- 3. What can we learn from these experiences navigating puberty and adolescent healthcare?

Method

Theoretical Framework

The research presented here is a portion of a wider PhD on cisnormativity, rights and well-being of trans children who socially transition before adolescence in the UK. The research is underpinned by a trans-emancipatory theoretical framework, building on wider work on emancipatory research (Noel, 2016). Here a trans-emancipatory framework is one that recognizes and takes account of the role of cisnormativity and pathologization of gender diversity in upholding structural injustice (Wesp et al., 2019). "Cisgender," or "cis" is a term for people who are not transgender (Cava, 2016). Cisnormativity is the assumption that everyone is cis, or should be (Keo-Meier & Ehrensaft, 2018). The author maintains an ethical commitment to a trans-emancipatory approach, recognizing that gender diversity is neither pathological nor problematic, acknowledging that trans lives are equal to cis lives, being attentive to cisnormativity or pathologization of gender diversity within and across the research, and building in ethical best practices for trans-related research (Ansara & Hegarty, 2012; ITHF, 2019; Vincent, 2018). Herein the word 'trans' is used to include those who are binary-oriented as well as non-binary

(Vincent, 2020). The term 'social transition' can denote a child's shift in name, pronouns, or presentation, as well as signifying a point of external recognition of a child's gender identity (Ehrensaft, 2020). This article uses the word 'children' when referring to groups that may contain both children and adolescents, and utilizes the term 'adolescent' when referencing a specific child who has started puberty, even if puberty has been suspended through puberty blocking medication. The article also distinguishes between 'endogenous puberty', which is puberty driven by the sex hormone produced in an adolescents' body; and 'exogenous puberty', which is a puberty driven by externally administered sex hormones or Hormone Replacement Therapy (HRT) (Chung et al., 2020).

Study Design

The research received ethical approval from the author's university. The inclusion criteria for parent interviewees were (a) being a parent or carer of a socially transitioned trans child in the UK, (b) their child having socially transitioned under the age of 11 years old, (c) their child currently being under age 16. To recruit parental participants, details about the study were shared on closed online spaces in six UK support groups for parents of trans children. Additional parental interviewees were brought in via snowball sampling, through introduction from other members of these parent support groups. Access to hard-to-reach families and children was enabled by the author's positionality as a non-binary parent of a trans child, helping overcome trust related barriers to hearing from this cohort. The author is a member of four of these closed online spaces and posted there directly, with other parents sharing details on two other groups. The sample of interviewed parents were also asked to consider inviting their trans child to participate, with a third of their trans children opting to participate. Research participants received a project information sheet in advance outlining the purpose of the research, their rights and how their data would be used, with one version tailored for child participants. Parents provided written informed consent, and for younger interviewees parents provided written consent on behalf of their child, with interviewed children of all ages additionally providing either written consent or verbal informed assent (Lundy et al., 2011).

Sample

Thirty parents were interviewed from across England, Scotland, and Wales. 100% of interviewees were cis; 90% were white; 93% were female, and 23% were disabled. Interviewees had a range of levels of education, with 20%

reporting secondary education as their highest qualification, 37% reporting a graduate degree, and 43% a post-graduate degree. In terms of sexual orientation, 60% of parental interviewees were heterosexual, 23% pansexual, 10% bisexual, and 7% gay or lesbian. The parents interviewed shared parental experiences with 30 socially transitioned trans children, including 15 girls, 12 boys, and three non-binary children. Their children had socially transitioned at an average age of 7 years-old (range 3–10 years old), and at time of parental interview their children were on average age 11 years old (range 6–16 years old). Ten trans children, children of a third of the interviewed parents, were also interviewed. These children were on average 12 years old at time of interview (range 9–16 years old), and had socially transitioned an average of 4.5 years before the interview.

Analysis of interview data revealed that nine children (ages 11–14, median age 12) in this sample had recently started puberty but were not yet on puberty blockers. Twelve children (average age 9.5, range 6–11) were approaching but not yet started in puberty, with the subject of puberty and potential access to puberty blocking medication a topic of significant concern. Seven children in the sample were currently on puberty blockers, including five boys, one girl, and one non-binary child, with the adolescents currently on blockers aged 11, 12, 13, 15, 15, 15, and 16. All of the adolescents on blockers had accessed blockers at age 11 or 12 years old. One child in the sample, a 12-year-old boy, had started puberty and had not accessed and had not wanted to access blockers, according to parental report. From the 10 children interviewed directly, four were currently on blockers, which they had been on for an average of 3 years. Three were in early puberty but not (yet) on blockers at time of interview. Three of the interviewed children were pre-pubertal.

Data Collection

Interviews were conducted remotely via Microsoft Teams during the period December 2020 to November 2021. Semi-structured interviews, covering broad topics including healthcare, education, and families lasted 1 to 3 hours (average 2 hours) for parents, and 20 to 50 minutes for children (average 25 minutes). This article considers a sub-set of the wider data corpus, focusing on portions of the interviews discussing experiences related to puberty and accessing or trying to access puberty blockers. Interviews utilized broad open-ended questions, allowing interviewees to talk openly and at length around each topic. Key parental questions relating to their experiences of puberty included "When did your child first reference anything related to puberty?" "Is your child aware of puberty blockers?" "How have you navigated puberty and or potential medical intervention?" Following each initial

answer prompts were used flexibly to elicit further responses. The interview methodology with trans children was flexible, adapting to individual child preference, with some interviews conducted one-to-one by the researcher, some conducted with their parent present, some with their parent asking questions and recording the interview, and one child providing written inputs. Questions for trans children were tailored to their age including broad questions such as "What's it like being 11?" "What do you like about being trans?" For the small number of children interviewed by their parent or in writing, the child selected from a longer list of potential broad questions which ones they would like to answer. Only where children referenced puberty blockers in interviews would further prompts include "What are your thoughts on puberty blockers?" Interviews were recorded, stored securely on an encrypted platform, and transcribed by the author. Transcripts were checked against the recording, with anonymized transcripts uploaded into NVivo.

Data Analysis

Data were analyzed through inductive reflexive thematic analysis, an approach suited to exploratory studies in novel or under-researched areas (Braun & Clarke, 2006; Rendle et al., 2019). The analysis sought to understand interviewee experiences and perspectives related to puberty, and when accessing or trying to access puberty blockers, with data-driven development of codes and themes. The analysis comprised re-reading each transcript to become familiar with the data, and generation of initial codes through section-by-section coding, coding diversely without pre-conceived coding categories. The initial codes were then reviewed to identify broader themes, with all extracts for each theme collated and re-read. The initial themes were then reviewed, and themes and sub-themes revised to ensure they were internally coherent, consistent, distinctive, and accurately capture the dataset. Each sub-theme was analyzed and interpreted, including with reference to existing literature. Indicative quotations from a range of interviewees were selected to accurately illustrate each sub-theme. The analysis is recognized as the author's interpretation, acknowledging the role of any researcher in actively interpreting data.

Findings

Interviewee accounts of puberty and puberty related medical interventions are presented within three major themes. These relate to pre-pubertal anxiety, difficulties accessing blockers, and experiences of relief and frustration on

blockers. These themes and associated sub-themes are each illustrated with quotations from parents [P] or children [C].

Pre-Pubertal Anxiety

The first theme relates to pre-pubertal anxiety, with sub-themes on early childhood anxiety about puberty, and experiences managing pre-pubertal anxiety.

Early childhood anxiety about puberty. Many parental interviewees recalled trans children talking about wanting to avoid secondary sex characteristics at a young age, before they were aware of the concept of puberty.

When she was four, starting to say, obviously, she didn't know what puberty was. She never heard that word. But what she was saying was, 'I don't want to grow into a man', 'I don't want to have beard'. 'I don't want to have a deep voice'. So, she was kind of listing things that are changes of puberty, that she was aware of just from watching the world around her. [P]

Parents reported that as their children started to understand more about puberty, it led to growing anxiety or fear.

It's always the middle of the night, isn't it? - It's always, they can't get to sleep and they come and knock on the door, and you end up having this great big, long, involved discussion at one o'clock in the morning. But it was things like, 'will I get a beard?', 'will I?', 'what's gonna happen to me?'. [P]

Heightened anxiety as adolescence approaches. Several parents noticed their child's distress rising as they started to see other children around them, and particularly elder siblings, enter into puberty. One parent noted her daughter's anxiety. "She's saying 'I'm not looking forward to puberty', because she's seeing her brother go through puberty, and seeing the changes that are happening to him. She said last night. 'I'm really worried about puberty'" [P]. Some parents found their child's response to the idea of imminent puberty concerning (trigger warning re self-harm).

So, like we got to a point where, when it was talking about puberty, my son was telling me, if he grows breasts, he will chop them off. And that was a big red flag for me, that he was already thinking in what I'd consider quite dangerous terms about himself and his body. And he would be desperately sad, and upset, if one of his friends, for example, started their periods very early. . .And one of

the things that happened, he stopped eating at one point. . .And he lost lots of weight very quickly. . .And it turned out that, basically, he'd got it in his head that you grow boobs and hips by eating food. And if he didn't eat, he wouldn't grow boobs and hips. . . as soon as he realised it made no difference, he started eating again. [P]

Other parents reflected on extreme fear and distress at the prospect of pubertal changes.

She's been quite clear in the past that, that developing sex (characteristics), you know, developing a deep voice, or developing facial hair, or anything like that, she's been quite clear that those things will make her life not worth living. . . And she's not, you know, she's not messing about, she's serious when she says things like that. I know she is. She's petrified of developing any of these things. . .One of the only sessions at [Gender Clinic] where they separated us was the session to talk about body parts - in the car driving home after the session, [Child] said, you know, I was really clear, I can't bear this part of my body. I'm not bothered so much about my top half mum, I cannot bear my genitals, and I will cut them off if they start growing and developing. . .I can't have my body change. [P]

A number of parents could see the approach of adolescence being a source of significant stress, with children worried about when it might start. "[Child] has always thought about it, and always worried about what will happen and when it's coming in, and how fast it will happen, and things like that" [P]. A number of parents described the time leading up to and in early puberty as a time of great stress for their child.

Yeah, so you know, over the last sort of couple of years, - not every day, but on and off, has obviously commented on things changing in her body, and how that makes her feel, and the distress that it causes. . .the changes are quite unwelcomed. [P]

It's all very difficult because puberty has kicked in - it's all really emotionally fraught. We have lots and lots of tears, and conversations about. . . 'why can't I just be a normal girl?' and her peers are in puberty, and her friends are talking about periods. [P]

One trans child, interviewed at the cusp of puberty, described puberty having been in her thoughts as a constant worry for over a year. "I properly started worrying about it when I was 10. . .. I'm reminded of it every day" [C]. Early pubertal changes were experienced as traumatic for some adolescents.

[Child] was always really clear. I do not want my body to develop as a boy. So, [Child] was always really clear that she wanted something that would stop testosterone and stop puberty. And she had a bit of a wobble just before her blocker started, because her voice started to deepen. And that freaked her out, because she thought, there will be some kind of permanent changes. . .She was so unhappy at the thought of it. As her voice started to deepen, she found that quite traumatising. [P]

Information on blockers providing reassurance for trans pre-adolescents. Parents reported that a majority of their trans children, average age 11 (range 6–16), were aware of the existence of blockers. Most parents had discussed blockers with their child years in advance of puberty starting, with several parents emphasizing their view that knowledge about the existence of puberty blockers was important for reducing their child's anxiety. "I think if you wait until your child is distressed, and then start talking about puberty blockers, you have unnecessarily caused them harm" [P]. Several parents described their pre-pubertal child as desperately wanting reassurance about ability to access blockers.

She's petrified that she's gonna get hairy, and get a deep voice like her dad. . . that's her worries. All she can think about when we go to [Gender Clinic], and have zoom meetings with them, is she wants the blockers. [P]

A number of parents felt a strong reassurance that blockers would be accessible, was vital for managing anxiety and well-being in the years leading up to puberty.

I think as long as she knows that her future is taken care of, and that we'd do anything to make sure that she never has a deep voice, and she never gets any facial hair, that she, you know, she's comfortable to be happy in her childhood now. It's almost like, essential, to lower her anxiety, and let her thrive in the here and now - that's why, it's like a promise I've made her, over my dead body, you will have the treatment you need, and deserve, whatever. It seemed to be the only thing that really alleviated that anxiety of hers for the future. And let her, like, live fully, in the present. [P]

I think she presumes everything will just be sorted out for her, which it always has been. So yeah, she didn't really show any anxiety or worry, really. But if you said to her, do you want to go through a male puberty? She'd be very clearly no. There was never any doubting that, but she didn't seem to worry about it. [P]

Parents of trans children at the edge of adolescence emphasized the importance of reassurance about blocker availability, even though they were aware

that accessing blockers might not be straightforward in the current UK context. Several parents spoke of being willing to go to whatever lengths necessary to access blockers for their child, as they felt they were so important for their well-being. "I would do whatever I could. . . it worries me that I might not be able to get them easily, but I'll do my best to get them" [P]. "If we can't persuade the NHS to do the right thing, then we'll be able to use [Private Service] and just pay. We're very fortunate to be in a position where we can find the money" [P]. Parents of trans children at the edge of adolescence, who were uncertain how they could access the blockers they felt were essential, spoke with heightened emotion.

Sorry I can't speak when I'm crying. It's so annoying. Just wait for it to pass. . . So, in my in my mind, blockers are a lifeline, an absolute lifeline. If everything goes wrong. You've got that to turn back to, the pause button, to stop, breathe. [P]

Difficulties Accessing Blockers

The second major theme on difficulties accessing blockers, is divided into two sub-themes, extensive assessments for blocker eligibility, and harmful delays.

Extensive assessment for blocker eligibility. Several parents were clear that having access to puberty blockers or HRT was their main reason for engaging with NHS children's gender services.

(The gender clinic) have always kind of been a means to an end to be honest. Because you know, it was all about relieving his distress. And the only way to do that was through the medication. I mean, what the point would be going at the moment with no hope of any medical intervention, I don't know. [P]

An adolescent described their experience of putting up with Gender Clinic appointments that they dislike, purely as a route to accessing affirmative medication.

Interviewer: Do you like your visits to [Gender Service]?

Child: No

Interviewer: What do you like about [Gender Service]? What parts are

helpful?

Child: It will help me get medication

Interviewer: Are any parts of visits to [Gender Service] difficult or upsetting for you?

Child: When we talk about genitals and bodies

Interviewer: What do you see as the purpose of your visits to [Gender

Service]?

Child: To get blockers and testosterone

Interviewer: How often would you like to see [Gender Service]

clinicians?

Child: As little as possible

An adolescent was clear that their only reason for accessing gender services was to get access to puberty blockers, describing their experience of an assessment that they found drawn out and difficult.

At the time, being like 10, or 11 and stuff, I just wanted blockers. So that was like, the aim of me going there. And so a lot of the sessions felt kind of just like jumping through hoops to get to one end goal, and it's kind of tricky, because it's - the whole thing is, like you have to prove that you're trans enough for blockers, or prove that you're, you know, that if you're sad, then it's because your gender identity isn't being expressed to how you want it to, and not for other reasons, or whatever. That's quite tricky. And I think, you know, when you're talking to kids about that, it's, I mean, it'd be hard for an adult to do, so as a kid. . . [C]

One parent found the assessment process for referral for blockers perplexing, with clinicians asking their child a lot of vague questions around identity and general self-image, without asking specifically how their child felt about puberty.

But like, immediately after I was like, if you want to know how they feel about puberty, 'hey (to child), how do you feel about puberty?' And my child's response was 'I would rather die'. And like, that was the only time I actually saw an emotional response from this guy. Like he, his eyes kind of went wide. And I was like, 'that is the information you need'. [P]

Some parents were concerned the assessment process was unnecessarily upsetting, particularly the expectations that their child would talk in depth about their feelings about their current body.

He will get upset. He's asked to talk about how he feels about his body, which he doesn't like to do. So that upsets him. And I'm not sure. Maybe they know, because they're more qualified than me in this business, but I'm not sure what the point is of upsetting him by making him talk about these things, whether that's got an aim, or whether it's just tick boxing: 'Oh, yeah, he gets upset when we talk about his hips, so we can tick that box'. I don't know. [P]

A number of parents within this sample were upset at clinicians sharing fringe views on puberty blockers, particularly an unevidenced theory that trans children would change to a cis identity if denied puberty blockers and forced through endogenous puberty.

They have said high proportions still change their minds - desist. And it's not true that many of them get really upset and self-harm and think about suicide. So that's a bit - because - I don't believe that's correct. [P]

They are saying that there is a high possibility that if we allow him to go through his natal puberty, he may change his mind. [P]

Parents of adolescents who had accessed blockers described the assessment as being extraordinarily drawn out, with clinicians wanting to assess identity or dysphoria over many years before permitting referral for blockers.

You're going up there for these blooming appointments, as I say, from the age of 9 to now 15, it's a heck of a long time. And that's when they said that, you know, there is blockers, but obviously we'd need to do an assessment, we'd need to decide, you know, whether it is transgender or whether it's something else. [P]

Another parent of an adolescent who had been prescribed blockers, described the length of assessment before referral to endocrine services as frustrating "We have to wait years, and years, and years. This is - we've been six years in the system." [P]. Parents who knew how important puberty blockers were for their child, felt worried about a requirement for their child to express their distress to strangers in order to be eligible. "I just feel, sometimes with the (Gender Service), that there's this, they must be very distressed, and (only) then we will give them puberty blockers" [P]. Several parents were concerned about their child being required to display distress at physically observable secondary sexual characteristics before becoming eligible for puberty blockers.

There seems to be this school of thought that they have to experience some pubertal changes, because then, they might realise they're just gay. . . that they'll suddenly go, "Oh, I'm not a girl, I'm a gay boy." And it's like, no - she's a girl and the distress is real, she does not need to, you know, physically go through, you know, proper changes. . .. With the puberty blockers, there's been a little bit of, 'well we need to hear from [Child], that she's really distressed and unhappy in her body and the changes' and it's like, so you, you want her to experience distress and unhappiness to prove? It's always about to kind of prove that she's really trans. [P]

Several parents felt clinicians wanted their child to express extreme distress with their primary sexual characteristics to be eligible for puberty blockers.

There's this undercurrent of having to prove that you're distressed about your body. And we've had conversations with [Child] about, you know, there are so many different ways to be trans. You don't have to have any surgery if you don't want to [P]

Parents described a suite of tests to measure pubertal stage, including physical examination, blood tests, and hand scans. Several parents mentioned their child's nervousness before the physical examination.

We went to endocrinology, they do a physical assessment which [Child] was nervous about. But she said it wasn't as bad as she thought afterwards. But - I don't know if I'm honest, I wasn't that impressed with the endocrinology consultant person we saw, just seemed a bit strange. And they kind of hold up these beads, is it called an orchidometer - compares the size of the testes to these wooden beads, it all seemed a bit weird if I'm honest. [P]

One adolescent described frustration at what they perceived to be cisnormative and trans-normative barriers to eligibility. "One of the workers told my friend that they did not have enough dysphoria to get blockers - which is absolute bullshit". [C]

Harmful delays. Within the NHS trans children are assessed by gender clinic psychologists first, who will only refer on to endocrine services once puberty has begun. Several parents described struggles to get gender service clinicians to believe that their child had started puberty.

I could see that [Child] had gone into puberty. This is when I was trying to push to get the referral to [Endocrinologist]. Every time I went I kept saying 'they're growing they're growing' (referring to chest area), and [Child] was telling me that he'd been pushing on them at night, because he thought if he did that, they wouldn't grow - and I was telling them all these things about the distress, and them not having showers, and he's starting to smell, and they were just "no, he's only a slight little thing. No, I don't think so. I don't think he's at that stage at all. When we can see, then we'll think about" and I thought no, you're not listening to me. As a parent I know, I can see. We're up here, what for an hour? He's got baggy clothes on, he's sitting like this (bent over), you're not going to be able to see that. [P]

The parent described having to push to get a referral.

And I had to really push to get them to refer us to [Endocrinologist]. The point I, I felt that I was, I was almost like giving them ammunition to think 'oh it's the bloody parent', because I kept push, push, pushing . . .and when we did eventually get the referral, and he was actually in the correct stage to have, well, more than the correct stage to have blockers. So, it - that peed me off, because I thought, actually, you know, we might have been able to catch this before any real breast tissue had potentially grown, because obviously, unfortunately, although he's on the blockers, there is still some there, you know, to try and alleviate, if he decides to go down that route, the need for any surgery. But to them, it was almost - I felt that the [Gender Service] was almost, like, no, 'let's wait, let's wait'. [P]

Another parent described having to fight clinicians who refused to believe puberty had started, and by the time they got to endocrinology, their child was progressed in puberty.

[Gender Service] have always been really, really - bit too casual, really, and where we are now, I'm quite cross about it all. . . they've always been very like: 'Well, it takes years and it's no rush', and 'it all happens, takes years to happen', and 'the voice changes, they all come much later on' and all this sort of stuff. So, I'm annoyed now, that they've let us go too far, when we've had such a long journey on this path, . . . I really am worried that we've left this too late. . .I think we were expecting (Tanner stage) 2 to 3. So, when we heard 3 to 4, it was a shock. . . it was upsetting for me, because I just - I wasn't expecting that we were there yet. . . I still wish I could rewind 6 months and push it more. [P]

Several parents felt clinicians had no care for the consequences of delayed referral, and were not guided by the child's need. A number of parents felt delays were damaging. "I know that during those early Tanner stages, pubertal changes are slow. But it's easy to say that, as an adult looking back - for the young person in it, every day feels unbearable" [P]. Many parents spoke about the delays that seemed built into the system, with any area in which a child failed to perform to clinician expectations, leading to further delays to access.

[Gender Service] insist on having these three appointments, where you talk about blockers and the consequences, talk about fertility, real kind of heavy stuff. I understand that they have to be sure that that young person understands what it is, so that they can give consent, I do get that. But it just dragged out. And I think because of Covid. And because it was on zoom, it didn't help us sometimes the meetings were 9 o'clock, and [Child] would have to be dragged out of bed, and she'd be in a foul mood. And she didn't want to talk. . . dragging

her out of bed and sitting there. One time she just refused to talk. They had to have these three sessions, and we had to rearrange one because [Child] wouldn't talk. [P]

Several parents with neurodiverse trans children felt the process was particularly drawn out.

I would say probably about 2, 2.5 years, something like that (trying to get approval for blockers). . . Sometimes there's a bit of-a bit of disjointedness when it comes to - especially for somebody like [Child], who is on the spectrum, talking to essentially strangers, you know, people at [Endocrine Service], [Gender Service] and truly expressing how she feels. . . I would say, yeah, 2.5 years there has been that discussion of, this is something that I would like. But it is a long process, isn't it? [P]

A trans adolescent considered hurdles and delays to accessing blockers to be an act of cis-dominance over trans youth, tracing a direct link between barriers to accessing blockers and wider anti-trans rights issues. "We should be able to consent to blockers because it is a human right. And trans folks, as of late, have had a lot of their rights revoked, and rolled back. . ." [C]. Another adolescent emphasized the urgency of getting access to puberty blockers. You need to get hormone blockers, like, quickly. . .you know, it's like, it's urgent, you can't wait for another 2, 3 years or whatever" [C].

Experiences of Relief and Frustration on Blockers

The final major theme considered experiences on blockers, focusing on the experiences of the sub-set of interviewees who were, or whose children were, currently on blockers. Out of the 30 trans children whose parent was interviewed, seven were currently on puberty blockers at time of parental interview. Out of the 10 trans children who were interviewed, four were on blockers at time of child interview. All of the adolescents currently on puberty blockers started on puberty blockers at age 11 or 12 years old. Sub-themes relate to the relief of having puberty blocked, as well as perspectives on the consequences of inflexible protocols for HRT.

Relief of having puberty blocked. One parent described feeling thankful that their child had been able to access blockers in early adolescence. "And so, by the time he was, I think by the time he was about 12, he was receiving hormone blockers. And I was so grateful and thankful that we've been able to do

that for him" [P]. An adolescent described the importance of blockers for them.

I'm very grateful that I managed to get on blockers at the kind of age that I did. Because it means. . . it means basically, I haven't kind of gone through female puberty, like very much at all. So, I'm very grateful for that. [C]

One parent described their child feeling relief each time they receive their blocker injection.

He's coming up for his fourth blocker now. So, he was 11 for his first one. And so [Child] has one blocker injection every 6 months. And he's got a bit of localised pain in the injection site for a couple of days. After that, he's relieved, he's so relieved. [P]

Another parent noted the blocker reducing their child's stress, reducing emotional liability. "Well, the meltdowns stopped along with the hormone blocker, which he accessed at a young age, so that helped a lot" [P]. Another parent reflected upon how the impact of puberty blockers on her child differed from what they had expected.

So, I thought he was happy. So, I just thought we were just protecting his happiness. I thought we were preventing him decreasing in confidence and happiness. What actually happened was - well, it turns out, he wasn't as happy as I thought. Because his happiness and his confidence grew once he started on blockers. Like, he was anxious about having the injection. And then after he'd had that first injection, it was like something had been lifted away. . .. The year before he started blockers, I would say every other week we would end up having a conversation about puberty. It was a constant topic of conversation for him. And it was a constant worry for him. And all of that stopped. We didn't talk about puberty anymore. He didn't ask me anything. He wasn't anxious about anything. He was just chilled. And he could just get on with being him. [P]

An adolescent described starting blockers as anti-climactic.

Before I had hormone blockers ever, I was like, starting to wear a binder. So, I'd already kind of had like, a bit of chest development and stuff. And at the time, it's, it's strange, because like, for so long I was like, oh yeah I want to be on hormone blockers. And then, it's almost a bit anticlimactic. Because when you get on hormone blockers, it's like the whole point is that everything like pauses, so it's kind of like, nothing changes. But I was - I definitely knew at the time what would happen if I wasn't going to go on hormone blockers - or what

the future would look like if I was not going to go on hormone blockers. So, at the time I was very like, you know, like, as quick as I can have them would be the best. So, I yeah, I felt that urgency. I mean, I think I would have been about 11 ish, when I went on blockers. [C]

The same adolescent emphasized what they saw as the purpose of blockers.

Like the positive of blockers isn't necessarily what the blockers do, it's more like, the kind of lack of negatives that comes with them. . .. I was living as a boy or I'd fully transitioned before the time that I was on blockers. So, I guess, in my head, I was, you know, quite content with how I was presenting. So, blockers, in my mind gave me time, just to kind of coast by until I was old enough to get on T. That was kind of what I viewed blockers as. I think I was quite steady, kind of before and during in terms of like, what my, I felt like my gender kind of identity was. So yeah, I don't feel that it necessarily bought time for me in that way. More in like a kind of just the medical way. [C]

One parent reflected upon the different areas of their child's life that access to blockers had impacted on.

Without them, I think [Child] would totally have recoiled and shrunk - you know, like (pre-blockers), that kind of literal, physical shrinking-ness of wanting to disappear, not wanting to be seen. And the difference that is afforded to [Child] by 'passing', which is, you know the blocker is a massive part of that, and therefore, able to you know, take part in sport - to be able to use their voice, not be, not be concerned about speaking – those basics of your fundamental human rights of participating in your life in the way that you choose. The blocker enables so many of those things, and I don't think anybody who's outside of, you know fighting for a trans kid or invested in this in whatever way really considers how those things are so life changing. [P]

Another parent reflected upon the impact that they had noticed in their child once on blockers.

I think her confidence has grown. Her, you know, being on a clinical pathway and blockers is a massive part of that. Because that has taken a pressure off her and a worry. That has definitely helped with her resilience and her confidence. [P]

Consequences of inflexible protocols for HRT. A few families spoke of harm being caused by rigid and inflexible protocols restricting access to HRT (exogenous estrogen or testosterone). In some cases, particularly for adolescents in later puberty, blockers without any sex hormone are known to cause

side-effects (Chew et al., 2018). One parent described the side-effects their child experienced. "[Child] was really struggling with side effects from the blocker. . . their hot flushes were like, they were awful. And, and their mood was quite flat" [P]. The family were advised by their endocrinologist that addition of a low-dose sex hormone was needed to alleviate symptoms, but were informed that they could (due to restrictive protocols) only offer estrogen, and not testosterone, to a trans boy. The boy in question, wanted the added hormone to be testosterone, and not the hormone that had just been blocked, estrogen. The parent described how the endocrinologist refused to meet their need, giving the adolescent the options of either coping with untreated side-effects, or taking the sex hormone he was taking blockers to avoid. Adherence to inflexible protocols, led to an impasse, as the parent elaborated.

We went round and round in circles until [Endocrinologist] literally stamped his foot and was like, we're not having this discussion anymore - this is your choice, you either have the (oestrogen) patch, or the (oestrogen) pill. That's your choice. And [Child] was like, 'it's not going to happen. You can prescribe it, but I'm not going to take it'. And so, it felt like we were at loggerheads. [P]

The parent spoke about their NHS General Practitioner (GP) being able to understand to their child's needs, and being willing to provide the healthcare they needed.

I booked an appointment with the GP and I basically sat and poured my heart out of like, I think [Child] needs some hormone, you know, they're sat there, they've got all of these symptoms, which all seem to suggest that their body is crying out for some hormone, [gender service endocrinologist] has said that the only hormone they can give him is the one that he actually desperately doesn't want, the one that's gonna really distress him. So why can't we give him a little bit of testosterone? - if we can just start giving a bit, so that his body is not basically in withdrawal? And the GP went, 'I think you're right,' like, 'this makes sense'. [P]

Several parents described the drawbacks of an inflexible one-size fits all approach that doesn't allow HRT until 16. One parent described their frustration at what they saw as NHS inflexibility, needing to look outside of the NHS for individualized and child-centered care.

What I find difficult is obviously with (gender service), you've got to be 16 to get hormones. But I think when you've got a child who's been this clear cut as our daughter has, and all her friends are now wearing bras and developing, and

the thought of having to wait till 16 for hormones is not good. And obviously, (private service) are much more open about prescribing that at the right time for the young person. So, we might look at that. [P]

Another parent described the extended delay before eligibility for HRT having social and emotional impacts on their child, contrasting the UK's rigid protocols with approaches they were aware of in other countries.

(He should have had HRT and started puberty at age) 13, 14 you know, with his peer group, so he's not left out all the time. It just feels like it's delayed. I feel like he's, you know, quite immature. Sensible, but kind of childlike in his likes, kind of films he watches, kind of TV that he likes, that kind of thing. . .It would have had an impact if he could have had it with his peers, when his peers were getting it. I mean, they do that in other countries. [P]

A trans adolescent who had been on a blocker for 5 years, but who was still waiting to be prescribed HRT commented "Testosterone should start at 14 or 15 and there shouldn't be a court date for it to be prescribed" [C]. Another adolescent, who had started Testosterone (accessed privately) after over 3 years on a blocker, shared his thoughts on the timing of initiation of HRT.

I started T when I was 15, maybe 14. And there's definitely a point, kind of just before I got on T that, like, when you look at the boys around you, you're kind of, like, oh. There's definitely a difference in terms of like voice or whatever. So, you know, I think if I'd gone on T when I was 16. I mean, I'm 16 now, and like, I think if I was still on blockers all that time and up until now. Like seeing the people around me, I think I would have been a lot more self-conscious than if I hadn't started T a while ago. I mean, ideally in my head I probably would have started T a bit earlier just because of the side effects of kind of being on the blockers for so long. But yeah, other than that - I think I was quite lucky with the age that I managed to get on T. [C]

Discussion

The first major theme in this dataset presented parent and child perceptions on pre-pubertal anxiety. A majority of parents in this sample described noticing their child's anxiety about puberty at a young age, even before children knew the word puberty. It is important to note here that this sample only included trans children who socially transitioned under age 11, excluding trans children who came to understand or disclose their identity at an older age. Parents in this sample described children's anxiety levels increasing as they got older, and particularly as they saw older siblings or peers progress

through puberty. Several parents reported their child exhibiting acute distress, with parents realizing that endogenous puberty would be intolerable for them. Parents in this sample were aware of their child's anxiety about puberty, though wider research has shown parents are likely to underestimate their trans adolescent's level of anxiety (McGuire et al., 2021). As puberty approached, many parents in this sample described their trans child bringing up the topic regularly, with the parent perceiving it as a chronic source of anxiety. A prepubescent trans girl highlighted worrying about puberty every single day. These research findings highlight the importance of managing anxiety in pre-pubertal trans children. Many parents in this sample discussed the existence of puberty blockers with their child as a way of reducing anxiety. Several parents felt strongly that categorical reassurance of the option of puberty blockers was critical for reducing anxiety and allowing their child to "thrive in the here and now." This finding complements existing research showing trans children and adolescents have heightened levels of anxiety when compared to cis peers (Lopez et al., 2018). It also reinforces research on how the use of puberty blockers reduces anxiety, enabling trans adolescents to learn and concentrate on other aspects of their lives (de Vries et al., 2014).

Whilst parents in this sample wanted to be able to reassure their children about the option of avoiding endogenous puberty, the parents were all clear that guaranteed access, as needed, to timely puberty blockers, was not feasible within the NHS. Only by looking to potential non-NHS options were parents able to guarantee their child they would not proceed through endogenous puberty. A number of parents who could not look outside of the NHS, felt unable to reassure their child that blockers were definitely an option. Several parents in this situation wished they could provide their pre-pubertal trans child with this reassurance, and felt this would have helped with pre-pubertal well-being. These findings align with research from other countries on family stress and fear over inaccessible healthcare, particularly where trans adolescent healthcare has become politicized rather than based on individual need (Abreu et al., 2021).

The second major theme examined difficulties accessing blockers, with sub-themes on extensive assessments and harmful delays. A majority of parents and several children described access to puberty blockers as their primary reason for engaging with NHS pediatric gender services, attending Gender Service appointments throughout childhood purely to ensure timely access to blockers at the start of puberty. For these children and families, drawn out assessments were a hurdle to accessing essential medication. One adolescent spoke of barriers to trans adolescent healthcare as a violation of human rights, an act of cis-dominance over trans youth's lives.

In terms of the assessments required for referral for puberty blockers, parents reported children being distressed at being expected to talk in depth, repeatedly, about their feelings about their current body over many months or years. A number of parental interviewees questioned why trans children needed to be distressed about their current body, and why the assessment could not simply focus on a child's feelings about endogenous puberty, the factor parents felt was key in determining need for blockers. Parents also questioned why children needed to tell clinicians in depth how distressing puberty would be for them, why they could not receive healthcare without needing to demonstrate their distress to cis psychologists. One adolescent commented on the power dynamic of a cis clinician judging whether a trans adolescent is sufficiently dysphoric to access puberty blockers. These findings resonate with work criticizing excessive assessment of trans children (Ashley, 2019). They also align with wider research on structural transphobia within healthcare and its negative impacts on trans communities, and particularly trans adolescents (Price et al., 2021).

A number of parents shared examples of their knowledge or their child's knowledge about their child's stage of puberty being dismissed by gender service clinicians. Several parents commented on what they felt were excessive barriers to getting clinicians to recognize the reality that puberty had started. Many parents spoke of psychologists wanting to themselves observe obvious pubertal changes before referring to endocrinologists, with endocrinologists wanting to further confirm through physical examination and a suite of other tests. These accounts present evidence of testimonial injustice. Testimonial injustice occurs when a person's account is disbelieved or distrusted, with their credibility undermined by some form of prejudice (Fricker & Jenkins, 2017). A body of literature outlines trans adults' experiences of testimonial injustice when accessing healthcare (Fricker & Jenkins, 2017; Pearce, 2018; Serano, 2016; Vincent, 2020). Other literature outlines testimonial injustice experienced by children and their carers within healthcare settings (Carel & Györffy, 2014). This existing literature reinforces trans children's vulnerability, as members of two groups known to experience testimonial injustice.

Parents also discussed experiences of delays to accessing timely treatment and the harms of delay. Many parents perceived delays as having contributed to high levels of short or medium-term stress for their child during the period of delay, as well as having longer-term physical and emotional consequences for adolescents who unwillingly progressed through stages of endogenous puberty. Several parents expressed frustration and felt badly let down when their child had not been able to access timely puberty blockers, despite engaging with the Gender Service for many years before puberty. Other parents

talked about ableism, highlighting how demanding the expectations were for neurodiverse children, particularly children who did not readily communicate their emotions to strangers. Several parents of neurodiverse children felt their child had faced additional delays to accessing puberty blockers, in a process that was not flexible or child-centered.

The final major theme explores experiences with puberty blockers drawn from the subset of the sample who had accessed or whose children had accessed blockers. A majority of parents whose children had accessed blockers spoke about immense relief once puberty was stopped. Others described blockers as anti-climactic, focusing instead on the frustration of delayed access to HRT. Parents and adolescents on blockers reflected upon the impacts of arbitrary age-based barriers to gender-concordant HRT, referencing the social, emotional and also physical consequences of inflexible protocols. These accounts from adolescents and parents align with the perspectives of a number of clinicians, who have written on the potential harms of inflexible protocols that inhibit options for gender-congruent peer-concordant puberty (Rosenthal, 2021).

Limitations

Three important limitations are noted, relating to parental perspective, to the make-up of the families in this sample, and to gaps in the dataset. Firstly, this research includes parental perspectives on child and adolescent experiences. Parental inferences about their child's experiences are limited and incomplete, vulnerable to parental misunderstanding, simplification or misrepresentation. Parents are also limited in only having access to the information that they have themselves seen, or that their child has been willing to share with them. This limitation is very important to note, especially in a context where trans-hostile parental accounts have been used to delegitimize trans youth and weaponized to advocate against trans rights including right to healthcare (Ashley, 2020).

Secondly, the parent and child experiences presented here come from families where trans children have socially transitioned under the age of eleven. Experiences here cannot be assumed to relate to other cohorts; in particular, to the experiences of adolescents who become aware of or disclose their transitude at an older age, or adolescents who have not had parental support in pre-adolescence. This parental sample comprises those parents who are actively supportive of trans children and connected with other families including through support groups. The sample was diverse in some respects, though a majority of interviewees were white cisgender women. Finally, gaps in the data are acknowledged. A majority of the parental interviewees were

interviewed when their child was at the cusp of adolescence (average age 11), with only seven of their children on puberty blockers at time of interview. Furthermore, in terms of the perspective of trans adolescents, only four from the ten interviewed children were on puberty blockers at time of interview. These data limitations are particularly relevant for the latter part of the findings, which focus on experiences whilst on blockers. Nevertheless, this dataset presents an important addition to the literature, and one that would benefit from further follow up as these children mature into adolescence and beyond. The research reinforces the importance of including child voice in research on trans adolescent healthcare. Future research needs to do more to prioritize inclusion of trans child and adolescent perspectives on well-being and access to healthcare.

Conclusion

This research provides unique insights into puberty from families where trans children socially transitioned in pre-adolescence. It emphasizes the value of reassurance of blocker availability for reducing pre-adolescent anxiety, with relevance for parents and carers of pre-adolescent trans children, and for wider professionals concerned for trans children's well-being. The research highlights the harms in extensive assessment or barriers to eligibility for puberty blockers, demonstrating that services need to place greater emphasis on safeguarding adolescent well-being, centering the rights of trans adolescents to de-pathologized healthcare. The research reinforces the critical importance of puberty blockers in preventing the development of incongruous secondary sexual characteristics, and protecting adolescent mental health and self-confidence. It also demonstrates the harms and consequences of restrictive age-based protocols for HRT, evidencing the needs for individualized healthcare. These findings have relevance for healthcare workers supporting trans children and adolescents; for healthcare policymakers; for families with trans children; and for those supporting trans adolescents' right to healthcare.

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