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“It’s like my kid came back overnight”: Experiences of trans and non-binary young people and their families seeking, finding and engaging with clinical care in England

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Abstract: “It’s like my kid came back overnight”: Experiences of trans and non-binary young people and their families seeking, finding and engaging with clinical care in England

Background: Trans and non-binary children and young people in England, UK struggle to gain access to affirming clinical care, despite the international research evidence pointing towards this best practice approach. Concurrently, they are subject to constant discussion in UK national media and politics, where many negative assumptions are made about their needs, experiences and clinical provision. Their journey to seek appropriate care has not yet been documented.

Aims: We trace the experiences of trans and non-binary children and youth and their families in their decision to seek, searches for and experiences with affirmative and non-affirmative clinical input for help with their gender.

Method: 27 dyadic, semi-structured interviews were undertaken with trans and non-binary children and young people and their parents from 13 families.

Results: The process of seeking support via National Health Service clinical routes in England, UK is beset with lengthy waiting lists, issues with geographical inaccessibility, a lack of relevant clinical knowledge, and a failure to recognise the value of family expertise. Family doctors provide contraceptive

hormones in lieu of proper access to puberty blocking or gender affirming hormones, and most families resort to private care they can ill afford.

Discussion: Training in gender identity and gender dysphoria is recommended for both family doctors, and children's mental health services. Gender identity development services could be decentralised, with local hubs offering more accessible support.

Keywords: gender dysphoria, non-binary, affirmative care, puberty suppression medication, CAMHS, waiting lists

Conflict of interest: The authors declare that they have no conflict of interest

Introduction

Despite the overwhelmingly supportive evidence to be found in the last fifteen years of international research on best practice models of clinical care which are gender-affirmative (Ashley 2020, Kunalanka et al 2020, Pullen Sansfaçon et al 2019, Riggs 2019, Nahata, Chelvakumar, and Leibowitz 2017, Edwards-Leeper, Liebowitz and Sangganjanavanich 2016, Ehrensaft 2016, Lev 2004), trans and non-binary (TNB) children and young people and their families in England, UK face many obstacles in accessing this best practice model of care (CRAE 2016). Waiting lists, delays in referral processing, and a lack of adequate training in the areas of gender-identity development and gender dysphoria are the norm (Carlile 2020, CRAE 2016). Despite the existence of free, point-of-care treatment via the National Health Service, many are pushed to find what they need in private practice. This paper illuminates some of the difficulties experienced by these families as they journey towards appropriate care.¹

Overview of literature

Early childhood conceptions of gender

The idea that there is any one route to coming out as TNB has been problematised (Pullen Sansfaçon et al 2020). However, Riggs (2019) draws on Fausto-Sterling's work

¹ A note on language: In this paper we use the acronym 'TNB' (trans and non-binary) in order to be inclusive of the diversity of the community and to allow for the range of terms used in self-identification in the UK (Adams et al 2017, Vincent 2018). It should be noted that the term 'trans and gender diverse' (TGD) is often used in literature which reports data on this topic collected in Australia (Strauss et al, 2020) and Canada (Pullen Sansfaçon et al, 2019, 2020). 'Trans' is also used in this article as an umbrella term where appropriate (Vincent 2018). To explain participants' journeys it is sometimes important to state their sex assigned at birth to distinguish between this and their gender; in these cases we use 'assigned sex' (Adams et al 2017). We also use the term 'non-binary' on its own to describe people whose gender identity falls outside the gender binary (Vincent 2018). We use 'cisgender' to refer to people who are not trans or non-binary (Adams et al 2017, Vincent 2018). In the 'Results' section, we use the terms the young people have used to describe themselves.

to suggest that many or most TNB children and young people seem to become aware of gender categories as very young children in a way that seems to be linked with the acquisition of language. Later on, some (but not all) TNB young people might experience a distressing sense of discomfort with their body, often as they start to experience the physical changes associated with puberty. This is described as ‘gender dysphoria’ in the DSM-5, a problematic diagnosis inconsistently defined within the clinical literature (Davy and Toze 2018).

Depending on context (Ashley 2020, Temple Newhook et al 2018), parents might hear about their child’s thoughts on gender several months or years after the child starts thinking about it. Conversely, parents might have thought that their child might be TNB for some time before the child mentions it. This undermines a common misconception that children and young people can suddenly and mistakenly come out as TNB as a result of peer pressure from TNB friendship groups (Ashley 2020, Ashley and Baril 2018). In any case, the concept of a common pathway from early vocalisation through social transition to consolidation as a fully transitioned adult within a binary notion of gender is fallacious, and undermines the variation in TNB people’s journeys (Ashley 2020, Pullen Sansfaçon et al 2020, Brandelli Costa 2019, Schei Jessen and Roen 2019).

Accessing services

Families in England UK with TNB children experience a highly inflexible approach to gatekeeping for services, often experienced as highly stressful (Carlile 2020).

Gatekeeping can include delays in referrals from primary care, and excessively long waiting lists (Crane et al 2018; Roughan and Stafford 2019; Taylor et al 2019) are also an increasingly urgent problem across UK general medicine and psychological clinical practice for children and young people (Ashley 2020). Whilst families, GPs and

CAMHS can refer to the UK's gender identity development service (GIDS), the GIDS is also a section of CAMHS and has its own increasingly lengthy waiting list. In other words, both have long waiting lists - so even if a family is given a CAMHS appointment, they still may have a long wait before accessing GIDS. Waiting lists are experienced as deeply distressing, not least because puberty does not wait, and its progress is linked with increasing distress often experienced as gender dysphoria (Ashley 2020, Carlile 2020; Schei Jessen and Roen 2019, Nahata, Chelvakumar, and Leibowitz 2017). Conversely, pre-puberty social transition is associated with an incidence of mental ill-health equal to that of the general population (Nahata, Chelvakumar, and Leibowitz 2017).

Lack of training

Once TNB children and young people in England manage to speak to a clinical professional they can often experience misconceptions and stereotyped assumptions rooted in a lack of adequate training in their specific needs and symptomology, resulting in experiences of misgendering, misuse of former names ('deadnaming'), and stereotypes which assume a binary model of appropriate gender presentation (Carlile 2020; Taylor et al 2019, CRAE 2016). Lack of training specifically in relation to the needs of TNB children and young people is a concern also evidenced in research undertaken internationally, including in Australia (Strauss et al 2017; 2020), Canada (Hoffman, Freeman and Swann 2009), Sweden (Erbenius and Gunnarsson Payne 2018) and in the US (Allen, Watson, and VanMattson 2020, Oransky, Burke and Steever 2019; Nahata, Chelvakumar, and Leibowitz 2017).

Prescription of hormones

The distress which many TNB young people link with the concept of gender dysphoria can be alleviated by the use of puberty blocking medication (Schei Jessen and Roen

2019; Butler, Wren and Carmichael 2019; Nahata, Chelvakumar, and Leibowitz 2017, Mahfouda et al 2017, Strauss et al 2017, Edwards-Leeper, Liebowitz and Sangganjanavanich 2016; Lynch, Khandheria and Meyer III 2015), often seen as functioning to allow time for TNB young people to make informed decisions about potential gender-affirming hormone therapy or surgical intervention (in England, this is not available for young people under seventeen years). Some clinicians, such as Zucker et al (2010) and Butler, Wren and Carmichael (2019), advocate caution and a lengthy timeframe before prescribing puberty blocking medication. However, both groups also cite lengthy waiting lists as a reason to avoid delay in starting puberty blocking medication when they finally arrive at a GIDS clinic (Butler, Wren and Carmichael 2019; Zucker et al 2010). Several months after the data was collected for this project, a UK High Court ruling in December 2020 stated that young people aged 15 and 16 may need to ask the court for permission to go onto puberty blocking medication where a parent did not agree, and that under that age it was highly unlikely that this would be granted (*Quincy Bell and Mrs A V The Tavistock and Portman NHS Foundation Trust* 2020). There is also a case pending involving a young person who is hoping to challenge the long waiting time for an appointment (Hunte 2020).

Gender-affirming hormones are recommended within current Endocrine Society Clinical Practice Guidelines (Mahfouda et al 2019) and may be prescribed either alone or following a period of puberty blockers. More research on their efficacy is called for (Mahfouda et al 2019), but they are thought to reduce gender dysphoria for some by bringing aspects of the body more in line with gender identity (Nahata, Chelvakumar, and Leibowitz 2017). This can improve other areas of social function such as participation in group physical activity (Jones et al 2017) which is often of key

importance to an improved social and bodily experience for TNB youth (Elling-Machartzki 2017, Caudwell 2014).

Gender-affirming hormones are prescribed via UK National Health Service (NHS) provision only after a very extensive period of psychological investigation, partly because the research published by GIDS clinicians in England, including the head of service, do not consider that there is adequate research on their long term impacts (Butler, Wren and Carmichael 2019). Whilst Nahata, Chelvakumar, and Leibowitz (2017) also caution the lack of such longitudinal research, they note the need to balance these concerns with the tangible positive effects the timely prescription of such medications are known to have on self-harm and suicidal ideation. Despite the issues with referrals from primary care and the long waiting lists, the ‘pacing’ of pathways towards the prescription of puberty blocking hormones and gender-affirming hormones within the GIDS in England is still described by those who prescribe it as ‘conservative’ (Butler, Wren and Carmichael 2019). In contexts where healthcare is insurance-funded, menstrual suppression medication is indicated as a viable alternative to puberty blockers and gender affirming hormones in situations where insurers have denied coverage (Nahata, Chelvakumar, and Leibowitz 2017). However, depending on the type of medication there can be a risk of undesired feminising physical effects caused by estrogen (Nahata, Chelvakumar, and Leibowitz 2017). In the context of long waiting lists, deliberately slow- paced clinical protocols and limited access to medication, many TNB people children, young people and adults in England have recourse to private clinical care via online TNB medical services such as GenderGP (Edenfield, Colton and Holmes 2019).

Methodology

This project was developed as an iteration of the Canadian research project, “ Stories of gender affirming care”, which aims to understand the experience of trans and gender diverse children and youth, and their parent, accessing gender affirming medical care (Pullen Sansfaçon et al 2019). This study, which uses the same semi-structured interview protocol, was also conducted in Australia (Riggs et al 2019) and Switzerland (Medico et al 2020) . To participate, the eligibility criteria required families to include a child or young person who had sought access to CAMHS and/or GIDS and was receiving some kind of clinical input regarding their gender.

Participants

Participants were found initially via a support group meeting for families with TNB children; some of these introduced the research team to others via the snowball method. Participants consisted of one parent and one child from twelve families, and one parent and two siblings from one family. All families lived in England and described themselves as ‘White British’ or ‘English’ except one which had arrived in the UK in the last year and was part of a minority ethnic group in Europe (details anonymised to protect identity), and another which described themselves as ‘Scottish and Welsh’. All the parents who agreed to be interviewed were cisgender women. The children’s ages ranged from five to twenty, with the mean and median ages both being fifteen. Six defined their gender as ‘trans male’ and one as ‘trans female’, two as ‘male’ and one as ‘a girl’. Finally, two participants defined their gender as ‘trans male and non-binary’ and two as ‘non-binary’.

Data collection methods

The data was collected by the first and second authors. It is important to conduct research about TNB people in a participatory way (Adams et al 2017; Vincent 2018) and so one of the researchers, a trans man, was invited to conduct interviews and to

advise on use of language and appropriate delivery of the research questions; later, he sense-checked and edited the data analysis (see below). The interview protocol was developed in the Canadian project led by the second author (Pullen Sansfaçon et al 2019) and was closely adhered to, to generate a comparable data set across countries. Questions were changed where contexts were not comparable. For example, the Canadian cohort were recruited via, and interviewed at gender identity clinics with affirmative approaches to treatment; the UK cohort do not have the same kind of access to this type of provision, and so questions referring to ‘this clinic’ were amended to instead ask about ‘the clinic you attend’.

The model is dyadic, requiring the interview to be administered with a parent and a child from each family. Slightly different questions were asked of parents and their children, but each interview covered the same topics. Children and parents were usually interviewed separately unless they requested otherwise.

Methods of Analysis

In line with the international study to which this study is related, the methodology was coded using an iterative thematic analysis approach (Pullen Sansfaçon et al 2019).

After interviews were recorded, they were transcribed by a third party transcription company. Transcripts were then read through by the first author while listening to the recordings to check for accuracy and as a first listen back to the data. During this period, a list of initial codes was established. These codes were discussed, grouped and refined in conversation with the second author and then entered into NVivo coding software. Each transcript was coded in the software, the data-populated coding nodes then being downloaded and shared with the second (trans) author for sense checking. The codes included gender identity, family, hobbies, and school. The interview schedule did ask about local community culture and context, and some

interesting findings emerged, particularly around religious spaces, but in the interest of space and focus, this paper concentrates on the data specifically relevant to the journey to and through clinical intervention.

Ethics

Ethical guidelines in the UK iteration of the project were drawn from the British Educational Research Association and ratified at an ethics committee at the first author's institution.

Information sheets were distributed to children and parents, and they were asked to sign consent forms. The text was amended for younger participants; the first author has developed a form of words about data protection laws specifically for children which have been adopted for use across her institution. Confidentiality is especially important in working with TNB people (Adams et al 2017); to this end all data is held on secure password-protected computers, pseudonyms have been used throughout, and other identifying details have been changed where necessary. For the same reasons we have also obscured the links between the sibling pair we interviewed. Questions were open-ended, which sensitively allowed for participants to introduce topics only to the extent that they felt comfortable. Where questions were designed to elicit data on particularly sensitive issues such as experiences of gender dysphoria, they were phrased in very non-specific ways, and were prefaced by a reiteration of the right of the participant to refuse to answer, to move on to the next question, or to stop the interview. One participant chose to 'pass' on some questions.

Results

This section will outline results in the areas of TNB children and young people's experiences of their own gender, and when they came out to themselves, and then their

parents. It will move on to look at their journey towards and through clinical intervention, including referrals, waiting lists, interactions with clinicians, and medication.

Approaching the family doctor

For the cohort interviewed, once they had come out to their parents, and if they felt it might be useful to see a professional, there were many delays before the provision of clinical input regarding their gender. One fairly common experience among the respondents was asking a family doctor (a 'General Practitioner', or 'GP') for a referral, and this request being refused. Even after a referral, a years-long waiting list, and a months-long assessment, respondents reported that GPs often refused to administer prescribed medication. One boy aged fourteen described his experience: "I'm assuming my mum told you about my GP? ... he'd just try and avoid everything about it, yeah he won't talk about it at all ... it's against their policy to support trans healthcare ... that's what he told us".

There was evidence in the data collected that families, GPs and CAMHS can appear to be unclear as to who can submit a referral to GIDS. Sam, aged eighteen, explained how his CAMHS worker had initially sent a referral back to the GP:

She was like, 'cool, we'll get you a referral to [the GIDS] and that'll be great, I just need to send this off to the GP and they can do the referral', and then the GP sent that back to her and they were like, 'nope, you need to do the referral, it needs to come from CAMHS, it can't come from us', and then CAMHS were like, 'no, the GP needs to do it', so it went back and forth and back and forth, and then eventually at some point someone sent it off but someone also messed up, and so they sent it to the adult clinic instead of the young person clinic.

It was a frequently reported experience among the respondents that even once they found a sympathetic GP or CAMHS worker, the wrong referral form was often completed, or the right form was completed but sent to the wrong place. In these cases, none of the families we interviewed had been told that their referral had not been correctly submitted or that they were not yet on the waiting list until they called, several months later (having been told to wait), to find out what was happening.

Some families had supportive GPs who learned alongside them. Shane, aged 20, found that his “really good GP” was “very helpful”, asking him a few questions “but nothing that was in any way critical, just in trying to help her understand what was the best referral process”. Shane’s mother explained: “they referred him straight away ... we’ve been very fortunate”. This theme of ‘fortune’ or ‘luck’ ran through many of the participants’ experiences.

Lack of awareness in mainstream child and adolescent mental health services

Because the GPs respondents met were reluctant to refer directly to GIDS, most of the families we interviewed were initially directed towards CAMHS. At CAMHS, most found themselves dealing with professionals who insisted that they would not refer to GIDS until they had diagnosed gender dysphoria. It is worth mentioning here that the central role of GIDS is to diagnose gender dysphoria - so by the time they arrive, the patients have often already been diagnosed. However, CAMHS clinicians are generalists rather than gender specialists, and the experiences reported by respondents often pointed towards a possible lack of training in this area. For example, gender stereotyping was common- as in Kieran’s case. Kieran, aged sixteen, was a member of a high-ranking youth ballet company. The ballet company had been very inclusive in its practice: they gave him men’s roles; they used his correct pronouns and they changed their data to reflect his new name. The ballet company was one place where this young

man reported that he felt accepted, affirmed, and safe. When he was asked in the research interview, “what are the things that make you feel really, really happy?” Kieran talked about his ballet company, and added: “Strangers getting my pronouns right, good new binder ... Feeling like I pass [that is, as male] when I look in the mirror, so a sort of ... gender euphoria”. Yet his CAMHS therapist used his continued involvement in ballet as a reason to query his ‘seriousness’ about his gender dysphoria and desire to transition. Kieran explained what he was told at CAMHS: “I’m wrong, I have to be a girl because I like doing ballet because ... it’s not football, that’s why and ... I’m not trans, I’m a type of lesbian”.

CAMHS is a generic mental health service for children and young people, so as an institution it is not built specifically around the needs of TNB service-users. This is evident in the administrative architecture of the organisation- for example, parents reported that its intake forms are not TNB-inclusive. Dex’s mother explained how she tries to correct this at each appointment: “in all the CAMHS forms it says ‘he’, ‘she’, ‘he’, ‘she’ and actually, when I go for Dex, I scribble in big writing across ‘he’, ‘she’ and I put ‘they’, ‘them’”. In addition, bureaucratic delays cause an added stress to the process. When Ash, a seventeen year old, requested their records to be changed to refer to their non-binary name and pronouns, they found the process to be “very slow”; later, a referral form was left unsent “for months”.

Interactions with GIDS therapists

Both parents and children in 11 of the 13 families interviewed expressed a strong dislike of the assessment process once they arrived at GIDS. It was said to be painful, for example, for children and young people to answer what they felt were intrusive and irrelevant questions about sexuality rather than gender. Shane, aged twenty, described his interaction with a GIDS clinician: “she just didn’t seem to understand at all ... I just

came out of every appointment crying and feeling so much worse off ... she kept on asking me about like my sexuality and like relationships with people and it was just so uncomfortable and I thought unnecessary, it didn't relate to my gender at all". 18-year-old Charlie also said that he found the process difficult. He explained how he was asked:

'are you sure you couldn't just be a lesbian that's butch but have issues with yourself?' ... I was like, 'no, I'm not' because I hate the idea of being called a lesbian. I used to identify as lesbian and now I'm just like yeah, I was just dumb and didn't know myself ... it made me mad when they asked it ... but then I went home, and I just couldn't stop thinking about it ... but then I came to the realisation that no, they're just trying to get in my head and like make me regret everything that I'm doing with myself. Because that's kind of what [GIDS] does to people but I'm like 'no, this is me, I'm Charlie, I am not a lesbian with gender issues. Because I don't even like girls anymore'.

The children and young people interviewed for this research reported that as part of the assessment process, they are asked at GIDS whether their gender identity has come about due to some sort of trauma or parental pressure. Charlie described how he had experienced the same line of questioning: "One of the people that I saw at [GIDS] ... said, 'I wouldn't do that to my own child' and she basically said to people that being trans is just due to trauma and ... she wouldn't let their kid transition because she'd think it's not an actual thing".

Alice, aged fifteen, was one of many who described how their several months long wait for GIDS had placed them much further along in their journey than the GIDS protocols seemed to recognise. She explained: "just getting my therapist to understand me was probably the most difficult process ... Like by the time I got to [GIDS] I'd socially transitioned, I'd changed my name, everything had been sorted, so it was just

kind of trying to show him that, that I don't need any help on the therapy side of things, I just need [puberty hormone] blocker referrals”.

Non-binary young people at GIDS

The non-binary young people interviewed were wary about mentioning anything other than a binary understanding of their own gender identity at GIDS for fear of treatment being rejected. Kieran, aged sixteen, explained:

I don't think I would tell [GIDS] that I am internally somewhat non-binary instead of just being sole male, because I do fear that they would say, 'No, we're not giving you testosterone, you've not made your mind up', or, 'You're non-binary, and non-binaries just don't go on testosterone'. But I am very much more than that and I do want to be read as male and I do want, you know, male things. But I do fear that if I admitted to not being 100% they would try and take things away from me.

Elliot aged fifteen, was able to talk about the non-binary aspect of his gender to his family, but was wary of expressing this outside the home. His mother explained: “I think he believes if he says anything to anybody other than, 'I am male', they will disbelieve anything he says about being who he is ... he was afraid to sort of acknowledge that there's a fluidity ... I think if he says it out loud to everybody they might go, 'alright, stop messing about!'” This fear was a theme for all of our non-binary interview participants, and meant that non-binary young people were unlikely to present themselves at GIDS as anything but a binary version of transgender.

Accessibility issues

As well as the difficult conversations they had to have when they got there, just getting to and from GIDS appointments was difficult, especially for participants who did not live close to the small number of urban centres where GIDS main or satellite clinics were available. Participants talked about long car or train trips, and missed days of

school. Charlie described the journey: “I was exhausted, I just wanted to collapse ... I’m travelling like eight hours ... I’ve got to get the train, then I’ve got to get [an underground train] and then I’ve got to walk. Then walk and [underground train], train home”.

Positive experiences

Two of the parents interviewed described how they had been well-served by GIDS. James, a fifteen year old, was referred and prescribed puberty blocking hormones within a mere fourteen months, possibly because of his serious self-harming and frequent suicide attempts. His mother felt that the service had been exceptionally fast, but she was also one of the parents who had the resources to advocate vociferously for her son. James wanted his parents to pay for private healthcare for a quicker route to medication, but his mother felt that the GIDS process was useful. She explained:

The Tavistock have always said, ‘you need to be meeting all these criteria for us to continue with your treatment. one of them obviously is ... taking steps to improve your mental health’. And I do think that has been positive because I think if we’d gone private and they weren’t insisting on that, he wouldn’t have been forcing himself to do all the things that help his mental health.

Family expertise: “I’m dead clued up, I know my stuff”

By the time families reached CAMHS or the GIDS, they often had a considerable level of expertise – not only in terms of the child or young person’s experience of gender, but on the academic peer-reviewed research available. Alice described how she and her parents had prepared for GIDS appointments: “We’d done a lot of research on the blocker[s] and hormones, like whilst we were on the waiting list, so that in our appointments we’d be able to be like, yeah, we already know all this stuff, please do the hormones”.

James's mother, had, like many of our respondents, developed a strong, well-informed approach to her clinical advocacy. She said: "I'm dead clued up, I know my stuff and ... I would push, and I would argue, and I would insist ... I said, 'Look, you said four to six appointments so, come on, we're on three, can you tell me that in the fourth, we will be moving forward? If not, what do you need to know?'" Having seen many families turned down for affirming treatment, she was tenacious in her communications: "I wouldn't let them get away with anything, we made formal complaints about CAMHS so, I think had there been any messing around, which I've seen parents backing down to, I'd have been straight in there with complaints ... So, I think possibly both of us have got that fighting spirit". James's CAMHS worker did acknowledge that he thought he had gender dysphoria, and that a hormone prescription would help with this. However, he still delayed the referral. Eventually, James's mother called the manager. She explained what the manager had done:

She spoke to him and said, 'you need to listen to the expert in the room', which I thought was quite good. I wrote a long letter and I ... just said, 'Can you pass this on as training for your whole staff please? Because it's utter bunkum. You don't know what you're talking about and how dare you. How dare you say that you know better than someone who has got a lived experience?'

Many parents in the cohort drew on their professional expertise to support their advocacy – the group of respondents included a teacher, a midwife and a counsellor, for example. Other respondents who did not have this sort of professional expertise were more likely to access private clinical care for their child's gender. The implications of this choice are discussed later in the paper.

A long wait for puberty blockers

Almost all the young people interviewed had either been prescribed puberty-blocking or gender affirming hormones, or were waiting to receive a prescription. However, the long wait for an appointment and then the subsequent long assessment process often collided with the onward march of puberty. Like many of the participants, Shane found the GIDS medication pathway, which requires all patients to take a year of puberty blocking medication before going onto gender affirming hormones, too rigid. He explained: “they tried to get me to agree to take blockers but I was already like, I’d been through puberty. The gender service is just like lagging behind, I think that’s like the main issue in that they have this like, like one size fits all approach to it which is just, it just doesn’t fit everyone”. Similarly, Alice explained that at GIDS she had to be really insistent to get the medication:

It was ... sad and frustrating ... I really want to be on blockers so I can stop all these changes that are happening to my body ... but I’m still on the waiting list and there’s nothing I can do to get blockers. And then when we were like actually talking with the therapist ... it was like, please just give me blockers so I can stop this as soon as possible. It was really frustrating and kind of like depressing to ... know what you want and then ... to just spend all your time convincing everyone else ...

For those respondents who had been prescribed puberty blocking medication, it was described as effective in addressing gender dysphoria. It seemed to potentially help young people to relax enough to be able to talk through their feelings with their assessor or therapist. Alice explained, “my main thing that I wanted from blockers was the ability to halt puberty and be able to think about, you know, do I want surgery? Do I want hormones? Is this right? And not have the pressure of making a decision”. Louis, aged sixteen, described the impact of puberty blocking hormones on his wellbeing: “I didn’t have to think so much about dysphoria and I knew I wasn’t becoming more and

more female ... just to know that my hips wouldn't get wider, my chest wouldn't get bigger, I wouldn't become more feminine was what I was excited for, and that's what happened".

High-dose contraceptives

Whilst they were waiting for puberty blocking or gender affirming hormones, most of the young men we interviewed explained that their GP had given them high doses of female contraceptive hormones for menstrual suppression. They reported that this was often suggested by GPs to address the gender dysphoria the young people associated with menstruation. They also said that sometimes GIDS clinicians themselves would suggest asking the GP for this medication while they were assessing for gender-affirming hormones. However, families explained that this was unsatisfactory and did not meet their child's needs, particularly as it involved a trial and error process with a range of high-dose hormones which, they felt, were a poor substitute for the hormones needed in the first place. As Charlie's mother explained: "...he went through all those contraceptive pills and things and you're telling me how dangerous blockers are ... you're giving my kid depot injections and high dose female hormone pills, which he doesn't want and you're telling me that that's safer? I don't think so". Jed, aged thirteen, also tried contraceptive medication to suppress menstruation, but reported that his gender dysphoria was triggered by taking the daily pill.

Gender affirming hormone medication

Respondents talked about how gender affirming hormone medication brought them a sense of relief and a new joy in experiencing their bodies. Charlie explained that testosterone made him feel: "more comfortable in my skin ... I've got way hairier legs

than I used to". Hair growth came up consistently in the interviews. Participants also talked about changes to their voices, fat and muscle redistribution, and face shapes.

Affirming approaches to medication generally were associated with interviewees with a positive effect on their mental wellbeing. James experienced positive changes in many areas of his life. His mother described his progress:

The year and a bit before the blockers, he was literally suicidal, we had to make God knows how many trips to A&E [Accident and Emergency; the Emergency Room] and that was just horrendous, we were on suicide watch constantly. He wouldn't get out of his bed, he wouldn't go anywhere, he was terrified of everything, it was horrific. The blockers kind of took half of that away and he was up and down but since ... T [testosterone], he's getting on trains and going out to meet friends on his own ... he's been volunteering in a school, he's joined the gym, he wants to join a theatre group ... It's like my kid came back overnight.

Paying for private clinical care

Given the long delays in referrals and GIDS treatment pathways, many families paid for private medical treatment they said that they could ill afford: for example, one family reported that they had a joint annual salary of £16,000, and had paid £10,000 for their eighteen year old son to have chest surgery. Some families said that they were advised by sympathetic CAMHS workers to go for private care. Sam gave up waiting for NHS GIDS treatment at the age of sixteen. His mother explained:

We went through [private care] when we realised that he wasn't going to be seen by [GIDS] for years. It got to the stage that I just thought that if I don't help him, I can't guarantee his own personal safety ... You do what any parent does, you do what is going to make your child feel happy and is going to make your child feel that life is worth living.

Families described the private care available in England as affirmative compared to the GIDS approach, but still consisting of a rigorous assessment procedure. Xavier, a 14-year-old, went for private care after a wait of over two years for GIDS. His mother explained that the approach was much less combative than the family's experience with CAMHS: "They're lovely, everyone that we've seen ... has all been really really kind and have just listened to him. Which is a novelty, and they've just listened to what he wants and been totally led by Xavier and myself, rather than making us jump through hoops all the time". Because most people in the UK can access the NHS, it is uncommon for people to have medical insurance, so going for private care is not a simple decision. Sam described how he and his mother worked out how to afford his treatment:

We were sat in a café ... and she was like, 'what if we went private to get you on T [testosterone]?', and I was like, 'that would be amazing', but I was also really like, 'that would also be very expensive' ... they had a reduced rate for people on a lower income, and it was just one of those things where you just think, 'we've got to make this work, we'll find the money from somewhere'. ... I got another weekend job to pay for it.

Charlie talked about a 17-year-old friend who was working hard to earn the £7000 he needed for surgery. Charlie himself obtained hormones via private care, using money donated by a family friend. He gave up his favourite sport to save the rest of the money.

Discussion

The families we interviewed shared stories of lengthy coming-out processes followed by several months of processing and acceptance time before families tried to access clinical care. Most of them discovered at this point that there would be another long wait before they could access care- and this only if the clinicians they met were knowledgeable and willing about their needs.

This lack of knowledge featured in the decisions of the non-binary young people we interviewed, who reported that they were less likely to give a nuanced view of their own gender and clinical needs when they spoke with clinical staff, for fear that if they were not uncomplicatedly binary in their identity they would not have been able to access affirmative interventions- something also found in Canada by Pullen Sansfaçon et al (2019). This fear appears to be well-founded. According to a literature review of ‘desistance studies’ on TNB children and young people (Temple Newhook et al 2018), research and practice has traditionally adopted a reductive desistance/persistence paradigm which does not recognise the validity of gender fluidity or non-binary identities (Clark et al 2018).

The quality of clinical care reported was somewhat affected by the capacity for parents to advocate for their children, echoing previous findings (Riggs 2019, Birnkrant and Przeworski 2017). For the families who took part in this research, the search for an affirmative approach to care was not straightforward. This aligns with other research by Carlile (2020) and CRAE (2016), who identified delays and difficulties in the UK system, and also with a comprehensive study by Strauss et al (2017) which found many barriers to accessing appropriate care in Australia. This is despite the fact that the affirmative approach is internationally respected as best practice (Ashley 2020, Kunalanka et al 2020, Pullen Sansfaçon et al 2019, Riggs 2019, Nahata, Chelvakumar, and Leibowitz 2017, Edwards-Leeper, Liebowitz and Sangganjanavanich 2016, Ehrensaft 2016, Lev 2004). For example, as reflected in many studies (Harris 2017, 2018; Children’s Commissioner 2018), our participants experienced long and distressing waiting lists for clinical services. In addition, gender stereotyping in CAMHS assessments for gender dysphoria was a problem for our participants – something also seen by Taylor et al (2019) in their research. A picture is emerging of

endemic problems with UK CAMHS training, delivery and bureaucracy - not just in the area of services for TNB young people, but more broadly (Tatlow-Golden et al 2016 and Crane et al 2018). Some families described how they felt 'lucky' if they happened on a supportive approach; it could be argued that what these supportive clinicians were in fact offering was a basic service to which they were entitled (Pearce 2018).

Families' experiences of frustration, delay, and desperation were especially apparent in any efforts to obtain a prescription for puberty blocking hormones. Puberty blockers are recognised as a useful approach to addressing the gender dysphoria many of our participants described (Schei Jessen and Roen 2019; Nahata, Chelvakumar, and Leibowitz 2017, Mahfouda et al 2017, Edwards-Leeper, Liebowitz and Sangganjanavanich 2016; Lynch, Khandheria and Meyer III 2015; Pullen Sansfacon et al 2019), including by the GIDS clinicians in England, UK (Butler, Wren and Carmichael 2019). The interviewees all described improved mood once affirmative treatment had started. The benefits extended into school attendance, friendships, and increased participation in society. However, most of our interviewees were delayed in receiving these medications. Instead, most of the participants we interviewed who were assigned female at birth were prescribed high-dose contraceptive hormones in the absence of puberty blocking or gender-affirming medication. These are recognised as an alternative treatment in countries where medical insurers refuse to pay for the alternative, but acknowledged as potentially harmful (Nahata, Chelvakumar, and Leibowitz 2017): their inconsistent impacts on menstrual bleeding and mood and physically feminising effects were described as highly undesirable by our interviewees.

Finally, the fact that so many of our interviewees sought out private services - in a country where National Insurance contributions should fund adequate health care via

the National Health Service - points towards a gap in the provision of TNB children's and young people's health care.

Limitations

This study was limited mostly to participants who defined their ethnicity as White British, Irish, Scottish, or English. Subsequent studies need to start purposively with a less ethnocentric recruitment of participants from minority ethnic groups in the UK. Although we interviewed a child of six years old, the average age was fifteen, and most of the participants were boys or young men. All of the parents who agreed to the interview were cisgender women. Some useful data emerged relating to the role of fathers; this will also be the subject of a separate paper.

Conclusion and Recommendations

The TNB children and young people we interviewed faced a struggle to access the internationally recommended affirmative model of clinical care. Wait times, under-trained clinical staff, and conservative treatment protocols conspired to produce a pessimistic scenario. Where appropriate medication was unavailable, many TNB young people assigned female at birth were placed on high dose contraceptive hormones instead. Parents who advocated powerfully for their children were more successful in obtaining the right treatment, and paying for private care was also a route families tended to take, even where money was tight. Families referred to being 'lucky' if they met a supportive, affirmative practitioner, suggesting that the system feels generally weighted against them.

In the light of the data presented here and the lack of evidence about puberty blockers presented by the GIDS in the recent court case *Quincy Bell and Mrs A V The Tavistock and Portman NHS Foundation Trust* (2020), it is recommended that GPs and

CAMHS clinicians are offered more comprehensive training opportunities to ensure that they are up to date with the internationally recommended affirmative treatment guidelines and referral pathways (CRAE 2016) such as the current Endocrine Society Clinical Practice Guidelines (Mahfouda et al 2019). This must include content on the needs of non-binary children and young people. Once this has been achieved, decentralising care from the sole GIDS in England, UK will allow for a better range of support, more local, accessible services, and a broader understanding of need.

Statement of human rights

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.

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