

Article

Experiencing “the Wrong Kind of Puberty”: Navigating Teenage Years with a Variation in Sex Characteristics

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Abstract: There are many different variations in sex characteristics, some of which have implications for how the body goes through puberty. This paper draws from critical disability studies and childhood and youth studies to understand the teenage experiences and aspirations of young people with variations in sex characteristics, focusing particularly on navigating puberty. We undertook a reflexive thematic analysis with interview data from 12 young people in England, all assigned female at birth. Our analysis produced a central theme: aspiring to certainty through “fixing” the wrong kind of puberty. Participants experience puberty as a time where things exist on a continuum of rightness and wrongness in comparison with their peers and in relation to their specific variation. We suggest that the neoliberal aspiration to and illusion of bodily control and certainty provides the context within which the medical management of variations in sex characteristics makes sense. Going through medical intervention in relation to a variation in sex characteristics provides a very particular aspirational context for young people. The experience of puberty is intersectionally differentiated for young people with variations in sex characteristics.

Keywords: youth; intersex; body; puberty; healthcare; qualitative



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1. Introduction

Variations in sex characteristics, also known as intersex variations, may be chromosomal, hormonal, genetic and/or anatomical [1]. These variations are often identified as medical phenomena during childhood or youth [2,3] and this can lead to medical interventions intended to “correct” the developmental pathway towards more “typical” male or female developmental pathways [4]. Medical intervention on the bodies of people with variations in sex characteristics can be understood in the context of the existing critiques within childhood and youth studies where the child’s body is understood to be “the target of constant measuring and monitoring . . . against pre-established norms [and, bodies that] . . . do not conform to these norms . . . are typically drawn into a network of expert intervention” [5]. There has been an extensive critique of medical intervention on intersex bodies, particularly from the 1990s onwards, and this critique has come from intersex researchers and advocates [6–11], human rights and law experts [12,13], social science researchers [14–18] and clinicians [19–24], among others. The present paper offers an innovative angle on this critique by drawing from the accounts of young people who have undergone diagnosis and intervention.

Existing non-medical research literature concerning young people with variations in sex characteristics focuses on topics such as the experience of receiving a diagnosis [25], learning to talk about having a variation [26,27] and providing or seeking psychological healthcare [2,28,29]. But little research focuses on how young people with a variation experience puberty and respond to changes during their teens. Puberty is often perceived as a time of change for young people that encompasses physical, emotional, psychological and relational dynamics [30]. There are many different variations in sex characteristics [31]. Some variations have implications for how the body goes through puberty, for example,

the body may not spontaneously go through pubertal changes at all. For some people with variations in sex characteristics, it may be during the teen years that the variation comes to be known, so the process of being a teen and coming to understand variations in sex characteristics happen simultaneously (for an example, see this link where a young person with Complete Androgen Insensitivity Syndrome describes what this means for them: <https://www.youtube.com/watch?v=5vDVUPjBjiM> (accessed on 2 March 2023). In some instances, the body might change in unexpected ways during puberty, or puberty might be an entirely medically mediated experience.

People with variations in sex characteristics have historically been denied access to information about their medical diagnosis and early childhood medical interventions [9,32]. Over the past 20 years, there has been movement towards changing this practice of denying information [3,33]. The present research explores the pubertal experiences and bodily aspirations of a new generation of young people who have been told about the diagnosis and involved in discussion of medical intervention through their teens.

This paper draws from critical disability studies and childhood and youth studies to understand the teenage experiences and aspirations of young people with variations in sex characteristics. This research is based on a critique of the way “norms of development have become more prescriptive” and “those who appear to fall away from such norms are [. . .] seen as [. . .] a problem to be treated” [34]. We work with an understanding of transgression that enables the exploration of how variation from “normative development need not be considered as pathological or in need of correction, but as locations/sites of renegotiation” [35].

We draw on Coffey’s [36] concept of “bodywork” to understand how young people perform “work”—with others and by themselves—on their bodies to fit into the expected developmental norms. Coffey explains that such work is about how “young people seek to shape and express identities through bodily presentation and performance” [37]. For example, such work might include dieting, exercising and plastic surgery. We contend that bodywork for young people with variations is complex and subject to levels of biomedical surveillance and pressure that other young people likely do not experience. Indeed, our research indicates that young people with variations in sex characteristics experience extraordinary bodywork pressures and choices on top of those that might be considered “normal”.

The idea that individuals make free choices about their lives is a key feature of neoliberal society [38]. Such choices are even expected of children and young people [39] and can include choices about how to present, “fix” and shape the body [37]. These choices are predicated on the assumption that the body—indeed every body—is a stable entity over which one can exert control. Assumptions of personal control and bodily stability do not mean that the body does not change, rather that the only accepted changes follow a predictable, normative developmental pattern [40]. Fatness, for example, is typically constructed as an individual failing, divorced from the structural and gendered influences and regarded as a deviation from an idealised norm [41]. Societal and neoliberal norms “get under the skin” through personal aspirations orienting the body, the person “towards a desired future” [42], p. 2. This neoliberal framework has been critiqued substantially, within both youth studies and body research [37,40]. The current research investigates how young people with variations in sex characteristics navigate puberty. This research employs the concept of body work and takes a critical approach to neoliberal assumptions about body choices.

2. Methodology

2.1. SENS Project

This work is based on data generated within the SENS project, carried out in Scotland, England, Norway and Sweden, focusing on the understandings that young people with variations in sex development, their parents, carers and health professionals bring to bear in making sense of bodily diversity and sex development. The SENS project started in 2012 and earlier publications from this research have been designed to support practitioners such

as health professionals [15,16,20,43] and educators [44] to improve practice. The second and third authors, Tove and Katrina, have been involved in the project since its inception, with the first author, Eileen, becoming involved in 2022.

The present paper focuses on the experiences of the 12 young people that Tove recruited and interviewed in England. The participants were recruited via a hospital-based clinic focusing on diagnoses relating to sex development ($n = 10$) and a community-based support group ($n = 2$) and were aged 15–26 years (mean age = 21). They were all assigned female at birth and identified as women. Four participants said they had been diagnosed at birth, one had been diagnosed well before puberty and the rest said they were diagnosed during adolescence.

The one-to-one interviews were carried out at a time and place that was convenient for the participant (e.g., in the clinic, university campus or by telephone). Participants were guided through the information leaflet and signed the consent sheet before the interview started. Consent was obtained from the young person and their parent for anyone under 18 years. The semi-structured interview guide prompted participants to talk about themselves and their life in general, how they experienced the process of receiving their diagnosis, their experiences of treatment and health care and their thoughts about the future. Follow-up questions were focused on what the young people themselves found important. The interviewer was sensitive to how their being older than the participants could create unequal power dynamics. With this in mind, they prioritised participants' preferences (including how they wanted their variations described and whether they wanted to skip questions and/or end the interview) and paid close attention to verbal and non-verbal communication. An overall ethics of care has been used in the data analysis with attention paid to how the young people's stories are represented. Participants were given a gift card of approximately GBP15 as a token of appreciation. The interviews were audio-recorded and transcribed word-for-word. Potentially identifying information was deleted and participants were given the pseudonyms (by Eileen and checked for appropriateness and retention of confidentiality by Tove) used to report the data below. The present paper centres on a reflexive thematic analysis of the interviews.

2.2. Reflexive Thematic Analysis with Multiple Authors

Coming together as a “new” research team, where Tove and Katrina were already familiar with the data and each other, presented unique challenges and opportunities. A key early decision was to use reflexive thematic analysis as a method. This choice meant that we could probe the nature of “truth” and “truths” in the data and reject the notion of the objective researcher [45]. Reflexive thematic analysis recognises that the author(s) is(are) a key resource in the analytic process and actively shapes the data; therefore, we had to consider how we respond to the data and each other in constructing this particular multi-authored story. This was an advantage to us as a new team engaging in research as it required us to “get to know each other” in a more considered way. However, there has been little discussion of how to conduct a multi-authored reflexive thematic analysis (Braun and Clarke do not *explicitly* offer guidance for multi-authored *reflexive* thematic analysis in their publications to date [46]), so what follows could be considered an initial discussion of somewhat messy and previously uncharted territory—by which we mean we make no claim to getting this “right”.

Getting to “know” each other in a “knowing” way (meaning specific attention is paid to how this might work for the research) was an evolving and reflexive process that was influenced by geography (Tove is based in Sweden, and Katrina and Eileen are in Aotearoa, New Zealand) and previous (un)familiarity with the data. In order to “bridge” these gaps, we used zoom, email conversations and shared written “reflexivity” statements about our own response to the data. We were further aided by Tove having already explored how they might have been more reflexive in their own engagement with this data in the past [46]. Coming together in this constructed and collaborative reflexive space meant highlighting the different ways we viewed the data. For example, Tove and Eileen are

parents; and Katrina, Tove and Eileen all approach the data from different queer and feminist perspectives. Notably, Tove was not a parent when they first engaged with the data. We had different and important perspectives on the data. Differences (for example, parenting status, length of time with the data) and similarities (feminist, queer and critical psychology lenses) allowed for a generative and open space to engage with the data. Such a generative space has, we believe, allowed for a situational and temporally boundaried reading of the data through which we have collectively authored a particular story.

2.3. “Doing” Reflexive Thematic Analysis

The “doing” of the six phases of reflexive thematic analysis [45] was undertaken pragmatically, meaning that it was not possible for all authors to participate in every phase (indeed, we would suggest that involving all authors in every stage of reflexive thematic analysis in multi-authored articles could come with its own unique set of challenges). As Eileen had no prior experience with the data, it made sense for her to conduct the initial familiarisation phase. After this initial stage and prior to “coding”, Eileen and Katrina met to work through three of the transcripts together and discuss what we had both noticed. These noticings then informed Eileen’s subsequent coding of the data (coding was conducted “by hand” with the assistance of QDAS software.). After coding, Katrina and Eileen then met to “play” with the codes on a whiteboard to explore potential stories. This session was a re-orientation and collective journeying through the data story thus far and codes were clustered into more meaningful arrangements. At this point in time, we knew we wanted to examine youth-specific aspects of the experience of living with a variation in sex characteristics. Eileen went back and collated all the data that related to this point—effectively creating a “bucket theme” [45] with the intention of sorting through the bucket more thoroughly to explore meaning making. A further “bucket”-sorting session occurred, again with the help of a whiteboard, and four protothemes were developed by Katrina and Eileen.

After initial analysis (by Eileen) and subsequent email conversations involving all three authors, we settled on a theme that centres the experience of young people with variations in sex characteristics and speaks to the focus of the current Special Issue. Katrina and Eileen developed this theme, refining the central organising concept [47]. During this refinement, we found the image of the “axis of the flower” (as the central organising concept) and the “petals”—or expressions of the theme—linked to the “axis” [48] to be particularly useful (see: Table 1).

Table 1. Overview of themes and main content.

Aspiring to Certainty through “Fixing” the Wrong Kind of Puberty	
Petals	Content
Petal 1: The wrong (or right) kind of puberty	the kind of body work needed to “fix” this wanting to feel normal imagining the perfect body the teenage years are difficult for everyone
Petal 2: Aspiring to certainty and control	the illusion of autonomy and control perceiving the body as fixed or fixable coming to re-know the body

Although we refer to variations in sex characteristics (and sometimes to “intersex”) throughout this research paper, these are not terms that research participants would likely recognise or use [49]. The interviews were carried out with young people who had been through a medical process and who described themselves as having a diagnosis but did not necessarily engage with any kind of politicised intersex discourse. Interviews were carried out in 2013, a few years prior to the development of the current “variations in sex characteristics” terminology now used in community contexts. Further, this paper

draws links between disabilities studies and queer youth research, although the research participants are unlikely to recognise themselves within either of these framings. Critical disability studies offer valuable opportunities to rethink “the relationship between medicine, bodily difference and normality” [50]. Queer studies provide a foundation for critiquing normativity in relation to the sexed body and have been a point of reference for intersex academic voices for at least two decades, e.g., [7,51]. Nevertheless, bringing these analytic frames to data from young people with the experiences described by the current research participants can only be a tentative and precarious process. Indeed, our decision to submit this particular analysis to an LGBTIQ Special Issue must be understood as tentative: we ask that readers do not interpellate the research participants unproblematically within an LGBTIQ framework with which they might not identify.

3. Analysis: Aspiring to Certainty through “Fixing” the Wrong Kind of Puberty

This analysis is organised under the following two headings:

3.1. *The Wrong (or Right) Kind of Puberty*

The participants talked about their experience of going through puberty differently from their peers. For some, pubertal changes had to be initiated and managed medically. For some, their variations were only detected when puberty did not proceed as anticipated. The participants acknowledged that teenage years in general, and puberty in particular, can be difficult for anyone. They felt, however, that it was particularly difficult for them. Some described wanting to feel “normal” and considered this to be a particularly difficult time of life to find out that they had a variation in sex characteristics.

Young people in our study said that their experiences ranged from the “normal” ups and downs of puberty to what Ella called “the wrong kind of puberty”, and Caitlin framed it as something being “really wrong” with her. Indeed, the line between what could be considered typical for any young person going through puberty and what was specifically part of being a teen with a variation in sex characteristics was frequently blurred and sometimes explicitly questioned. Ella’s and Caitlin’s statements about wrongness in puberty prompt questions about what right puberty might look like.

For Ella, the wrongness was centred on physical changes. She talks about “going through some kind of puberty”, as evidenced by her pubic hair; however, she then contrasts this with an absence of menstruation, breast development and hip broadening. To illustrate how wrong she felt, she explains, “I could kind of like with my fingers [. . .] feel my testicles”. While the other markers of puberty she lists as lacking could potentially have other explanations, feeling her testicles indicates, for Ella, a sense of wrongness.

Caitlin too noted that her puberty was different because “obviously all my friends around me were developing normally, and I still hadn’t”. Like Ella, Caitlin refers to peers as providing the norm from which she deviates. However, Caitlin managed this by taking hormones to try and bring about a puberty that was “as organic as possible”, even while medical puberty induction left her feeling “like a . . . sort of person in a lab”. Here, we see a tension between the assumptions about the naturalness of puberty and the realities of medically mediated puberty. On one hand, medical intervention seems to promise to bring Caitlin’s development more in line with social norms and with her peers. On the other hand, having to take hormones at all leaves Caitlin feeling somehow wrong. Caitlin reflects a dynamic that is explained by McLaughlin et al., that those whose bodies do not conform to norms, are “encouraged to manage their difference [and] work to get closer to the norm” and yet “the requirement that they do so is further evidence of the ways in which they differ from others” [34]. Hormones reiterate the difference and wrongness Caitlin feels with her puberty being a constructed and manipulated process.

Distress about the body during puberty was not always framed as wrong; indeed, the changes and challenges that Cheryl and Josephine noted with their weight might be considered to be a normal (if problematic) part of growing up, especially as a young woman. Cheryl considered that “at sixteen you’re . . . just starting to grow up”, and at that age, “I

think I was . . . a bit all over the place". She explained how "I ended up losing a lot of weight when I first got told [about my diagnosis] 'cause I was always quite a tubby kid". Here, Cheryl connects being sixteen with what she frames as a normal period of uncertainty that she then links to finding out about her variation and subsequently experiencing weight loss. Her variation adds to and perhaps compounds the normalised complexities of teenage life. The challenges reflected here could be understood as an "amplified version of typical adolescence" [52]. Managing feelings about her weight can be normalised as an ordinary, yet still problematic, part of being a young woman.

For Josephine, the complexity of teenage life was amplified through medical surveillance of her body. She noted that health professional concern about her weight was "like the running vein through every appointment". Josephine explained that all the other things needed at these appointments (such as blood tests) were fine, but being told that she was "obese" and having her diet questioned "hurt". If interactions with health professionals reiterate a negative focus on bodily difference—in this case, body size—this may exacerbate a young woman's sense of objectification. This is likely to "hurt". Medical monitoring may further intensify the process of self-monitoring that young women are typically drawn into and that is associated with dissatisfaction in relation to one's own body [53]. For young women, managing weight issues in conjunction with medicalised processes has also been documented within critical disability studies. McLaughlin, for example, observes the "self-monitoring of weight . . . [and the] particular dynamics of body scrutiny linked to . . . discomfort with embodied difference" [54].

Both Josephine and Cheryl experienced challenges relating to their weight, and that is not an unusual part of growing up as a young Western woman [41]. It is also a recognised aspect of some specific variations in sex characteristics. Both Josephine and Cheryl assess their weight as an issue (for either themselves or others). This, as well as having a variation in sex characteristics, potentially compounds the sense of wrongness with their body, even if their distress about their body is not unusual for young women and could be understood in relation to typical puberty.

The idea that normalised teen bodily distress may be compounded by a variation in sex characteristics is echoed by Ella, who, in the context of being told her diagnosis, was told by her parents that she had "extra bits":

I just think then like being told that you have "extra bits" is kind of like really not a good way to improve your body image, and I was a teenager and I was doing different things from all of my female friends, so it was like . . . I felt diff-, it was difficult enough as it is dealing with the changes that my body was undergoing without being told that I had extra bits, so.

For Ella, being told by her parents that parts of her body are not needed compounds challenges in teenage body image connected to already having a different body. What Cheryl, Josephine and Ella experience is body image that is intersectionally differentiated in relation to age, body size and sex characteristics. Their bodies exceed the "normal" teen variations and so require extra work to manage and maintain. This extra work can be understood in relation to the concept of bodywork [36].

Bodywork may take multiple forms for a teen with a variation in sex characteristics. There is the practical work of taking medication and attending appointments—noted by young people and their parents as hard to fit in around otherwise busy lives—and the emotional work of managing turbulent teenage lives. Ashley spoke about the challenge of fitting in weekend activities and going to support groups, and taking her morning medication when she does not want to set an alarm clock. Other participants referred to negative emotions as normal for teens but made worse by their medical condition. Rachel, for instance, noted that her condition "coupled with like general teenage angst . . . just makes it a little bit trickier", and Maggie explained that "you are at that age where you . . . are just a difficult, moody teenager anyway".

Our interpretation of the data suggests that the participants experienced puberty as a time where things exist on a continuum of rightness and wrongness in comparison with

their peers and in relation to their specific variation. Societal norms about things that might be considered typical during puberty messily intersect with consideration for how (much) their bodies differ and the work they need to do to manage their difference, their medical condition and their lives as teenagers. This work of managing difference can be read as part of a “disciplining dynamic [. . .] at the level of the self as people [seek to . . .] monitor and manage their bodies against medical norms” [50]. We also understand this as part of the “cultural” bodywork [55] people do to maintain the body as “acceptable in everyday life” [50].

3.2. Aspiring to Certainty and Control

The young research participants talked about the negotiation of (un)certainly that is an inevitable part of life in general and may be particularly salient when living with a variation in sex characteristics. They also talked about things that are within their control and things that are not within their control. This talk resonates with the literature on autonomy, control and choice—things many citizens of neoliberal societies find challenging to negotiate [56]. We begin this part of the analysis by identifying the idea of being in control and making autonomous choices (about one’s life and one’s body) as central to neoliberal thinking. We present the data from the young people illustrating how they consider themselves to be negotiating the possibility of control, particularly in relation to the body. We suggest that the neoliberal aspiration to and illusion of (bodily) control and certainty provides the context within which the medical management of variations in sex characteristics makes sense.

Caitlin described herself as someone who sought clear information and solutions from health professionals, effectively asking, “what is it, well what’s the solution for this, . . . and what if this happens?” She described herself as “getting everything I can get out of [health professionals]”. Once she understood her diagnosis and the options health professionals were giving her, she was not satisfied:

I don’t think anything was going to be good enough (laughing). I just wanted to be normal. Yeah, there wasn’t like a sort of compromise in me at the time, it was more sort of like, ‘You need to fix this,’ but they weren’t ever going to be able to fix it, so yeah.

Caitlin is not unusual in simply aspiring “to be normal” and expecting health professionals “to fix it”. For any person in a neoliberal context, it is not unusual to seek certainty and expect to be able to control the situation one finds oneself in; indeed, such understandings of control are embedded in neoliberal discourse [57]. Caitlin is not unusual in seeking to control the body by opting for a medical “solution”. These features run through our interview data, and they resonate with dominant discourse. As Coffey and Watson explain, “The personal responsibility of the individual to control his/her body is a taken-for-granted discourse embodied from childhood” [58]. This thinking is elaborated by researchers in critical disability studies who consider how “notions of fixing” inform the relationships that people with disabilities “have with their bodies, and other bodies considered working and *normal*” [50], (*italics in original*). For the purpose of examining in more detail these ideas about medical “fixing” and body norms, we consider Cheryl’s experience at some length.

Cheryl describes her experience of the medical intervention required to bring about her puberty. This intervention did not necessarily produce the physical changes expected, but at times it led to dramatic changes in her well-being: “I got really bad headaches . . . I got very down and depressed”, and sometimes she became “very, very angry”. Despite the challenges that came with the medication, Cheryl’s period “did come, but . . . never came regularly”. She says her “breasts probably still haven’t grown at all . . . but then I’ve kind of come to terms with that. (laughing)”. Her medication was changed a number of times to try and bring about the intended physical development while reducing the side effects. She explains that the purpose was to “keep the womb developing” and “they tried so many different medications”. Eventually, after taking medication for six years and becoming “quite ill”, Cheryl told the endocrinologist “I want to stop all medication now”. By the time Tove spoke to Cheryl, she had stopped taking medication altogether, and she said, “since I’ve been off it, I’ve been absolutely fine”.

It is worth considering how this six-year period of treatment resonates with what Cheryl herself wanted. Whose aspirations lay behind these treatment decisions? We asked Cheryl what priorities were guiding the medical treatment. Cheryl explained that she thought the doctors' "biggest goal is for me to be able to hold a child . . . so I can still give birth, but for me that wasn't really the biggest thing, I just kind of wanted to, carry on and not have to always be taking medication". Given the extent of Cheryl's struggles with medication, it makes perfect sense that her aspiration came to be as simple as "just kind of want[ing] to carry on" without medication. It seems that Cheryl's struggle with the effects of medication and her experience of going through pubertal changes in a medical context gave rise to particular kinds of aspirations for Cheryl. It may be that the doctors' aspiration for Cheryl was that she would one day be able to carry a child. Such medicalised aspirations have been critiqued by queer scholars [59] concerned about the effects of unquestioningly (re)creating "femaleness" as close to sex binary norms as possible.

As a result of the sometimes-debilitating medical treatments, however, Cheryl's own aspirations were much more simple. Although she acknowledged this mismatch between her own and her doctors' imaginings of her future, she went on to explain, "I suppose that's their [the doctors'] job, that's what their goal is". For Cheryl, however, this "happened at such a difficult time" during her teenage years, "I mean, people grow up massively within that time". She explained that during that time "I think my thoughts and my feelings and everything changed . . . as well as my looks and everything". During the years of medical intervention, Cheryl's ideas about what she wanted were in flux. She explained this as a function of her age: "I think it was a very difficult time to start changing things, and my mind kept changing on what I wanted to be the outcome. . . . I still don't really know. (laughing)". Cheryl wrestles with the idea that she, like the health professionals, ought to have a goal. Here, Cheryl's thoughts juxtapose neoliberal notions of control and choice about bodies with a contextualised and temporal position of non-choice: paradoxically she chooses to not choose and, therefore, to resist a fixed goal.

Cheryl's and Caitlin's accounts remind us that bodies are unruly and do not conform to our wishes. This is especially so for adolescent bodies and for bodies with variations in sex characteristics. In any case, bodies do not reliably conform to social norms and medical interventions do not necessarily produce the hoped-for, often normative, outcomes [60]. For a young person who is simultaneously managing their emergence into early adulthood and living with a variation in sex characteristics, the illusory nature of certainty and control may become particularly pertinent. Any young person is likely to aspire to greater autonomy and control over their life and their body. A young person whose variation leads them to undergo medical intervention during this time is likely to find that they must negotiate autonomy and control over their body, both with their parents and with health professionals. Considering aspiration as "an orientation towards a desired future", going through medical intervention in relation to a variation in sex characteristics provides a very particular aspirational context for young people.

Some girls with variations in sex characteristics find out as teenagers that they do not have the XX chromosomes that other girls have. Some find out that they have testes or internal gonads that are not ovaries. These discoveries can lead to periods of uncertainty and, for some, a desire to regain control of the situation, perhaps by undergoing surgery. Jessica recalled being 16 when she discovered that she did not have ovaries, and it seemed that "no one could really say what I was", leaving her feeling "in limbo . . . like . . . what the hell am I?".

Jessica described her understanding that having internal gonads represented "something that internally isn't right with you" as well as "something you can't like automatically change". Jessica spoke explicitly about control, identifying things that were within her control. She said, "Because I had these things in me it was like, right I want to get them out . . . that's something I can control". Jessica's approach resonates with the "notions and practices of fixing, embedded in medical narratives" [50], which have also been noted in the accounts of young people with disabilities. Jessica described how after the operation to

remove her gonads she thought, “now I’m no different than other people, but I obviously am”. She sees herself as taking an active and responsible role, suggesting it was “up to me to make it who I was”. She stated, “you have to tell yourself . . . who you are and that you are a woman”. Jessica strove for certainty in her sense of herself as a woman, using strategies such as telling herself “you are a woman” and having surgery as soon as possible.

Jessica said, “I remember just saying to my mum, like I don’t really know who am I anymore”, and this comment resonates with Josephine’s thoughts on gender identity: “I did go through the whole, ‘Am I a boy? Am I a girl?’ stage”. For Jessica and Josephine, uncertainties arose where things had previously seemed certain. This can lead to a sense of not knowing oneself anymore.

For Josephine, the troubling of gender is presented as a moment that has to be gone through, requires a self-evident settling—the newly wobbly state must return to balance. For her, balance is sought through reconciling who she is, “not at all girly”, with this new knowledge that she is “different” and her mother’s assurances that “loads of tests” confirmed she “weighed more on the female side”. Unlike Jessica, Josephine seemed willing to hold some uncertainty without regarding it as too much of a problem. She said,

I suppose there’s that little doubt, I suppose everyone else is very sure generally of what they’re born as. . . . even though there isn’t that question mark, there is still a question mark . . . like part of me thinks well if . . . you don’t develop right is that, like your body trying tell you something? . . . there’s still that . . . question mark. But . . . it’s not one that I like, have a problem with or anything it’s just . . .

Josephine struggles to find the words to articulate an in-between position. She situates herself as outside a fixed norm, as not certain, however, suggests the body might be “trying to tell you something” as though there might be a bodily knowing. Josephine accepts that she cannot translate that bodily knowing with certainty.

The young people we interviewed reach for certainty and wrestle with how fixed their body is and has been. Notions of who they are shift with newly acquired knowledge about their body; the imagined body no longer matches their (perceived) actual body. It is often reassuring to reach for certainty, and when things no longer feel certain, there may be an attempt at fixing or correction. However, such remedial strategies may be points of tension.

We follow Zipin et al. in considering emergent aspirations as “imaginings, voicings and agentic impulses towards alternative futures” [61]. In this analysis, we are interested in the way the aspirations of young people with variations in sex characteristics can be read from the accounts of their teen years and their body experiences. We are particularly interested in the way these imaginaries work as discursive devices as well as “having effects on the things people do to their bodies” and the things done to the bodies of people with variations in sex characteristics “to enable them to be recognised within such imaginaries” [50]. The research participants express varying degrees of agency as they reflect on their relationship with the body and medical intervention.

4. Conclusions

The period between childhood and adulthood is typically a time when social norms are experienced as particularly important, and the possibility of bodily autonomy comes into focus. This is intersectionally differentiated for young people with variations in sex characteristics. While aspiring to greater autonomy broadly may be relevant for young people in general, in the case of young people with a variation in sex characteristics this process may become focused around bodily changes that are mediated by medical interventions. Any medical process involves monitoring and control, with parents and health professionals playing key roles, and has implications for a young person’s aspirations and sense of autonomy. Some medical processes may be understood as part of the bodywork that is undertaken with a view to bringing the body into line with social norms. This work can compound the bodywork pressures and demands that young people normally experience. Like McLaughlin and Coleman-Fountain, we found that there are “forms of

embodied, relational agency at work as [the young research participants] draw medical practices into the versions of self-hood they are developing” [50].

The data we analysed for this article position choice and control over young bodies with variations in sex characteristics as particularly complex. Here, there are no simple binaries. Rather, the young people’s stories often suggest that free and rational control and choice (i.e., the neoliberal ideal), and notions of body fixity, are illusory and bound by societal norms and expectations. The bodywork that young people with variations in sex characteristics therefore perform plays out in spaces where their aspiration to conform to neoliberal ideals of control and choice sits in tension with an alternative view that all bodies fluctuate and are also worked on by society: bodies are work and are worked on by individuals and society at the same time. The experiences of young people with variations in sex characteristics tell a story about not only their bodies and aspirations but about bodies and aspirations more generally. This is what makes the present research pertinent in the context of queer youth studies particularly and youth studies generally. All bodies disrupt the notion that they are fixed (and/or can be fixed to a particular norm). Despite the bodily aspirations young people might have, bodies are unruly and developmental progression is not simply natural or linear.

Neoliberal societies are saturated with assumptions about individuals making free choices, and these assumptions are deeply embedded in young people’s aspirations. The young people in this study demonstrate the point that aspirations are “always formed in interaction and in the thick of social life” [62]. It is no surprise that, for young people with medically diagnosed variations, medically mediated bodily processes are almost unavoidably part of the context within which aspirations are forged.

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References

1. Roen, K. Intersex/DSD. In *The Palgrave Handbook of the Psychology of Sexuality and Gender*; Barker, M.J., Richards, C., Eds.; Palgrave: Basingstoke, UK, 2015; pp. 183–197.
2. Carmichael, P.; Alderson, J. Psychological care in disorders of sexual differentiation and determination. In *Paediatric and Adolescent Gynaecology*; Balen, A., Ed.; Cambridge University Press: Cambridge, UK, 2004; pp. 158–178.
3. Cools, M.; Nordenström, A.; Robeva, R.; Hall, J.; Westerveld, P.; Flück, C.; Köhler, B.; Berra, M.; Springer, A.; Schweizer, K.; et al. Caring for individuals with a difference of sex development (DSD): A Consensus Statement. *Nat. Rev. Endocrinol.* **2018**, *14*, 415–429. [[CrossRef](#)] [[PubMed](#)]
4. Ahmed, S.F.; Achermann, J.C.; Arlt, W.; Balen, A.; Conway, G.; Edwards, Z.; Elford, S.; Hughes, I.A.; Izatt, L.; Krone, N.; et al. Society for Endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development (Revised 2015). *Clin. Endocrinol.* **2016**, *84*, 771–788. [[CrossRef](#)] [[PubMed](#)]
5. Lupton, D. Infant embodiment and interembodiment: A review of sociocultural perspectives. *Child. Cph.Den.* **2013**, *20*, 37–50. [[CrossRef](#)]

6. Chase, C. Surgical Progress is Not the Answer to Intersexuality. *J. Clin. Ethics* **1998**, *9*, 385–392. [CrossRef] [PubMed]
7. Holmes, M. Queer Cut Bodies. In *Queer Frontiers: Millennial Geographies, Genders, and Generations*; Boone, J.A., Martin, D., Martin, M., Karin, Q., Cindy, S., Debra, S., Rosemary, W., Eds.; The University of Wisconsin Press: Madison, WI, USA, 2002; pp. 84–110.
8. Morland, I. Intimate Violations: Intersex and the Ethics of Bodily Integrity. *Fem. Psychol.* **2008**, *18*, 425–430. [CrossRef]
9. Davis, G. *Contesting Intersex: The Dubious Diagnosis*; New York University Press: New York, NY, USA, 2015.
10. Carpenter, M. The “normalization” of intersex bodies and “othering” of intersex identities in Australia. *J. Bioethical Inq.* **2018**, *15*, 487–495. [CrossRef]
11. Holmes, M. (Ed.) *Critical Intersex*; Ashgate Farnham Surrey: Farnham, UK, 2009.
12. Greenberg, J.A. *Intersexuality and the Law: Why Sex Matters*; NYU Press: New York, NY, USA, 2012.
13. Garland, F.; Travis, M. Making the State Responsible: Intersex Embodiment, Medical Jurisdiction, and State Responsibility. *J. Law Soc.* **2020**, *47*, 298–324. [CrossRef]
14. Roen, K. “But We Have to Do Something: ‘Surgical’ Correction” of Atypical Genitalia. *Body Soc.* **2008**, *14*, 47–66. [CrossRef]
15. Roen, K.; Creighton, S.M.; Hegarty, P.; Liao, L.-M. Vaginal construction and treatment providers’ experiences: A qualitative analysis. *J. Pediatr. Adolesc. Gynecol.* **2018**, *31*, 247–251. [CrossRef]
16. Roen, K.; Hegarty, P. Shaping parents, shaping penises: How medical teams frame parents’ decisions in response to hypospadias. *Br. J. Health Psychol.* **2018**, *23*, 967–981. [CrossRef]
17. Kessler, S.J. *Lessons from the Intersexed*; Rutgers University Press: New Brunswick, NJ, USA, 1998.
18. Karkazis, K. *Fixing Sex: Intersex, Medical Authority, and Lived Experience*; Duke University Press: Durham, NC, USA, 2008.
19. Liao, L.-M.; Wood, D.; Creighton, S.M. Parental choice on normalising cosmetic genital surgery: Between a rock and a hard place. *BMJ* **2015**, *351*, h5124. [CrossRef] [PubMed]
20. Liao, L.-M.; Hegarty, P.; Creighton, S.; Lundberg, T.; Roen, K. Clitoral surgery on minors: An interview study with clinical experts of differences of sex development. *BMJ Open* **2019**, *9*, e025821. [CrossRef] [PubMed]
21. Liao, L.-M. *Variations in Sex Development: Medicine, Culture and Psychological Practice*; Cambridge University Press: Cambridge, UK, 2022. [CrossRef]
22. Creighton, S. Long-term sequelae of genital surgery. In *Paediatric and Adolescent Gynaecology*; Balen, A., Ed.; Cambridge University Press: Cambridge, UK, 2004.
23. Michala, L.; Liao, L.-M.; Wood, D.; Conway, G.S.; Creighton, S.M. Practice changes in childhood surgery for ambiguous genitalia? *J. Pediatr. Urol.* **2014**, *10*, 934–939. [CrossRef] [PubMed]
24. Kipnis, K.; Diamond, M. Pediatric ethics and the surgical assignment of sex. *J. Clin. Ethics* **1998**, *9*, 398–410. [CrossRef] [PubMed]
25. Lundberg, T.; Roen, K.; Hirschberg, A.L.; Frisén, L. “It’s part of me, not all of me”: Young women’s experiences of receiving a diagnosis related to diverse sex development. *J. Pediatr. Adolesc. Gynaecol.* **2016**, *29*, 338–343. [CrossRef] [PubMed]
26. McCauley, E. Challenges in educating patients and parents about differences in sex development. *Am. J. Med. Genet.* **2017**, *175*, 293–299. [CrossRef]
27. Ernst, M.E.; Sandberg, D.E.; Keegan, C.; Quint, E.H.; Lossie, A.C.; Yashar, B.M. The lived experience of MRKH: Sharing health information with peers. *J. Pediatr. Adolesc. Gynecol.* **2016**, *29*, 154–158. [CrossRef]
28. Alderson, J.; Roen, K.; Muscarella, M. Psychological care and evaluation in pediatric and adolescent gynecology practice. In *Pediatric and Adolescent Gynecology: A Problem-Based Approach*; Creighton, S.M., Balen, A., Breech, L., Liao, L.-M., Eds.; Cambridge University Press: Cambridge, UK, 2018; pp. 150–157.
29. Steers, D.M.; Andrews, G.L.; Wiltshire, E.J.; Ballantyne, A.J.; Collings, S.C.; Stubbe, M.H. Young people with a variation in sex characteristics in Aotearoa/New Zealand: Identity, activism and healthcare decision-making. *Cult. Health Sex.* **2021**, *23*, 457–471. [CrossRef]
30. Pinto, P.; Macleod, C.I. *A Genealogy of Puberty Science: Monsters, Abnormals, and Everyone Else*; Routledge: Oxfordshire, UK, 2019. [CrossRef]
31. Intersex Youth Aotearoa. A Support Guide for Parents of Intersex Rangatahi [Youth]. Available online: <https://simplebooklet.com/yourchildisataongaforparentsofintersexyouth#page=9> (accessed on 2 March 2023).
32. Dreger, A. *Intersex in the Age of Ethics*; University Publishing Group: Hagerstown, MD, USA, 1999.
33. Carmichael, P.; Ransley, P.G. Telling Children about a Physical Intersex Condition. *Dialogues Pediatr. Urol.* **2002**, *25*, 7–8.
34. McLaughlin, J.; Coleman-Fountain, E.; Clavering, E. *Disabled Childhoods: Monitoring Differences and Emerging Identities*; Routledge: Oxfordshire, UK, 2016. [CrossRef]
35. O’Dell, L.; Bertilsdotter-Rosqvist, H.; Brownlow, C. *Different Childhoods Non/Normative Development and Transgressive Trajectories*, 1st ed.; Taylor and Francis: London, UK, 2017. [CrossRef]
36. Coffey, J. *Body Work: Youth, Gender and Health*; Routledge: Oxfordshire, UK, 2016. [CrossRef]
37. Coffey, J. *Everyday Embodiment: Rethinking Youth Body Image*; Palgrave Macmillan: London, UK, 2017.
38. Stanley-Clarke, N. Key ideologies: The theories of social policy. In *Social Policy for Social Work and Human Services in Aotearoa New Zealand Diverse Perspectives*; Maidment, J., Beddoe, J., Eds.; Canterbury University Press: Christchurch, New Zealand, 2016; pp. 48–63.
39. Kjørholt, A.T. Childhood as Social Investment, Rights and the Valuing of Education. *Child. Soc.* **2013**, *27*, 245–257. [CrossRef]
40. Burman, E. *Deconstructing Developmental Psychology*, 3rd ed.; Routledge: Oxfordshire, UK, 2017.

41. Bordo, S. *Unbearable Weight: Feminism, Western Culture, and the Body*; University of California Press: Berkeley, CA, USA, 2003.
42. Huijsmans, R.; Ansell, N.; Froerer, P. Introduction: Development, Young People, and the Social Production of Aspirations. *Eur. J. Dev. Res.* **2021**, *33*, 1–15. [[CrossRef](#)] [[PubMed](#)]
43. Liao, L.-M.; Roen, K. The role of psychologists in multi-disciplinary teams for intersex/diverse sex development: Interviews with British and Swedish clinical specialists. *Psychol. Sex.* **2021**, *12*, 202–216. [[CrossRef](#)]
44. Lundberg, T.; Roen, K.; Kraft, C.; Hegarty, P. How young people talk about their variations in sex characteristics: Making the topic of intersex talkable via sex education. *Sex Educ.* **2021**, *21*, 552–567. [[CrossRef](#)]
45. Braun, V.; Clarke, V. *Thematic Analysis: A Practical Guide*; Sage: Newcastle upon Tyne, UK, 2022.
46. Lundberg, T. Becoming ‘unstuck’ among positionalities, terms and disciplines via conversation (with myself): Exploring potentials for affective reflexivity in critical intersex studies. In *The Politics and Ethics of Representation in Qualitative Research*; Agarwal, P., Djampour, P., Farsakoglu, E., Kolankiewicz, M., Eds.; Routledge: Oxfordshire, UK, 2021; pp. 9–29.
47. Braun, V.; Clarke, V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qual. Res. Psychol.* **2021**, *18*, 328–352. [[CrossRef](#)]
48. Joy, E.; Braun, V.; Clarke, V. Doing reflexive thematic analysis: A reflexive account. In *Research Methods for Education and the Social Disciplines in Aotearoa New Zealand*; Meyer, F., Meissel, K., Eds.; NZCER Press: Wellington, New Zealand, 2023; pp. 155–171.
49. Lundberg, T.; Hegarty, P.; Roen, K. Making sense of ‘Intersex’ and ‘DSD’: How laypeople understand and use terminology. *Psychol. Sex.* **2018**, *9*, 161–173. [[CrossRef](#)]
50. McLaughlin, J.; Coleman-Fountain, E. The unfinished body: The medical and social reshaping of disabled young bodies. *Soc. Sci. Med.* **2014**, *120*, 76–84. [[CrossRef](#)]
51. Morland, I. What can queer theory do for intersex? *GLQ J. Lesbian Gay Stud.* **2009**, *15*, 285–312. [[CrossRef](#)]
52. Tankersley, A.P.; Gafsky, E.L.; Dike, J.; Jones, R.T. Risk and Resilience Factors for Mental Health among Transgender and Gender Nonconforming (TGNC) Youth: A Systematic Review. *Clin. Child Fam. Psychol. Rev.* **2021**, *24*, 183–206. [[CrossRef](#)] [[PubMed](#)]
53. Budgeon, S. Theorizing Subjectivity and Feminine Embodiment: Feminist Approaches and Debates. In *Handbook of Children and Youth Studies*; Wyn, J., Cahill, H., Eds.; Springer: Singapore, 2015; pp. 1–12. [[CrossRef](#)]
54. McLaughlin, J. The medical reshaping of disabled bodies as a response to stigma and a route to normality. *Med. Humanit.* **2017**, *43*, 244–250. [[CrossRef](#)]
55. Shilling, C. *The Body in Culture, Technology and Society*; SAGE: London, UK, 2005.
56. Skilling, P. Collective desolation, individual consolations: Contours of everyday neoliberal subjectivities. *Crit. Policy Stud.* **2019**, *15*, 55–73. [[CrossRef](#)]
57. Rose, N. *Governing the Soul: The Shaping of the Private Self*, 2nd ed.; Free Association Books: London, UK, 1999.
58. Coffey, J.; Watson, J. Bodies: Corporeality and Embodiment in Childhood and Youth Studies. In *Handbook of Children and Youth Studies*; Wyn, J., Cahill, H., Eds.; Springer: Singapore, 2015; pp. 1–13. [[CrossRef](#)]
59. Stritzke, N.; Scaramuzza, E. Trans*, intersex, and the question of pregnancy: Beyond repronormative reproduction. In *Transgender and Intersex: Theoretical, Practical, and Artistic Perspectives*; Horlacher, S., Ed.; Springer: Berlin/Heidelberg, Germany, 2016; pp. 141–163.
60. Butler, J. *Undoing Gender*; Routledge: New York, NY, USA, 2004.
61. Zipin, L.; Sellar, S.; Brennan, M.; Gale, T. Educating for Futures in Marginalized Regions: A sociological framework for rethinking and researching aspirations. *Educ. Philos. Theory* **2015**, *47*, 227–246. [[CrossRef](#)]
62. Appadurai, A. The capacity to aspire: Culture and the terms of recognition. In *Culture and Public Action*; Rao, V., Walton, M., Eds.; Stanford University Press: Stanford, CA, USA, 2004; pp. 59–84.

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