

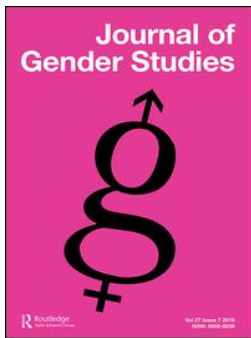
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## 'We just want the best for this child': contestations of intersex/DSD and transgender healthcare interventions

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### ABSTRACT

Intersex/DSD and transgender healthcare for children and adolescents has increasingly become a topic for public and academic debate. Key contestations concern early healthcare interventions in intersex/DSD care and 'cautious gatekeeping' in transgender care. With this article, which is based on an integrative literature review and expert interviews, we offer more insight into these debates, by mapping and comparing the arguments used by different stakeholders in both fields. Our analytical comparison of the debates reveals that contradictory perceptions of gender, the malleability of bodies and the autonomy of children/adolescents guide the arguments. While medical and psychological research may provide valuable input to further the debates, they remain inherently ethical and interwoven with gendered norms and expectations. This necessitates critical inter- and multidisciplinary conversations both in healthcare and in academic research.

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Intersex/DSD; transgender; healthcare; children; adolescents

## Introduction

Healthcare professionals are powerful actors in defining and 'managing' sex/gender variations in western countries, but their views and practices are increasingly challenged (Bakker, 2018; Dreger, 1998; Karkazis, 2008; Lundberg, 2017; van Heesch, 2015).

For instance, since the mid-twentieth century, surgery and other healthcare interventions such as certain hormonal treatments have been performed on children with 'atypical' sex characteristics in order to 'normalize' their bodies, but this protocol is being questioned by experiential experts (those whose expertise is based on their own personal experiences, and their proxies), advocates, activists, academics, and healthcare professionals themselves (Carpenter, 2018; Karkazis, 2008; van Heesch, 2015). Also, international organizations including the European Union Agency for Fundamental Rights (FRA),<sup>1</sup> the European Parliament and the United Nations have issued statements against these 'normalizing' procedures (Liao, Wood, & Creighton, 2015).

While healthcare interventions are increasingly criticized in relation to intersex/DSD<sup>2</sup> care, it is the *lack* of access to such interventions that is at the heart of the debate about transgender care (Davis,

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Dewey, & Murphy, 2016). Especially access to somatic healthcare may be difficult for transgender people, because it must be negotiated with healthcare professionals such as psychologists and psychiatrists (Davis et al., 2016; Gerritse et al., 2018; Whitehead, Thomas, Forkner, & LaMonica, 2012). This has received criticism from different parties including academics (for example, Ashley, 2019).

Based on an interdisciplinary approach, this article explores these contestations of present-day intersex/DSD and transgender healthcare for children and adolescents. We map the arguments used in academic literature and by different stakeholders to challenge, or defend, key elements of intersex/DSD and transgender healthcare.

Connecting these two fields enables us to demonstrate how stakeholders base their arguments on different, sometimes contradictory perceptions of gender, the malleability of bodies, and the autonomy of children/adolescents. While the article focuses on the Dutch context, the analysis engages with international (especially European and North American) debates.

## Methods

This article is based on an integrative literature review and in-depth qualitative expert interviews. For the literature review, we explored how authors from different fields (medical sciences, psychology, social sciences, philosophy, gender studies and queer studies) evaluate present-day intersex/DSD and transgender care and which arguments they use to challenge or defend current practices. Rather than systematically analysing all studies concerning one specific clinical question, as is the aim of systematic reviews, we critically explored the main ideas and contestations regarding a particular phenomenon, which is characteristic of the integrative review (Snyder, 2019).

We searched for literature that explicitly dealt with contestations of intersex/DSD healthcare (especially early interventions on babies and children), and transgender healthcare (especially access to healthcare interventions). We used RUQuest, a Radboud University search engine that searches almost 300 databases, including Web of Science, ScienceDirect, PubMed and JSTOR. We used the keywords intersex, DSD, differences/disorders of sex development and transgender, in combination with the term healthcare and more specific keywords such as early interventions, outcomes, gate-keeping, desistance, social media, gender identity, ethics and dilemmas. Moreover, we used the reference lists of publications to find other publications. In addition to academic literature, articles and reports from key stakeholders such as advocacy groups were analysed. By creating an interaction between multiple academic disciplines, and between academic and non-academic sources, we were able to perform a critical analysis of current debates.

Our literature review is limited to texts written in English or Dutch, which means that critical texts from the non-Anglo-Saxon scientific community were excluded. Moreover, as is argued by Whittemore and Knafl (2005), bias can occur in literature reviews, as the selection of literature may be incomplete and the analysis inaccurate. In order to enhance the rigour of our review, we used four types of 'hard' triangulation, which is characterized by the challenging and testing of findings (Turner & Turner, 2009). We deliberately searched for counter-arguments to the arguments that we found earlier, aiming to map contestations rather than to merge different perspectives or take positions.

First, we used methodological triangulation, combining literature review with in-depth expert interviews. In-depth interviews provided us with data to deepen our analysis by discussing arguments from the literature with experts. We interviewed 10 experts in eight interviews. All interviewees have been anonymized. They are referred to by a number (1–10), field of expertise (I for intersex/DSD, T for transgender) and role as healthcare professional (H), advocate/activist (A) and/or experiential expert (E).

Secondly, we used data triangulation: we obtained data from different sources, not just different types of literature (different academic fields; academic and non-academic sources), but also different 'types' of experts, namely healthcare professionals, advocates/activists and experiential experts.

Third, we used investigator triangulation where the selection and interpretation of literature was discussed among the six authors of the article and their colleagues (see acknowledgements).

Finally, we used theoretical triangulation. The authors of the article brought to the table different disciplinary backgrounds, including medical sciences, psychology, social sciences, philosophy, political science, gender studies and queer studies, thus reducing the risk of interdisciplinary bias.

As was confirmed by the Radboudumc ethical committee (dossier number 2020–6794, 8 July 2020), this study does not fall under the scope of the Dutch Medical Research Involving Human Subjects Act (WMO), and does not require ethical approval. Participants provided verbal consent for being interviewed and quoted in any publication that might result from the study. A draft of the present article was sent to all participants, who were invited to comment on the quotes that were used. This resulted in small edits, which contributed to the quotes becoming more precise and sensitive to the complexity of people's experiences.

## Terms and definitions

### *Intersex/DSD*

Even though sex is often regarded as a binary system, the male-female dichotomy does not do justice to the complexity and diversity of human bodies (Fausto-Sterling, 2019; Karkazis, 2019). Different concepts have been used to refer to people with sex characteristics that differ from what is generally understood to be male or female, such as 'atypical' chromosomes (including, XXY, XO, XYY, XYY, see Blackless et al. (2000)), an 'ambiguous' external anatomy and/or 'atypical' combinations of chromosomes, hormones, internal sex structures, gonads and/or external anatomy (such as, a vulva with undescended testes, see Mendoza, Rodriguez-Alcalá, Motos, and Salamanca (2017)). While advocacy groups generally prefer the concept intersex (Johnson et al., 2017; Lundberg, 2017; van Lisdonk, 2014), healthcare providers often use the term disorders of sex development (DSD) that was proposed in the 2006 consensus statement on the medical 'management' of these variations (Hughes et al., 2006).

The latter concept has been contested from the start however, with experiential experts, activists, advocates, human rights organizations, and academic researchers arguing that bodily variations are not pathological disorders, but an expression of human diversity (for example, Carpenter, 2018; Johnson et al., 2017; Lundberg, 2017; van Lisdonk, 2014). Many healthcare professionals and academics still maintain the acronym DSD, but meaning differences or divergence rather than disorders of sex development. Others choose yet other concepts such as variations of sex development (for more elaborate discussions of nomenclature, see Carpenter, 2018; Reis, 2007).

Following van Lisdonk (2014) and Lundberg (2017), in order to enable conversation with both medical and non-medical stakeholders, we will use the term intersex/DSD in this article to refer to (healthcare aimed at) all people whose bodies are considered as 'different' from what is generally understood to be male or female based on their chromosomes, hormones, internal sex structures, gonads and/or external anatomy.

### *Transgender*

People who perceive their gender identities, expressions and/or experiences as not 'matching' the category they were assigned at birth, are usually referred to as transgender. This includes people who want to alter their bodies through hormones and/or surgery (formerly known as transsexuals) and people who do not want to alter their bodies.

Several concepts are used in healthcare contexts to describe and/or diagnose transgender people who apply for healthcare interventions. One of these is gender identity disorder, a term that was used in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-4, 1994, revision 2000), but was replaced in the fifth edition (2013) with gender dysphoria (dysphoria

meaning profound distress) to remove the connotation that transgender people are disordered.<sup>3</sup> The *International Classification of Diseases* (ICD-11) published by the World Health Organization in 2019 employs gender incongruence rather than gender dysphoria, recognizing that not all transgender individuals who search for healthcare interventions suffer from the distress that is regarded as a criterion for gender dysphoria (Drescher, Cohen-Kettenis, & Reed, 2016; Turban & Ehrensaft, 2018).

In this article, the term transgender will be used rather than these diagnostic terms, as transgender is an inclusive concept that enables conversation with both medical and non-medical stakeholders. Since our focus is on access to (somatic) healthcare, we mainly discuss the experiences of transgender people who want to alter their bodies.

### Contestations of intersex/DSD care

Sometimes, intersex/DSD variations are a sign of a life-threatening condition that needs medical evaluation and treatment when a child is born (Ahmed & Rodie, 2010). For instance, a child with salt-wasting congenital adrenal hyperplasia (CAH) will die without hormonal treatment, and even milder types of CAH may result in the development of harmful and potentially deadly conditions such as high blood pressure if not treated with hormones. Other intersex/DSD variations are not life-threatening. In those cases, interventions are not necessary to save the child's life. Over recent years, healthcare professionals have become more reserved about performing (especially irreversible, somatic) interventions on children (2-I-H). Both in the Netherlands and beyond however, early healthcare interventions including surgery and certain hormone treatments such as testosterone and pre-natal dexamethasone treatment are still performed, also on children with intersex/DSD variations that are not life threatening (Human Rights Watch, & InterACT, 2017; Rijk, van Alfen-van der Velden, & Claahsen-van der Grinten, 2017; UN Committee against Torture, 2018). This may be informed by parents' wishes (2-I-H), while experimental research indicates that these wishes are in turn influenced by how professionals frame the situation (Streuli, Vayena, Cavicchia-Balmer, & Huber, 2013).

Key arguments for early healthcare interventions are strongly interwoven with the hegemony of the sex/gender binary. It is argued by different stakeholders that it may be important for children's development to have a physical anatomy that is consistent with current understandings of sex/gender; that such an anatomy improves later chances of having satisfying (heteronormative) sex; that 'normalization' will protect children from being bullied or abused; and that physical and psychological healthcare interventions can prevent psychological problems in children and their parents, although there is no compelling evidence to support these claims (for critical reviews, see Gardner & Sandberg, 2018; Roen, 2008; Timmermans et al., 2019).

In this approach, an intersex variation is thus interpreted as a problem that will cause suffering, either because of children's own feelings about their body, or because of other people's responses to that body. In an interview, the parents of a child with 'ambiguous genitals' who was labelled a boy based on other characteristics, recount their worries after their child was born:

What will happen when he grows up? [...] What if he goes out to play with friends and they want to pee against a wall together? [...] What will happen when he gets a relationship? [...] We therefore considered surgery, but eventually decided against it. (4-I-E).

This quote demonstrates how these parents struggled with the finding that their child's anatomy did not 'fit' hegemonic, dichotomous gender categories. They expected this to cause difficulties in the child's future and for that reason, they initially considered surgery.

Especially in cases where a child's body is interpreted as 'mostly male' or 'mostly female', the conclusion is often that rather than being an intersex child, the child is a boy or a girl with a medical 'condition', who may benefit from medical intervention. This is explained by a urologist:

I see a lot of children with different degrees of hypospadias.<sup>4</sup> I believe that if a child has two testicles and a scrotum, and no genetic condition that causes decreased testosterone levels or insensitivity to testosterone,

[...] and genetically it's a boy, then it's a boy with hypospadias. I see no reason to label such a child as intersex. In these cases, we usually decide with the parents for surgery (2-I-H).

This interviewee interprets this hypothetical child as a boy, not an intersex child, because they have many characteristics that are regarded as male. The characteristic that does not 'fit', the child's 'atypical' penis, is then interpreted as a medical problem that can be solved by surgery. A similar argument has been made by experiential experts who argue that their categorization as intersex is incorrect, because they see themselves as men or women, not both or in between (quoted in van Lisdonk, 2017). Some of these people understand their condition as a medical disorder that can be 'solved' in order to prevent future suffering.

With regard to timing, especially of somatic care, it has been argued that *early* intervention is to be preferred over *later* intervention, because if children are still young, they will not remember the intervention and they will start on an unambiguous gender path (Roen, 2008). Early surgery can also have technical advantages over later surgery: 'The tissue is more elastic, it heals faster, there's less infections [...], scars are smoother' (2-I-H) (see also Binet, Lardy, Geslin, Francois-Fiquet, & Poli-Merol, 2016; Hemesath et al., 2019). Furthermore, it is argued that early intervention can be preferable because in some cases there is an increased risk of tumour development in intersex children's gonads, which may easily be overlooked as these are not palpable from the outside. Removing the gonads eliminates this risk. Chances of such malignancies vary from 0.8% to 30%, depending on the specific variation, although these percentages should be used with caution, as data may be biased for various reasons (Pleskacova et al., 2010).

In arguing for early healthcare interventions, some stakeholders bolster their argument by referring to follow-up studies that were conducted mostly among women with congenital adrenal hyperplasia (CAH) who received early genital surgery, and that suggest predominantly positive attitudes among these women towards early surgery (such as, Binet et al., 2016; Fagerholm et al., 2011). Studies such as these have been criticized, however, because of significant non-response and biased questionnaires (Baratz & Feder, 2015). Higher quality follow-up studies among diverse groups of intersex people are therefore needed before claims can be made about experiential experts' views on early surgery.

Those who challenge early interventions are supported by a review done by Nordenström (2015), showing that quantitative follow-up studies about surgical results, sexual function and psychosexual outcome indicate unsatisfactory results in many cases, and the limited number of studies concerning quality of life are inconsistent, with a majority of studies pointing at (mildly) impaired quality of life. Psychosocial outcomes of healthcare interventions have been interrogated as well (Human Rights Watch, & InterACT, 2017; Lundberg, 2017; Timmermans et al., 2019), with patient narratives pointing at the potential psychological harm of multiple operations and repeated genital examinations (Davis & Feder, 2015; Human Rights Watch, & InterACT, 2017).

Mental healthcare for children and parents can be experienced as helpful in medical trajectories and is recommended in guidelines (Bennecke et al., 2015; Hughes et al., 2006; Nordenström, 2015; Sandberg, Gardner, Callens, & Mazur, 2017), but may also be experienced as a burden and may be interpreted by a child as a message that something is wrong with them (Carmichael & Alderson, 2004). Interestingly, the impact and effect of psychosocial interventions is hardly investigated.

Another contentious issue is that the child may eventually not identify with the sex/gender assigned at birth (such as, Liao et al., 2015; Timmermans et al., 2019). This makes especially irreversible healthcare interventions problematic:

In cases where doctors believe that the sex/gender can be determined, they see that as a reason to perform surgery. [...] Let's assume that they are right in 95% of all these cases. [...] Is it okay to perform surgery on 100% of these children, [...] and make 5% of them unhappy? Yes, say doctors. [...] But from a human rights perspective, this is different. Because human rights are individual rights, and if you violate the rights of one child, that's already problematic. Even more so: [...] you take the gamble for each child again, so you don't violate the rights of just those 5%, but of 100% (3-I-AE).

The fact that gender cannot be measured, and the sheer possibility that children will not identify with the sex/gender they are assigned at birth, is thus an important argument for postponing healthcare interventions, especially irreversible interventions. Moreover, even if a person with an intersex/DSD variation identifies with the assigned sex/gender, and is happy about the result, they may disagree with any healthcare intervention having been performed without their consent (Human Rights Watch, & InterACT, 2017).

Several academic and non-academic stakeholders have pointed out that the discussion about the best care for intersex children is hampered by a severe lack of longitudinal data about outcomes (Gardner & Sandberg, 2018; Timmermans et al., 2019). Especially data about people who did *not* undergo interventions are scarce (Liao et al., 2015). This can make decision-making very difficult, says this parent:

We don't know of any stories about children who did not undergo surgery, and how they experience puberty and adulthood, especially in relation to psychological aspects. How they feel now, and whether they are happy that their parents chose not to perform surgery. I really would like to know more about that (S-I-E).

Some information is available however, as several stories are known of people with intersex/DSD variations who did not undergo healthcare interventions and fare well (Carmack, Notini, & Earp, 2016; Dreger, 1998, 1999; Mak, 2012). Recent evidence indicates for instance that many individuals with hypospadias do not experience the difficulties commonly attributed to the condition (Carmack et al., 2016). Human Rights Watch and InterACT (2017), who interviewed parents that rejected early surgery on their children, reported that the children had not faced unusual amounts of bullying or harassment, and were able to go to school, make friends and access healthcare just like other children.

Even if more data about (long-term) outcomes were available, these would always be outdated, since they would refer to interventions undertaken years or even decades ago (Timmermans et al., 2019). Moreover, outcome criteria are often established by healthcare providers, who may adopt different criteria than patients, and patients' feelings about the outcomes may not reflect surgeons' evaluations (Roen, 2008; van de Grift, 2017). The combination of data gaps, obsolescence of data and data bias further complicates the process of clinical decision-making, which leads Timmermans et al. (2019) to argue that until today, decisions remain based to a large extent on normative, binary 'gender imaginaries' and speculative anticipated futures of the child in question.

## Contestations of transgender care

In transgender care, children/adolescents are generally older when they start investigating the options for healthcare interventions, often together with parents/caretakers. According to international guidelines, gender-affirming hormones and surgeries should be available only for youth who are able to give informed consent, generally operationalized as the age of 16 (Coleman et al., 2012; Hembree et al., 2017; Nederlandse Internisten Vereniging, Nederlands Huisartsen Genootschap, Nederlands Instituut van Psychologen, Nederlandse Vereniging voor Kindergeneeskunde, Nederlandse Vereniging voor Obstetrie & Gynaecologie, Nederlandse Vereniging voor Plastische Chirurgie, Nederlandse Vereniging voor Psychiatrie, & Transvisie, 2019). In the Dutch Standards of Care, some surgical interventions are advised to be undertaken only from the age of 18 (Nederlandse Internisten Vereniging, Nederlands Huisartsen Genootschap, Nederlands Instituut van Psychologen, Nederlandse Vereniging voor Kindergeneeskunde, Nederlandse Vereniging voor Obstetrie & Gynaecologie, Nederlandse Vereniging voor Plastische Chirurgie, Nederlandse Vereniging voor Psychiatrie, & Transvisie, 2019). In many countries including the Netherlands, children under 16 can apply for psychological care and, when they reach puberty, for puberty suppression through GnRH analogues. These temporarily halt physical processes associated with the development of typically male or female bodily features (Sherer, Baum, Ehrensaft, & Rosenthal, 2015).



In order to gain access to puberty blockers, hormone replacement therapy and/or surgery, transgender people first have to go through a diagnostic phase, in which a psychologist and/or psychiatrist evaluates their eligibility for treatment. In the Netherlands, this diagnostic trajectory lasts nine to ten months on average (Zorgvuldig Advies & Transvisie, 2019), in addition to current extensive waiting periods.

Because of their crucial role in mediating access to healthcare services, psychologists and psychiatrists in transgender care are often labelled as gatekeepers (Schulz, 2018), a characterization that is confirmed by this psychiatrist: 'You want to be someone who stands by a family's side. [...] But realistically, if we don't agree that a treatment is a good idea, well, then people will not get the treatment' (7-T-H). This approach, where healthcare professionals play a key role in assessing a person's eligibility for treatment, has been labelled cautious gatekeeping (Butler, Wren, & Carmichael, 2019), an issue that only recently became the topic of research (Ashley, 2019).

Underlying cautious gatekeeping may be a specific perception of transgender bodies and identities:

These [puberty blockers, gender affirming hormones, surgery] are medical interventions in an otherwise healthy body. [...] I believe that there is developmental value in letting children grow up the way they are, [...] and not directing them onto a path too easily that also involves, in a later stadium, cutting in a healthy body and transforming them into a patient for the rest of their lives (7-T-H).

This quote exemplifies how transgender children's bodies are constructed as healthy, which turns healthcare interventions into a radical choice (see also Coleman et al., 2012; Dreher et al., 2018). Moreover, the quote reveals an assumption that medical interventions necessarily include surgery ('cutting in a healthy body'), even though this is not always the case. Finally, the quote constructs healthcare interventions as steering children in a certain direction with regard to their gender identity, while refraining from intervening is constructed as the neutral option that allows children to grow up 'the way they are': with the body they were born in.

This conceptualization differs from the views of many transgender people. One interviewee (9-T-AE) explained how for him, his body was extremely problematic, as it did not match his gender identity. Refraining from intervening was not a neutral option that would allow him to 'be who he was'. To the contrary: he felt that he needed healthcare interventions to become the person he had always been. This reflects a conceptualization of the body not as healthy, but as causing psychological suffering. Moreover, it prioritizes a person's own evaluation of their identity over the sex/gender they were assigned at birth.

Reluctance with regard to early healthcare interventions in transgender care may be related to a fear of 'desistance', a contested notion used in medical research to describe gender-nonconforming children who later identify as cisgender and/or decide not to transition (for a critical review, see Temple Newhook et al., 2018). Despite criticism, the notion has been used in studies that are frequently cited to support a 'desistance rate' of approximately 80%. These studies raise several concerns, however. Most notably, research participants who were studied in childhood often displayed various kinds of gender non-conforming behaviour, but never desired bodily alterations, which probably resulted in an overestimation of 'desistance' (Temple Newhook et al., 2018).

A study conducted by Steensma and colleagues (2013) confirmed earlier studies demonstrating that children with more intense cross-gender identifications have a greater chance of persisting gender dysphoria. Steensma and colleagues conclude that 'explicitly asking gender dysphoric children with which sex they identify seems to be of great value in predicting a future outcome' (2013, p. 588). Indeed, this is also what advocates, activists, scientists and experiential experts have emphasized (9-T-AE) (Ashley, 2019).

Another argument in favour of cautious gatekeeping is the potential loss of fertility due to healthcare interventions (8-T-HE). This is a remarkable argument given that until 2004, all European countries required sterilization for transgender people who wanted to legally change

their gender (Dunne, 2017) and in the Netherlands this requirement was abolished only in 2014 (Bakker, 2018). Moreover, while confirming the importance of discussing fertility issues, this advocate and experiential expert states that loss of fertility should not be a reason to withhold care:

Because if you do that, you [...] say that the potential future wish to have a child is more important than what this person is going through right now, which impacts all aspects of someone's life at this very moment (10-T-AE).

Research about transgender people's desire to have children is limited and indicates a discrepancy between adults and adolescents, with the latter expressing a much less pronounced desire for biologically related children (Cheng, Pastuszak, Myers, Goodwin, & Hotaling, 2019). Again, long-term outcomes are scarce, and data will often be obsolete, considering developments in healthcare practices, fertility techniques and social norms regarding fertility.

Yet another argument to defend cautious gatekeeping is that adolescents presumably focus more on short-term satisfaction than on the long-term consequences of their choices (American Psychological Association, 2015), which implies that it is hard or even impossible for children to give informed consent for healthcare interventions. This argument was central to a high-profile UK court case in 2020, where the High Court ruled it 'highly unlikely' that children can understand and weigh the long-term risks and consequences of puberty blockers, especially when they are under 16 (Dyer, 2020). This ruling, which may lead to a situation where prescriptions of puberty blockers have to be authorized by the Court,<sup>5</sup> demonstrates and reproduces an understanding of youth as impulsive and unable to make balanced long-term decisions, a conceptualization that has been challenged (for example, Romer, Reyna, & Satterthwaite, 2017).

Cautious gatekeeping is furthermore defended with the argument that children and adolescents may present with 'co-occurring psychological concerns' (American Psychological Association, 2015) such as autism, which may pose challenges for healthcare interventions (de Graaf & Carmichael, 2019; Strang et al., 2018). Yet, autism may also have positive effects: youth with autistic traits may be less worried about other people's response to their transition and they may have increased treatment adherence related to their strength in following routines (Strang et al., 2018).

In relation to other psychological concerns, psychologists and psychiatrists argue that a certain level of 'psychological stability' should come before transgender healthcare interventions (6-T-H, 7-T-H). Advocates, activists and experiential experts argue that it might work the other way around:

You're trying to solve the depression, while that depression is caused by the fact that your body is developing in a way that is not congruent with how you feel. Or [you're trying to solve] the anxiety disorder, which has developed because you get so many negative reactions, or because you're afraid of getting such reactions. [...] Those problems will only be solved with a social or medical transition (10-T-AE).

This line of reasoning is supported by studies reporting a reduction in psychopathology and higher levels of wellbeing after healthcare interventions, including puberty blockers (American Psychological Association, 2015; Coleman et al., 2012; Costa et al., 2015; de Vries et al., 2014; de Vries, Steensma, Doreleijers, & Cohen-Kettenis, 2011; Heylens, Verroken, De Cock, T'Sjoen, & De Cuypere, 2014; Murad et al., 2010), although information about long-term outcomes is scarce, as will be discussed later.

In terms of physical outcomes, defenders of cautious gatekeeping have argued that physical results may not be as positive as transgender people presumably expect them to be: 'When you look at surgery for instance, and the techniques that we have nowadays, the body will never become like the body of a person who was born like that' (8-T-HE). Such arguments reflect modest expectations with regard to the malleability of bodies.

Scarcity of high-quality information about long-term patient satisfaction and outcomes (Barone, Cogliandro, Di Stefano, Tambone, & Persichetti, 2017) makes it hard to assess potential long-term outcomes of (withholding) healthcare interventions (Vrouenraets, Fredriks, Hannema, Cohen-Kettenis, & de Vries, 2015). Scarce studies about regret indicate that regret about healthcare

interventions is rare (Coleman et al., 2012; de Vries et al., 2014; Wiepjes et al., 2018), also in clinics where clients undergo interventions without in-depth mental health evaluation (Schulz, 2018).

In addition to (limited) research suggesting positive outcomes of interventions, those who challenge cautious gatekeeping have argued that withholding or postponing healthcare interventions may have severe negative consequences for people's physical and psychological well-being (Coleman et al., 2012) and may result in self-medication (van den Boom, 2016), self-surgery (Rotondi et al., 2013) or suicidal ideation and attempts (Bauer, Scheim, Pyne, Travers, & Hammond, 2015).

A different line of argument refers to the role of social media. Defenders of cautious gatekeeping have suggested that social media use may contribute to what was labelled as 'rapid onset of gender dysphoria' in a US article (Littman, 2018). This article was fundamentally flawed in its conceptualization, design and analysis, however (Restar, 2020).

Other authors have described the role of social media in a more nuanced way, explaining how the internet and social media provide young LGBTQI\* people with additional opportunities to explore gender and sexuality (for example, Cho, 2015; de Graaf & Carmichael, 2019; Naezer, Rommes, & Jansen, 2017; Pullen & Cooper, 2010). While this may enable young people to recognize and act upon transgender feelings, it does not mean that they 'become transgender' because of social media, or that the information they find and share is only positive and encouraging. To the contrary: 'I'm really honest, like: a transition is tough, really incredibly tough. I was only able to do it because for me, there was no other option.' (9-T-AE). This interviewee, along with others, actually raises awareness about the *negative* aspects of healthcare interventions. Finally, transphobic online content may hinder rather than encourage young people to identify as transgender and apply for healthcare interventions.

## Conclusions and research agenda

In this article, we explored contestations of intersex and transgender healthcare for children and adolescents, especially early healthcare interventions in intersex/DSD care and cautious gatekeeping in transgender healthcare.

Arguments that are generally used to defend current practices have been challenged, and it has been pointed out that scientific evidence for many of these claims is scarce, biased, inconclusive and/or contradicted by other scientific evidence or personal experiences. Additionally, our analysis has shown that different, sometimes contradictory perceptions of gender, the malleability of bodies and the autonomy of children/adolescents underlie the claims made by defenders and challengers of the status quo.

With regard to *gender*, there is disagreement about whether it is problematic if a body does not 'correspond' with a person's (presumed) gender identity according to hegemonic, binary gender norms. In intersex/DSD care, those who defend early interventions often consider intersex bodies as problematic, while those who challenge these interventions often consider intersex bodies as 'natural variations' that deserve protection against healthcare interventions. In transgender care, defenders of the status quo (including some healthcare professionals) consider bodies of transgender youth to be healthy and in need of protection against medical interventions, while those challenging the status quo argue that bodies may, in fact, be problematic if they do not 'match' a person's gender identity, and that medical interventions may be necessary for people to 'become who they are', namely, the sex/gender with which they identify.

With regard to the *malleability of bodies*, there is disagreement about the meaning of present-day possibilities to alter bodies. In the field of intersex/DSD care, the arguments of those defending the status quo reflect optimism about current possibilities to alter bodies, whereas those challenging the status quo depict these possibilities in a more modest way. In the field of transgender care, both parties seem rather modest about the possibilities to alter bodies, but while defenders of the status quo often seem to interpret this as a reason to be reluctant in providing interventions, those

challenging the status quo seem to remain more positive about the added value of these interventions.

With regard to *children's/adolescents' autonomy*, there is disagreement about the extent to which children/adolescents should have control over healthcare interventions. Both in the field of intersex/DSD care and transgender care, those defending the status quo, most notably healthcare professionals, seem reluctant in giving children and adolescents more control over their healthcare trajectory. Those challenging the status quo argue for more autonomy and self-determination for children and adolescents, both in intersex/DSD and transgender care. These arguments are in line with appeals for the depathologization of transgender identities and intersex bodies.

To some extent, medical and psychological studies about the long-term outcomes of (not) intervening at different ages, can help to further these debates, and this would be an important suggestion for future research. At the same time, these issues are inherently ethical and interwoven with gendered norms and expectations, which necessitates ongoing critical, inter- and multidisciplinary conversations both in healthcare and in academic research.

While this article provides an overview of two key debates about intersex and transgender healthcare, several of the issues that were touched upon would benefit from more extensive explorations. Future research could provide more insight into linkages between the arguments used and broader discussions about children's and adolescents' (perceived) capabilities with regard to decision-making and providing informed consent; about the (perceived) possibilities and responsibilities of healthcare systems; and about socio-cultural norms regarding gender and sexuality. Moreover, more remains to be said about how power relations between actors influence both healthcare practices and debates about these practices. Future research should reflect on the impact of contextual factors on the debates, such as (changes in) funding systems, legal or state structures, or political dynamics. These analyses would benefit from cross-cultural and cross-national comparison, which would offer meaningful insights into the different ways in which gender diversity can be interpreted and responded to within and outside of healthcare contexts.

## Notes

1. [https://fra.europa.eu/sites/default/files/fra\\_uploads/fra-2015-focus-04-intersex\\_en.pdf](https://fra.europa.eu/sites/default/files/fra_uploads/fra-2015-focus-04-intersex_en.pdf).
2. The abbreviation DSD may refer to either 'disorders', 'differences' or 'divergence' of sex development, as will be discussed in the section on terminology and definitions.
3. [https://www.psychiatry.org/File%20Library/Psychiatrists/Practice/DSM/APA\\_DSM-5-Gender-Dysphoria.pdf](https://www.psychiatry.org/File%20Library/Psychiatrists/Practice/DSM/APA_DSM-5-Gender-Dysphoria.pdf).
4. A person with hypospadias has a penis in which the urethral meatus is located in a lower position than is generally the case, in which the shaft may be more or less curved, and the foreskin is less developed. Hypospadias exists in different degrees. In a more 'severe' degree it may be regarded as an intersex/DSD variation (Hughes et al., 2006).
5. For a more elaborate discussion, see <http://www.transparencyproject.org.uk/bell-v-tavistock-in-the-high-court-an-explainer/>.

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