Do Parents Really Know Best? Informed Consent to Sex Assigning and 'Normalising' Treatment of Minors with Variations of Sex Characteristics

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Abstract

This paper aims to explore how pervasive constructions regarding a person's sex and gender identity in society and law limit the human rights of persons with variations of sex characteristics. Societal culture promulgates a binary (male/female) gender ideal which includes standards of normality for our bodies. People who do not easily fit these culturally constructed norms, such as persons with variations of sex characteristics, encounter numerous difficulties. The legal conceptualisation of 'sex' according to the binary maintains the medicalisation of variations of sex characteristics and reinforces the focus on sex 'normalising' treatment of children who are too young to provide their informed consent. The paper makes use of Belgium as an illustration. Not only is comprehensive legal research concerning variations of sex characteristics absent in Belgium, but the country has also been responsive to human rights claims regarding sexual identity in recent years. With regard to the sex assigning or 'normalising' treatment of persons with variations of sex characteristics, this article argues that by accepting the substitution of the child's informed consent for the opinion of the legal representative in the absence of urgent medical necessity, Belgian law fails to protect the former's right to bodily integrity and best interests.

Keywords: variations of sex characteristics, intersex/DSD, sex 'normalising' treatment, personal autonomy, child's best interests

Introduction

Most societies around the globe share cultural norms derived from the simplistic idea of a dichotomy of two mutually exclusive and biologically fixed sexes to whom different roles and behaviour are traditionally ascribed (Butler 1999; Agius and Tobler 2012). Societal culture promulgates a binary gender ideal which includes standards of normality for our bodies and how we think about them (Weiss 2001). People who do not easily fit these culturally constructed norms, such as persons with variations of sex characteristics, encounter numerous difficulties, both at the practical level of everyday life and at the legal level (Agius and Tobler 2012).

This paper focuses on one particular and controversial challenge for persons with variations of sex characteristics, i.e. the legal regulation of their exposure to so-called sex assigning and sex 'normalising' treatment, which can be seen as the dominant cultural response to the 'emergency' caused by the incidence of variations to the binary sex model. It begins by briefly addressing the origins and current practices of these forms of medical treatment. It then moves to explain how these practices are embedded in law and how the law has not been capable of preventing and tackling human rights violations. Finally, it discussed how the law might be reformed in order to respect, protect and fulfil the human rights of persons with variations of sex characteristics.

Throughout tis paper, Belgium's legal system is used as an illustration. Not only is comprehensive legal research concerning variations of sex characteristics absent in Belgium, but the country has also been highly responsive to human rights claims regarding sexual identity in recent years. Moreover, in 2019 Belgium received a clear recommendation by the UN Committee on the Rights of the Child to prohibit the performing of unnecessary medical or surgical treatment on intersex children where those procedures may be safely deferred until children are able to provide their informed consent.[1] In 2020, the UN Committee on Economic, Social and Cultural Rights also expressed concern about practices of unnecessary treatment.[2] Resultantly, the country can be considered 'fertile' ground for studying the human rights of persons with variations of sex characteristics.

While it remains unclear how future reform will look like, it is still useful to analyse the existing legal framework. Indeed, any legislative change will eventually depart from the status quo. Moreover, given the call for a *lex specialis* for treatment on a person's sex characteristics in the absence of medical necessity, thorough knowledge of the existing system's failures is required. Any special regime will arguably benefit from maximum coherence with the general legal framework. Although this paper has a specific territorial focus, research in other national contexts can benefit from its findings. After all, persons with variations of sex characteristics face similar difficulties in most (Western) legal systems (Monro, Crocetti and Yeadon-Lee 2019).

Sex, Variations of Sex Characteristics and Binary Normativity

The Sociocultural Construction of 'Sex'

Sex is generally seen as a biological concept of a factual nature, determined by the

presence of a certain configuration of X and Y-chromosomes, hormones, gonads, internal morphology, genitalia and secondary characteristics in an individual (Silver 2014). Although genitalia are only one of the constituting elements of a person's sex, they are usually decisive for determining that person's sex at birth (Greenberg 1999). Sex is most usually interpreted as a person's biological status as either male or female, and hence as a binary concept (Reeves 2009). However, advances in science, as well as the experiences of individuals with variations of sex characteristics reveal that sex is much more nuanced than the binary categories would have us believe (Clark Hofman 2012).[3] While sex characteristics are congruent for most individuals, this is not the case for millions of people around the globe (Greenberg 1999).

Careful considerations of all biological elements of sex suggest that the idea of the concept as a strictly delimited binary is a social construct, informed and defined by cultural ideas of binary gender identity, gender expression and gender role (Clark Hofman 2012), and therefore not a pre-discursive notion that is fixed on individuals (Butler 1999). Importantly, cultural assumptions about the existence of only male and female gender identities map onto our biological bodies, resulting in (external) genitalia becoming a crucial part of difference and identity (Callens 2014). It is inaccurate to think of the body as already fixed by biology which is then interpreted culturally: once it is understood that bodies are also socially produced, then manifold creative possibilities for the expression of gender identity, desire and sexuality can surface (Otto 2016). Sex thus constitutes a social construct and is a regulatory ideal which, together with the binary notions of 'men' and 'women', instructs subjects to perceive themselves, despite their unique physical features, as either female or male and consequentially to behave womanly or manly (i.e. in line with predefined gender identities) in order to live up to their sexed nature (Weiss 2001). As Wilchins (1997) so fittingly states: 'Sex is what culture makes when it genders my body'.

The Cultural and Medical Emergency of Variations of Sex Characteristics

Diverging definitions and sources of identification of variations of sex characteristics compromise a clear-cut quantification of their prevalence (Dickens 2018). Nevertheless, between at least 0.05 (Monro et al. 2017) and four percent (Fausto-Sterling 1993) of the population is considered to have some variation of sex characteristics, which includes variants of sex chromosomes (e.g. Klinefelter Syndrome and Turner Syndrome), variants of hormonal composition (e.g. Androgen Insensitivity Syndrome), 'ambiguous' genitalia (e.g. micropenis, Congenital Adrenal Hyperplasia), variants of internal morphologic sex (e.g. Persistent Müllerian Duct Syndrome), or gonadal variants (e.g. ovotestes). For Belgium, this prevalence is for instance equivalent to the total number of twins in the current population (Callens, Motmans and Longman 2017). Some variations, including hypospadias, are not always considered to be an intersex condition, hence the variation in figures (Monro et al. 2017).

While the existence of persons with variations of sex characteristics refutes society's cultural binary ideal, it is important to state that the majority of people with this range of conditions still identify within the binary, i.e. as a man or woman (Richards et al. 2016). Although some persons with variations of sex characteristics voluntarily seek treatment on their sex characteristics for aesthetic, cultural or social reasons, others do not support surgical intervention (MacKenzie et al. 2009).

Variations of sex characteristics cannot be explained satisfactorily under the essentialist binary theory of sex, revealing inner contradictions in the theoretical framework (Weiss 2001). The dominant approach has therefore consisted of surgically or hormonally modifying the 'abnormality' shortly after birth, or sometimes during adolescence, to bring the individual concerned in accordance with the binary, enforcing the bipolar duality of sex and gender (Garland and Travis 2018). Persons with variations of sex characteristics have thus routinely been subjected to medical and surgical sex assigning and/or 'normalising' treatments without their personal prior and fully informed consent, even though they do not usually face actual health problems due to their status (Fox and Thomson 2017).

Sex assigning/'normalising' treatment of persons with variations of sex characteristics has also been embedded in societal heteronormativity and rigid cultural gender stereotypes (Monro et al. 2017). Treatment goals include the reduction of anxiety by enabling children to conform to gender norms and cultural expectations (Council of Europe Committee on Bioethics 2017), such as the ability and social need for boys to stand while urinating. According to Garland and Diamond (2018, 86), three interwoven ambitions were sought on the basis of this medical policy:

> '(1) bring the genital appearance in line with the assigned gender in order to facilitate the acceptance of the child […] in the social environment; (2) minimise the occurrence of later body image problems and gender doubts of the child through gender-appropriate-rearing; and (3) provide the capacity for penile-vaginal intercourse in adulthood'.

Studies of non-treated persons with variations of sex characteristics provide evidence that they do not necessarily suffer from the psychological harms assumed to follow from the lack of medical intervention (Travis 2015). Moreover, there is no conclusive research showing that early, medically unnecessary, surgery is helpful to the child with variations of sex characteristics (Scherpe 2018; Brussels Collaboration on Bodily Integrity 2019). Indeed, recent qualitative research based on interviews with persons with variations of sex characteristics indicated that cosmetic genital surgeries on children have no certifiable benefit and instead often contribute to long-term mental and physical health problems (Garland and Travis 2018).

In 2005-06, criticism of the medical model for dealing with variations of sex characteristics prompted an international symposium in Chicago involving clinicians, researchers and advocacy groups, which resulted in a consensus statement containing new guidelines in the form of the Consensus Statement on the Management of Intersex Disorders, or the 'Chicago Consensus', that remains the benchmark for the medical management of variations of sex characteristics until today (Kennedy 2016). The Statement calls for more caution with regard to early genital surgery on children and represents the medical community's retreat from the belief that a child's psychosexual development is determined by its genitalia and gender assigned by the child's doctor and parents (White 2014). However, there are numerous indications that the recommendations are not implemented in practice (Monro, Crocetti and Yeadon-Lee 2019), including in Belgium (Callens, Motmans and Longman 2016). Although a 2016 update to the Chicago Consensus noted that physicians should be aware that there has been a movement in recent years among legal and human rights bodies to increasingly

emphasise the importance of maintaining patient autonomy (Lee et al. 2016), it did not recommend a cessation of sex assigning/'normalising' treatment on children with variations of sex characteristics. Moreover, expert statements have neither sufficiently addressed scientific uncertainty concerning the criteria for sex/gender assignment – and their respective weight – nor the legal implications of wrongful assignment or the non-consensual medical interventions to reinforce such assignment (Garland and Diamond 2018).

Despite the fact that most medical treatment of children born with a variation of sex characteristics is socially motivated, some early interventions are life-saving and necessary, for example if a baby is born without the capacity to urinate or if immediate hormonal treatment is required (as in the case with variations of Congenital Adrenal Hyperplasia (CAH)) (Monro et al. 2017). However, life-saving treatment may also be complemented with cosmetic treatment, such as vaginal construction and dilation. Although, for instance, many parents consent to 'normalising' vaginal surgery in order to have their child conform to sociocultural expectations about female genitalia, clitoral reduction and/or clitoroplasty can greatly reduce or eliminate sexual sensation in the future adult, and can contribute to sexual difficulties (Monro et al. 2017). Moreover, as Monro et al. (2017) point out, five to ten per cent of children with CAH define themselves as men when they are older. Early non-consensual and irreversible treatment may therefore become even more problematic in the light of the child's developed gender.

Variations in sex characteristics and human rights

Indicative of shortcomings in the social and legal 'response' to variations of sex characteristics is the heightened attention for the matter with (international) institutional human rights actors. Indeed, several United Nations bodies have expressed concerns about non-consensual treatment of persons with variations of sex characteristics and have increasingly called for specific legislative measures explicitly prohibiting the performance of deferrable surgical and other medical treatment on children with variations of sex characteristics until they reach an age when they can provide their free, prior and informed consent.

The same concern regarding the need to better guarantee the human rights of persons with variations of sex characteristics – and especially their autonomy rights – can also be found among European institutional human rights actors. Importantly, in October 2017, the Council of Europe Parliamentary Assembly adopted a comprehensive and ground-breaking resolution "Promoting the Human Rights of and Eliminating Discrimination against Intersex People".[4] The resolution recognised the serious breaches of physical integrity for children or infants with variations of sex characteristics who (have to) undergo non-consensual, medically unnecessary sex assigning/normalising treatment, based on considerations of 'social emergency'. The Parliamentary Assembly therefore called for a legal prohibition of medically unnecessary sex normalising surgery, sterilisation and other treatments practised on children with variations of sex characteristics without their informed consent.

As Jones (2017) holds, the most important human rights standards concerning children's health and well-being, and children's rights generally, are to be found in the Convention on the Rights of the Child. Many provisions of the Convention

apply to the situation of children with variations of sex characteristics. The principle that the best interest of the child is to be the primary consideration in decisions affecting children is included in Article 3. Article 19 protects the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child. The Committee of the Rights of the Child, a body consisting of experts that monitors the implementation of the CRC by States parties, has repeatedly considered in various country specific reports that non-consensual, non-emergency, invasive and irreversible surgical and hormonal interventions in children with variations of sex characteristics are harmful and in violation of the rights of the child.[5]

Sex Assigning and 'Normalising' Treatment under Belgian Law

The medicalisation of persons with variations of sex characteristics has traditionally placed these issues within the private sphere and outside of public concern (Garland and Travis 2018). Nevertheless, as set out in the previous section, it is clear that medical treatment on the sex characteristics of persons with variations of sex characteristics, especially when performed without their personal, free, prior and informed consent, comes within the scope of their human rights, and therefore State responsibility (Office of the United Nations High Commissioner for Human Rights 2015).

It is therefore important to analyse and evaluate how the law enables or prevents these medical interventions. Whereas much scholarly attention goes to evaluating medical practice as such in light of international human rights law, this contribution analyses how a legal framework that conform to general human rights standards on bodily integrity still effectively fails to protect and respect the human rights and best interests of children with variations of sex characteristics. As mentioned above, this paper will make use of Belgian law as illustration.

The following subsections will first describe the Belgian legal framework regarding informed consent to medical treatment. This framework will subsequently be evaluated from a human rights perspective, predominantly focusing on the right to personal autonomy of persons with variations of sex characteristics and the protection of the best interests of minors with variations of sex characteristics. Respect for a child's personal autonomy and the protection of its best interests are closely related. As Fox and Thomson (2017) – based on the work of Feinberg (1980) – set out, protecting the child's best interests in relation to bodily integrity entails postponing serious and final commitments until the child is mature and legally capable of autonomously making the decision themselves. The analysis will be informed by the sociocultural understandings of sex and binary normativity set out in the first part of this article.

Informed Consent to Medical Treatment of Minors in Belgian Law

It is a well-known rule of biomedical ethics that biomedical treatment may only be carried out after a patient has been informed of the purpose, nature, risks and possible consequences of the intervention, and has freely consented to it (Dunne 2018). Indeed, informed consent changes what would otherwise be a violation of fundamental rights into a legitimate medical intervention (Silver 2014). This principle of free, prior and informed consent regarding medical treatment can be found in Belgian law, more

specifically in the Patients' Rights Act of 22 August 2002.[6] According to Belgian law, a person comes of age when they turn eighteen years old. Until that moment, a person does not have the legal capacity to act alone and will be legally represented by their parents or guardian. Therefore, although a minor is bearer of rights from birth, those rights will be exercised by the parents/legal guardian until that person comes of age, even when the situation concerns personality rights. In the medical context, this means that minors will not necessarily personally exercise their right to provide free, prior and informed consent.

Belgium does not have any legislation directly dealing with sex assigning/'normalising' treatment of persons with variations of sex characteristics and the necessity of informed consent in that regard. The most specific applicable norm is the abovementioned Patients' Rights Act. According to Article 2 of the Act, a patient is any natural person who receives medical treatment, whether at their own request or not. It is clear that persons with variations of sex characteristics who receive medical treatment on their sex characteristics – with or without their personal informed consent – fall within the scope of this provision. The combination of various provisions of the Act clearly sets out that patients have the principal right to choose whether they give their informed consent to treatment or not.

Article 12 of the Patients' Rights Act holds a system of representation of minors in the medical context. When the provision is read together with the general definition of a 'patient' *ex* Article 2, one learns that, although minors who receive medical treatment are considered to be patients and therefore bearers of rights, they are not (automatically) granted the autonomy to exercise those rights. However, by derogation from the general rules on the (absence of) legal capacity during minority, some minors are considered to be capable of making a reasonable assessment of their interests in cases of medical treatment. Yet even when minors can be considered sufficiently capable of doing so, Article 12 of the Act only foresees a possibility that they act independently to provide informed consent to the medical treatment concerned (Lemmens 2014). In all other cases, the rights of minors are exercised by the legal representative(s), with involvement of the minor, taking into account their age and maturity. Thus, when interpreting Article 12 of the Act, there are three stages in a minor's (medical) life (Lemmens 2014):

- In a first stage, the minor is incompetent to provide an informed opinion (e.g. new-born children). The legal representative will fully exercise the rights on behalf of the minor, taking into account their best interests;
- In a second stage, the minor is able to form and express an informed opinion, although not sufficiently to act alone (e.g. most ten-year-old children). The legal representative still exercises the minor's rights, although in cooperation with the latter;
- In a third stage, the minor has acquired the capacity to exercise rights independently from the legal representative (e.g. seventeen-year-old minors). The latter will nevertheless *de facto* still be involved in the minor's decision making.

The assessment of the age and maturity of minors, or their capacity to make a reasonable assessment of their interests, is made solely by the medical professional. It

is the responsibility of the professional to secure the minor's participation as much as possible, both from a quantitative and qualitative perspective (Lemmens 2014). However, neither the text of the Act, nor the related parliamentary documents give any guidance as to how the professional has to perform this assessment, although the age of fourteen frequently returns in the latter source as a usable caesura.[7] Several context-specific elements are mentioned as having an effect on the outcome of the question, which have to be assessed *in concreto*: the patient's age, their personal experience with decision making, their social and psychological development, the familial and social environment, the level of education, the nature of the decision, the patient's experience with illness, quantity and quality of the information, the nature and risks of the treatment etc. (Borry 2016). The medical professional therefore is the true gatekeeper to the minor patient's exercise of the autonomy to provide informed consent to medical treatment. This status of the professional comes with responsibility: carelessly assuming the minor's capacity to provide informed consent could lead to liability due to the lack of consent by the legal representative; not asking for the informed consent of the minor who is capable of providing it could lead to liability due to the violation of the minor's right to physical integrity (Lemmens 2014). When professionals doubt whether the opinion of the minor concerned is in their best interests – for instance, because of negative effects for their health – they will also often question the minor's capacity to decide in the first place (Borry 2016). The professional is therefore advised to consult a multidisciplinary team and to carefully register the reason for their decision concerning the minor's capacity to provide informed consent in the patient's file (Lemmens 2014).

Belgian law does not explicitly specify the circumstances in which the legal representative may exercise the rights of the minor patient, nor that they have to take into account the child's best interests, even though they are considered to do so (Borry 2016). The literature suggests that the far-reaching and irreversible nature of the treatment could negatively influence the minor's capacity to decide independently (Lemmens 2014; Borry 2016). Moreover, the Patients' Rights Act does not specify the procedure that has to be followed when a conflict arises between the legal representative and minors in the exercise of their rights. According to the parliamentary documents, the opinion of the former takes precedence, unless the professional argues that the minor is capable to exercise their rights independently.[8] Nevertheless, although the representative exercises the right to consent, they have to take into account the opinion of the child. So, in practice, the professional can only impose the treatment on the minor by relying on the emergency clause provided for in Article 15, §2 of the Act. In all other cases, a judge would have to take the minor's opinion very seriously, in accordance with their age and maturity (Lemmens 2014). In exceptional, urgent situations where the representative's decision could lead to a serious impairment of the child's health, the medical professional has a legal duty to act without parental consent if they disagree with a child's parents' decision. In the first stage of minority, the minor who faces medical treatment is thus fully dependent on the opinion of the legal representative or the medical professional. In the second stage of minority, the nature of the treatment concerned is of vital importance: the more serious the case, the more margin will be given to the legal representative to exercise the minor's rights. In any case, the medical professional retains the right to overrule any decision in case of a threat to the minor's patient's life or risk of serious impairment of the minor's health.

Specifically, in relation to children, a medical professional also has the obligation under the Patients' Rights Act to refuse to perform treatment when no therapeutic intention is present (Lemmens 2014). Doing otherwise would violate the right of the minor patient to high quality health care under Article 5 of the Act and the right to physical integrity. However, this therapeutic intention may be interpreted broadly, for instance by taking into account the dominant cultural vision regarding the well-being of the child (Lemmens 2014). Nevertheless, it is suggested that in case of doubt, no treatment may take place until the child has reached phase three of minority or has come of age (Lemmens 2014).

Evaluation in the Light of the Right to Personal Autonomy and the Child's Best Interests Principle

At first sight, the currently applicable Belgian framework concerning informed consent to medical treatment seems to be in line with generally accepted human rights provisions regarding medical treatment of patients. It foresees – among other things – a right to high quality health care according to the patient's needs, a comprehensive right to information and the right to free, prior and informed consent regarding treatment. In addition, it provides a system of protection to persons who lack the capacity to exercise their rights, such as minors. However, one could question whether the Belgian legal framework is capable of effectively respecting and protecting the rights of persons – especially children – with variations of sex characteristics, given the continued occurrence of sex assigning and 'normalising' treatment in Belgium. It is therefore important to examine the implementation of the Belgian framework regarding informed consent to medical treatment from the perspective of the right to personal autonomy of persons with variations of sex characteristics, and the child's best interests principle.

Substitution of Personal Autonomy for Consent by Proxy

Autonomy is seen as a limit on paternalist approaches that might ignore the wish of the patient, especially in situations where in practice the patient is not offered any option but to agree to the procedure which the medical staff consider appropriate in view of the circumstances. With regards to medical treatment, this precedence of individual autonomy over paternalism is represented by the prerequisite of personal informed consent (Silver 2014). Although Belgian legislation foresees that a minor patient has to be involved in the consent by the legal representative to medical treatment or even has to be granted autonomy towards the end of minority, the personal exercise of rights depends on the child's age, maturity and the nature and risks of the treatment, which are all assessed by the medical professional. Specifically, for children with variations of sex characteristics, the application and assessment of these criteria creates a gap in the protection of their personal autonomy. After all, these criteria in practice may hamper the opportunities for children with variations of sex characteristics to autonomously exercise their right to bodily integrity or even participate in decision-making proceedings. Indeed, as mentioned above, on the basis of the socially constructed treatment model, deferrable and medically unnecessary sex assigning/'normalising' treatment often occurs close to a child's birth or in early childhood, and often takes the form of serious and invasive hormonal or surgical intervention, with risks for the

person's fertility, genital sensitivity and sexual life (Clark Hofman 2012). Treatment decisions are often presented as inherently parental, medical, necessary and urgent to protect the child's future well-being. However, respecting the (anticipatory) autonomy rights of children with variations of sex characteristics demands that any deferrable, irreversible decision be postponed until the child is mature and legally capable of making the decision themselves (Fox and Thomson 2017).

As mentioned above, the Patients' Rights Act does not explicitly specify in which situations the legal representative may exercise the rights of the minor patient. However, these circumstances, e.g. the degree or urgency of the treatment, the nature of the treatment or the possible consequences, lie at the very centre of the issues that persons with variations of sex characteristics face. Even though a variation of sex characteristics rarely causes health risks that immediately require medical intervention (Clark Hofman 2012), there is no indication in the implementation of the Act that these observations negatively influence the margin for consent by proxy with regard to the timing of the treatment. The legal requirement that treatment needs to serve a therapeutic purpose, also does not appear to significantly influenced the performance of sex assigning/'normalising' treatment on the basis of consent by proxy. These observations combine to create a *de facto* dominance of and preference for parental consent over the personal autonomy of the person with variations of sex characteristics, and therefore a substitution of the latter's will in favour of the legal representative's will (Clark Hofman 2012).

The already inherently questionable nature of this finding is exacerbated by the problematic position of parents when a child is born with a variation of sex characteristics (Garland and Diamond 2018). Parents of a new-born are not always best placed to make decisions that will have life-long implications for their child, especially about matters that parents may not want to contemplate so early on in their child's life, such as the adult child's sexual life or potential gender identity (McDonald 2015). As research has shown, (binary) gender allocation at birth does not necessarily conform to the person's lived experience later on in life (Schweizer et al. 2014). According to Clark Hofman (2012), cases regarding medical treatment of children with variations of sex characteristics involve significant hurdles for providing parental informed consent: parents are confronted with their own cultural upbringing, stereotypes, and biases regarding (binary) sex and gender, and are often presented with information indicating a false sense of medical urgency based on the physicians' apparent authority.

Conflicted by their own distress, anxieties, guilt, shame or repugnance, parents may not be able to act solely in their child's best interests (Sandberg 2018; Beh and Diamond 2005). Moreover, qualitative research from 2013 indicates that parents often tend to disfavour postponing surgery until the child is old enough to provide its own consent, despite lack of evidence concerning outcome data and despite being informed about issues such as their child's potential loss of sexual sensation (Streuli Vayena, Cavicchia Balmer and Huber 2013). According to this same research, the origin of this readiness to consent to sex assigning/normalising treatment during childhood is unclear: some sources invoke social pressure or parents' long-held attitudes, others see parents influenced by the behaviour of professionals and the information they provide, which can appear medicalised or demedicalised, mainly depending on the context, cause and proposed solution (Streuli Vayena, Cavicchia-Balmer and Huber 2013). Recent Flemish research has also shown that parents want to protect their children from having

to make difficult decisions concerning treatment on their sex characteristics (Callens, Longman and Motmans 2017). Thus, the reliance on parental informed consent to perform non-consensual sex assigning/'normalising' treatment is essentially justified based on the risk of social stigma in childhood, parental distress and parental preferences, despite official recommendations of caution and regardless of statistical evidence of high risks of dissatisfaction regarding sex/gender assignment (Garland and Diamond 2018; Dunne 2018).

These circumstances bring Jones (2017) to believe that the best interests of the child with variations of sex characteristics are not sufficiently protected by the general legal framework regarding medical treatment of minors, in violation of Article 3 of the CRC. Parents of children with variations in sex characteristics love their children and believe that medical intervention is very much in the child's interests. Yet, they are caught in a cultural whirlwind which dictates the ideological construction of what should and should not be done in the child's best interests, while it is hard to think of a matter more central to the child than bodily integrity (Jones 2017).

The Role of Social Constructionism and cultural norms

It should be clear by now that many forms of medical treatment of persons with variations of sex characteristics are not based on evidence-based medical necessity, but on cultural considerations regarding the perceived socio-psychological well-being of the person concerned and cultural norms (Dickens 2018). The proposed interventions supposedly enable the individual to fit into the binary model of sex and avoid possible social stigmatisation and alienation. The medical model therefore reinforces a social constructionist norm by failing to respect the autonomy of children with variations of sex characteristics.

Medical professionals who, in the information they provide, focus mainly on the essentiality of sex assigning/'normalising' treatment for the (social) development of a person with variations of sex characteristics, often disguise its true (lack of) urgency. This enforcement of uncertain social constructions, together with the high level of scientific uncertainty regarding the benefits and/or negative consequences of sex assigning/'normalising' treatment deprives the medical model of non-consensual, unnecessary treatment of its (legal and ethical) legitimacy (Greenberg 2012). By interpreting the best interests of a child with variations of sex characteristics through the lens of the interests of society in maintaining the binary conceptualisation of sex, the child's emerging subjectivity is ignored. As Fox and Thomson (2017) hold, respect for the child's emerging subjectivity means that its needs are never necessarily synonymous with those of others, or merely an extension of them.

Conclusion

The valorisation of bodily autonomy and the interpretation of a child's best interests are culturally constructed phenomena. Persons with variations of sex characteristics have been and are still subjected to treatment on their sex characteristics in order to align them with society's culturally constructed binary sex normativity, often during (early) childhood and therefore before their personal informed consent can be provided. Although the Belgian legal framework concerning medical treatment (of minors) complies with the requirement of the general patient rights standards, it has not been

able to prevent violations of the right to personal autonomy of persons born with variations of sex characteristics who have been subjected to non-consensual, deferrable sex assigning/'normalising' treatment. Indeed, while criteria such as 'age', 'maturity', 'nature of the treatment' and 'risks of treatment' appear to be self-evident in order to evaluate a minor's capacity to provide informed consent to medical treatment they are supposed to undergo, they are particularly harmful for minors born with variations of sex characteristics. After all, these criteria do not lead to a challenge of the inherently sociocultural nature of sex assigning/'normalising' treatment, nor the bias with many parents that growing up with 'normal' sex characteristics as soon as possible is of paramount importance for their child's well-being and functioning in society. In other words, although the parental representation of minors who are not capable to autonomously decide on medical treatment conforms to general international human rights standards, parents do not necessarily know best when it comes to the bodily integrity of their child with variations of sex characteristics.

While the law in itself is not capable of solely challenging and reforming the practice of 'translating' the 'social emergency' that a variation of sex characteristics presents, into a proper assessment of medical necessity of treatment, it can be argued that a strong and specific legal framework regarding variations of sex characteristics could tackle pressing human rights violations. For instance, both Malta and Portugal have recently adopted legislation prohibiting non-consensual, deferrable treatment on a minor's sex characteristics until that minor is capable of providing informed consent. According to Travis and Garland (2018), the Maltese and Portuguese models represent an approach to legal reform based on a substantive equality model that concentrates on protecting the bodily integrity of children with variations of sex characteristics.

It is to be recommended that Belgium follows the Maltese and Portuguese legislative example by banning deferrable, non-consensual treatment on the sex characteristics of a minor who is not able to provide consent (autonomously or through the legal representative), but keeping the possibility to perform treatment in exceptional circumstances on the basis of explicit informed consent by the legal representative(s). As in the Maltese framework, these 'exceptional circumstances' should not amount to social reasons given the lack of participation of the minor concerned in the decision-making process. In other words, in the suggested model, it would become prohibited to perform treatment in order to create congruence between the child's sex characteristics and presumed gender identity, to aesthetically 'normalise' the child's sex characteristics, or to avoid situations of social stigma. A legal ban on unnecessary, non-consensual treatment on the sex characteristics of a minor, would thus strengthen the latter's 'default' position, in light of the problematic lack of comprehensive multidisciplinary scientific research on all aspects related to a variation of sex characteristics and the fears, biases and stereotypes with many parents.

A framework that enables the individual person's choice and control to consent to 'normalising' treatments on one's sex characteristics, necessarily needs to be complemented by not only increased social acceptance of variations of sex characteristics, but also the (further) development of accessible and appropriate healthcare (Monro et al. 2017). Indeed, despite the required depathologisation of variations of sex characteristics, every person with variations of sex characteristics has the right to have their specific condition appropriately assessed (at birth and/or later in life), in order to ensure sufficient medical follow-up and/or care during their lives

(Carpenter 2018). Aside from a legal provision to stop non-consensual, deferrable and medically unnecessary treatment on a person's sex characteristics, the culturally constructed reasons underlying these acts should also be challenged through various legislative, administrative and other measures tackling harmful stereotypes concerning sex and gender in society. As this paper has shown, the social and legal 'response' to the existence of variations of sex characteristics would greatly benefit from intensive, interdisciplinary cooperation between all relevant stakeholders in the near future. Legal reform detached from any understanding of the sociocultural construction of sex, that is not correctly implemented by medical professionals, or which is insufficiently complemented by emancipatory policy efforts to achieve cultural change, will eventually become a dead letter.

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Footnotes

[1] Concluding observations of the UN Children's Rights Committee (CRC) on Belgium, CRC/C/BEL/CO/5-6 (2019).

[2] Concluding observations of the UN Committee on Economic, Social and Cultural Rights on Belgium, E/C.12/BEL/CO/5 (2020).

[3] Persons with variations of sex characteristics are also often referred to as intersex persons.

[4] Resolution 2191 (2017) 'Promoting the human rights of and eliminating discrimination against intersex people'.

[5] See, for instance, concluding observations of the CRC on South Africa CRC/C/ZAF/CO/2 (2016); Denmark CRC/C/DNK/CO/5 (2017); Spain CRC/C/ESP/CO/5-6 (2018); Argentina CRC/C/ARG/CO/5-6 (2018); Italy CRC/C/ITA/CO/5-6 (2019).

[6] Act of 22 August 2002 concerning the rights of the patient, Belgian Gazette 26 September 2002, p. 43719.

[7] Parl.Doc. Chamber of representatives, 50-1642, p. 29, 30, 34, 35.

[8] Parl.Doc. Chamber of representatives, 50-1642, p. 95.