

Human rights violations in normalizing procedures on intersex children

Violações de direitos humanos nos procedimentos normalizadores em crianças intersexo

Violaciones de derechos humanos en procedimientos de normalización de niños intersexuales

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Abstract

Intersex children in Brazil are still subjected to “normalizing” surgical procedures and subsequent bodily interventions to make their bodies conform to binary views of sex. Resolution n. 1,664/2003 of the Brazilian Federal Council of Medicine legitimizes interventions upon intersex bodies, being the only national normative instrument that address the subject. However, the demands of international intersex political activism have denounced how early childhood interventions for sex designation mutilate children’s bodies and violate a number of human rights. This research discusses how early, irreversible, and normalizing procedures performed without the intersex person’s consent are human rights violations. Based on the concept of epistemic (in)justice, we first look at the disputes surrounding the evidence that underpin medical practices. We demonstrate how such procedures violate human rights to health, body integrity, autonomy, and sexual and reproductive rights, analyzing which strategies were put into place to prevent them. We propose that intersex people be at the center of decisions regarding their bodies, that non-surgical paths be discussed with patients and their family members, and that early, invasive, mutilating, harmful, cosmetic, and unconsented surgical interventions on intersex children be prohibited. Guiding tools must introduce changes into its regulatory bias to, from an interdisciplinary perspective, include bioethical and human rights bodies, as well as intersex activists.

Intersex Persons; Child; Human Rights; Bioethics

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Introduction

Evaluations concerning the intersex body are still strongly guided and produced by biomedical knowledge. In Brazil, this fact is made evident, among other aspects, by *Resolution n. 1,664/2003*¹ of the Brazilian Federal Council of Medicine (CFM), which legitimizes interventions on such bodies and “defines the technical standards necessary for treating patients with disorders of sex development”. Among the Brazilian medical community, “anomalies of sexual differentiation” (ASD) or “disorders of sex development” (DSD) are terms used to refer to intersex people. When biomedical knowledge employs “anomaly” and “disorder”, they reiterate the reality of the intersex body as a pathology and, from this perspective, normalize interventions that aim to define the child’s sex (in female or male) as “corrective” and “necessary”. This knowledge contributes to produce so-called scientific evidence, which usually base decision-making within clinical care.

In opposition to biomedical postulations, since the 1990s, intersex activism claim the right to bodily self-determination and adopt the term “intersexuality” as an ethical and political category. Intersexuality refers to people who are born with sexual characteristics – whether genetic, anatomical and/or related to reproductive and genital organs – that do not fit the normative definitions for male or female bodies². Based on this understanding, intersex activists have denounced how early interventions during childhood for sex designation mutilate children’s bodies and violate a series of human rights^{3,4,5}.

The political movement of the Intersex Society of North America (ISNA) and Mauro Cabral’s intellectual and political work strongly influenced the development of Brazilian academic research from an interdisciplinary, critical, anthropological, legal, biomedical, bioethical, and educational perspective^{6,7,8,9,10,11,12}. It also echoed on international human rights and health protection organizations, which have edited documents calling on national states to prohibit unnecessary surgeries on intersex children^{2,13,14}, as these procedures violate human rights to health, mental and physical integrity, and autonomy, as well as the right to live free from torture. That said, some States have laid down conditions for performing the surgeries, such as Colombia^{15,16,17,18,19}, Germany²⁰ and Greece²¹, with Portugal²² and Malta²³ being the only countries to actually prohibit these interventions on children under the minimum age of consent.

However, this understanding of early and medically unnecessary surgical procedures performed on intersex children as a human rights violation is not consensual. Biomedical discourse acts in the opposite direction, arguing that performing such procedures would have precisely the power to ensure rights to health and protect the child’s best interest, since they would conform intersex children to the social norms regarding sexed bodies, as can be observed in the works by Fagerholm et al.²⁴, Binet et al.²⁵, Hemesath et al.²⁶ and Jesus²⁷, among others. Such procedures include cosmetic genital surgeries and early hormonal interventions not consented by the intersex people themselves.

Intersex activism and human and social sciences research call into question the biomedical notion of what is understood as scientific evidence. Their critical perspective centers the narratives of intersex people, not as elements of experience to be validated by the biomedical field, but as producers of valid knowledge, as proposed by the agency-based approach to intersex²⁸. When, on the contrary, intersex people are unfairly treated in their ability to know or describe their experiences in the world, we are faced with what Fricker²⁹ calls epistemic injustice. Such a category allows us to understand the processes by which intersex subjects are erased in the evidence produced about their own bodies and in the healthcare practices provided to them.

Based on the concept of epistemic (in)justice, this essay discusses how early, irreversible, and normalizing surgical procedures performed without the intersex person’s consent violate the rights to health, body integrity, autonomy, and sexual and reproductive rights. We first look at the disputes waged by intersex activists against the evidence that underpin medical practices to show their repercussions on critical academic productions, on the agenda of human rights organizations and on the production of new legislation. Finally, based on the analysis of judicial decisions and national laws, we seek to identify what strategies have been put into place to prevent human rights violations by the performance of early, irreversible, and normalizing surgical procedures.

Epistemic injustice and disputes over evidence about intersex bodies

According to Freitas & Machado ³⁰, the pathologization and medicalization of intersexuality mobilize different practices and knowledge that are articulated around what will be considered scientific “evidence” by biomedical agents. As they suggest, “*pursuing the idea of evidence means showing how it unfolds and in which dynamics among biomedical specialties and among intersex people, it fits*” ³⁰ (p. 499). Following this debate, some questions are fundamental: who produces scientific evidence in the context of intersex bodies? Are intersex people heard in decision-making regarding their rights, including the right to their own bodies? Or, as the authors put it: “*by which mechanism is the evidence of violence and mutilation narrated by intersex people disqualified as medical evidence?*” ³⁰ (p. 500).

Machado et al. ³¹ noted the limitations and lack of clinical studies that propose to evaluate, in the long or medium term, practices aimed at “normalizing” intersex bodies. By means of a systematic review, they found that the results of interventions and the advocacy for their implementation are supported by little consolidated evidence and diverse methodologies. Constructs such as “satisfaction” and “quality of life” vary in terms of definition and ways of measuring it, and can often have little consistency. Similar weaknesses were observed by Jones ³² in a systematic review, pointing to an existing tension between publications regarding the ethical-analytical perspective used: on the one hand, those based on a biomedical and pathologizing view and, on the other, critical theories that adopt an approach centered on the experiences of intersex subjects and criticizes the pathologization and cosmetic procedures imposed on intersex bodies.

In analyzing biomedical studies, Zeeman & Aranda ³³ showed that clinical practice based on the pathologization of intersex bodies and early, unnecessary medicalization without the subjects’ consent has led to harmful consequences and increase dissatisfaction with healthcare services. Arguing that these interventions are performed to uphold a binary sex, the authors propose that the field of health start to interrogate, undo, and rethink sex and gender to expand these concepts beyond the binarism.

Between 2017 and 2018, the European project dsd-LIFE ³⁴, carried out in 14 medical centers with 1,040 people with differences or disorders in sex development (dsd), published its results, which has been used as a reference to discuss current practices and improvements to the health care and well-being of intersex people. Its publications advocate the need for efficient communication based on listening to people assisted in health services, asking them what terminology they prefer to use. To maintain a critical distancing from the medical terminology DSD (disorders of sex development), psychosocial research that dialogues with health services has adopted the term dsd, in lowercase letters.

Although the dsd-LIFE research makes great efforts to listen to intersex people ³⁴, the researchers still focus on biomedical practices; after all, the participants recruited were patients at these medical centers, in addition to reviewing medical records and physical examinations to confirm diagnoses. Nevertheless, among the dsd-LIFE results on the health status of people with dsd, 8.6% reported poor or very poor overall health and 6.8% reported attempted suicide. Research shows that practices in these European clinical centers vary greatly, and suggest the use of alternative terminology: differences in sex development.

Conversely, a U.S. research developed by Rosenwohl-Mack et al. ³⁵ seeks to describe the health of adult intersex people based on a methodology constructed with participation of the intersex community. The researchers noted the difficulty of recruiting intersex people due to past trauma, exploitation, and stigmatization experienced in clinical and research settings. Highlights include: 43% of the participants classified their physical health as regular/poor, 53% reported regular/poor mental health and almost a third said they had already attempted suicide.

European ³⁴ and United States ³⁵ studies show that the research contexts and constituent elements influence the results produced. After all, they share different assumptions and understanding of what consists as research evidence. In the European study ³⁴, 8.6% of participants reporting poor or very poor general health is a significant finding, but lower when compared to the 43% observed in the U.S. research ³⁵: the European context consisted of a hierarchical biomedical locus (outpatient clinics and medical records), whereas the U.S. research was produced horizontally, together with intersex activists.

In this regard, Crocetti et al. ²⁸ propose an agency-based model to approach intersex, variations of sex characteristics (VSC) and DSD/dsd health. Such a model must: be based on non-discrimination

policies and ethics, respect, and self-determination; question sexual and gender binarism, as well as heterosexual norms; discuss sex variations; improve communication with patients and, when necessary, with family members; develop non-surgical pathways; and provide care centered on the intersex person's agency. The researchers also point out that, when it comes to intersex children, the agency-based model must protect and support the future capacity for agency.

Biomedical and pathologizing practices of intersex bodies are even imposed by language. Machado et al.'s ³¹ research reveals the massive use of expressions such as "according to our experience" or "we believe that". Bastien-Charlebois & Guillot ³⁶, when finding similar statements from healthcare providers, point out that different degrees of credibility are afforded to different discourses: the statements of intersex people, for example, are disregarded as evidence because they are experience-based. However, the researchers point out that both healthcare providers and intersex activists use their experiences to support their arguments and practices. Machado et al. ³¹, for example, show how most studies uphold the logic of hormonal and surgical interventions, as well as different regulations of the sexed body, which is not based exclusively on empirical evidence.

Seeking to problematize the status quo legitimized by scientific authority and empiricism based on an external object of knowledge, Fricker ²⁹ analyzes how the voices of marginalized populations are treated and shows that being present in the discussion is simply not enough. By exploring the concept of epistemic injustice, the philosopher reflects on how some forms of knowledge are validated as more important than others, which voices are given prominence to, and why some experiences are afforded more credibility than others. Epistemic injustice occurs when someone is wronged in their capacity to know something or in their ability to describe their experiences in the world. For the author, there are two forms of epistemic injustice: testimonial injustice and hermeneutical injustice.

Testimonial injustice occurs when, due to ingrained prejudices, one gives the speaker less credibility. Credibility attribution is not a neutral process; it is rather influenced by conscious or unconscious social codes and assumptions about how expertise is built, and who is in a better position to see things "as they truly are" (emphasis on the original) ²⁹. Hermeneutical injustice, in turn, refers to a gap in collective interpretation either because people from a given group sometimes lack specific words to describe their experiences, or because they and those from another group do not have the same shared experiences. This form of injustice points to a gap between experience, the capacity to express it, on the one hand, and the capacity to understand it, on the other.

In the discursive games between biomedical agents and intersex people, these two forms of epistemic injustice are articulated. While intersex people seek validation and credibility for their voice and experiences to make decisions about their own bodies, biomedical knowledge has its own discursively hierarchical language (therefore asymmetrical in relation to those who claim their voices to be heard), which monologues among their peers about how to normalize bodies they deem anomalous and deviant. According to Fricker ²⁹, people from dominant groups – here, represented by the biomedical body – have their voices validated as more objective and more expert, whereas people from subalternized groups – here, intersex people – are interpreted as those who are biased and more subjective, with political agendas, and are seen as those who do not know what they are talking about. Silencing and discrediting the voices of intersex people cause their own narratives to be delegitimized, dehumanizing them in the face of those who hold a supposed knowledge-power.

Intersex bodies are understood as political territory to be dominated by those who have the power to correct it, under the guise of a supposed normalization according to binary patterns of biological sex. We see thus a hegemonic biomedical regulation of bodies that force intersex people to conform to a heteronormative and bio-normative hegemonic coercive system ³⁷.

Costa ⁸ analyzes the logics of (biological, economic, cultural, political, technological, moral) development, observing how they produce and are produced in the medical, activist, and media versions of intersexuality. Costa understands development as a categorization regime that classifies, based on hierarchical relations of power, narratives and experiences as more or less legitimate, normal or deviant, threatened or threatening. Thus, to think about the narrative disputes around intersexuality is to talk about the notions of development that structure them. The author highlights that the notions of development suggest different paths when intersected by each field studied, leading the very definitions regarding the temporalities (urgency, precocity, delays, postponements, continuities) that involve surgical procedures on intersex bodies, as well as access to them, to take multiple contours.

Giving up dichotomies – delayed/advanced, conservative/progressive, normal/pathological – shows that it is impossible to establish a single development narrative to define the bodies, memories, identities, and experiences of intersex people.

For Bastien-Charlebois³⁸, medical professionals not only produce intervention techniques and protocols, but legitimate them to their peers and to the public, as well as to human rights organizations and State officials. Pathologizing language and practices harm and dehumanize the intersex population, since the assumptions (and prejudices) underneath them provide legitimacy to unconsented interventions for intersex children and to the understanding of such differences as failures to be corrected³⁸. In this regard, Bastien-Charlebois^{38,39} points out that harm and dehumanization occur when such biomedical discourse deny full participation to this population, questioning their representativeness, refusing to listen to their criticisms or complaints about unconsented interventions, and even minimizing the harm suffered due to the procedures performed. Moreover, healthcare providers who echo such discourse end up treating intersex people as a mere source of information about their bodies, while refusing to effect epistemic justice, which would imply, for example, consulting or referencing texts produced by intersex people^{38,39}.

In this regard, Carpenter⁴⁰ points out that structural change is necessary to end the pathologization and stigmatization of intersex bodies. This would require a series of actions, such as eliminating harmful medical practices; recognizing the right of intersex people to full, free and informed consent; changing the International Classification of Diseases (ICD) diagnoses in light of human rights; addressing the rhetoric of inclusion; encouraging, supporting, and expanding intersex-led initiatives; and understanding that intersex people must be at the center of biomedical, bioethical and human rights decisions and management regarding intersexuality¹².

From the perspective of epistemic justice, early, irreversible, and normalizing surgical procedures performed without the intersex person's consent violate human rights, as we will discuss as follow.

Early, irreversible, and normalizing surgical interventions as human rights violations

Disputes surrounding the notion of evidence affect what is understood as guarantee of human rights. For hegemonic biomedical knowledge, performing early surgical procedures on intersex children would ensure their right to health and to a normal life, and would therefore constitute the appropriate conduct to protect the children's best interests. For intersex activism and other experience-centered approaches, such procedures are mutilating and violate the rights to health and autonomy of the subjects who are subjected to them in the first years of life. From the perspective of epistemic justice – for which intersex people must have their voices validated, their experiences attributed credibility, and decisions about their own bodies respected – early, irreversible, and normalizing surgical procedures performed without the consent of intersex subjects are human rights violations.

In this section, we map human rights instruments, updating research such as that by Pretes¹⁰, navigating this thread that connects such disputes surrounding the notion of evidence. These provisions, based on the demands of intersex movements, via human rights organizations, have called on States to ban medically unnecessary procedures on intersex children. This assertion is based on the recognition that, as pointed out, these interventions violate human rights, such as the rights to health, mental and physical integrity, sexual and reproductive rights, the right to be free from torture and mistreatment, and the right to autonomy. We argue that evidence is not a neutral starting point for decision-making, but rather a complex entanglement that articulates tensions and hierarchies of credibility, with particular developments in the field of intersex rights.

The Inter-American Court of Human Rights ruled in *Advisory Opinion (AO) 24/17*⁴¹ on the interpretation of the American Convention on Human Rights regarding the recognition of gender identity, materialized in name rectifications. Although the ruling does not specifically address intersex people, it does raise important points that can be employed for this population. One point refers to the unnecessary need for hormonal and surgical interventions as a condition for changing the civil registry, recognizing self-declaration as a sufficient element to carry out this procedure. Another point concerns recognizing the rights of children and adolescents to gender identity, which implies

listening to them in all life-affecting decisions. This argument can be used to reflect on the plight of both trans and intersex children, who should be heard before unnecessary surgical and hormonal procedures are performed.

The Inter-American Commission on Human Rights and the Parliamentary Assembly of Europe have recommended that States review medical protocols that foresee unnecessary surgical interventions on children and that procedures be postponed until children are capable of giving their full, free and informed consent ^{42,43,44,45}. This position is reiterated by the *Born Free and Equal: Sexual Orientation, Gender Identity and Sex Characteristics in International Human Rights Law* ² document, for which invasive procedures (surgeries and painful examinations, among others) cause long-term physical and psychological suffering that affect the rights of intersex children to physical integrity, health, and autonomy and may amount to torture or ill-treatment.

The right to health, understood as a state of complete physical, mental, and social well-being ^{46,47}, which permeates the debate about performing early surgical procedures on intersex children, cannot be separated from the right to autonomously decide whether or not to undergo such procedures. Such discussion reiterates the assertion that intersex children who undergo “sex-normalizing” procedures have their sexual and reproductive health rights violated, as stated in a document authored by a group of eight United Nations (UN) agencies, including the World Health Organization (WHO) ⁴⁸.

In a statement for *Intersex Awareness Day*, a group of UN human rights experts called for an urgent end to human rights violations against intersex children and adults ⁴⁹. The statement argues that intersex children who undergo body-“normalizing” procedures suffer “*permanent infertility, incontinence, loss of sexual sensation, causing life-long pain and severe psychological suffering, including depression and shame linked to attempts to hide and erase intersex traits*” ⁴⁹. Among the measures recommended for States are: strengthen the integration of human rights principles in protocols issued by regulatory and professional agencies; investigate human rights violations against intersex people; “*hold those found guilty of perpetrating such violations accountable and provide intersex people subjected to abuse with redress and compensation*” ⁴⁹, and provide training to health professionals and public officials.

The right to physical and mental integrity and to be free from torture are set out in several human rights standards ^{50,51}. The Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, in a document ⁵² presented before the UN General Assembly, states that surgeries performed to assign a sex cause severe mental suffering and permanent and irreversible infertility. Finally, the report calls for banning such procedures from being performed without intersex people’s consent. Similarly, the Yogyakarta Principles plus 10 ¹⁴, when addressing the right to freedom from torture and cruel, inhuman or degrading treatment or punishment, prohibits any intrusive and irreversible treatments, such as forced genital-normalizing surgery, when performed without consent.

Human rights violations resulting from surgeries performed on intersex children illustrates how the rights to health and physical and mental integrity are integrated into our understanding regarding the rights to autonomy, free and informed consent, and the best interests of the child. Such fundamentals are used by the biomedical field to justify these procedures, even when the subjects are not in a position to participate in the decision-making.

Full, free and informed consent is one of the core concepts in bioethics. It is effective when a health service user or research participant, capable of deciding autonomously, receives adequate information, understands and unquestionably expresses their wish to undergo a certain intervention or participate in research. The information provided must be comprehensible, covering the risks and benefits associated with the procedure and existing alternatives. This type of consent is the embodiment of the right to autonomy, free determination, and human dignity; moreover, it is linked to the rights to non-discrimination, freedom of thought and expression, and recognition before the law ^{53,54}.

Eler & Oliveira ⁵⁵ state that it is common to opt for an age criterion to try to facilitate the operability of the consent processes. However, such criterion is insufficient to determine a certain level of capacity or maturity. In Brazil, full legal capacity is attained only at the age of 18, and persons under 16 are considered absolutely incapable of personally exercising the acts of civil life (art. 3 of the *Brazilian Civil Code* ⁵⁶). Bioethical consent, however, should not be tied to civil capacity.

As Borges et al. ⁵⁷ point out, the theory of capabilities, which is enshrined in the *Brazilian Civil Code*, was developed at a time when Civil Law was guided by the protection of property interests. This

perspective is insufficient today, because it does not address the interests linked to personality, such as privacy, body, life, image, name, honor, and freedom. In this regard, the Italian jurist Perlingieri⁵⁸ highlights that the rigid separation between capacity and disability, majority and minority, foreseen in civil laws, is limited. After all, personality rights do not protect only specific existential situations (such as those related to property), but rather the value of the person, seen as a unit, under the perspective of legal personality. Thus, the obstacles of law that prevent the gradual exercise according to the subject's maturity and development must be overcome for the progressive fulfillment of their autonomy⁵⁸. We must afford the subjects considered incapable by the *Brazilian Civil Code*, such as children, some degree of autonomy, which derives precisely from their status as a person and, therefore, cannot be fully limited, under penalty of violating their legal personality.

In this regard, article 12 of the Convention on the Rights of Children⁵⁹ ensures children the right to be heard and considers that, according to their age and maturity, they can “*form their own judgments*” and have “*the right to express their opinions freely*”. In Brazil, one of the possible ramifications of this right is the expectation that children must give their consent to participate in research, even after acquiring consent from their guardians⁶⁰.

CFM *Recommendation n. 1/2016*⁶¹, which addresses obtaining free and informed consent, briefly touches on assent by encouraging child participation in obtaining informed assent. But assent alone is not enough when it comes to protecting the physical integrity and autonomy of intersex children, since it is not a possible alternative in the first 24 months of life, when interventions on their bodies usually begin.

CFM *Resolution n. 1,664/2003*¹, which regulates interventions performed on the bodies of intersex children, by calling on a biological and social imperative to justify such early procedures, hinders the agency of intersex people in deciding about their bodies. The resolution establishes that early surgical interventions can take place based on the participation and consent of family members and guardians. Another question therefore arises on whether parents should have the power to consent to performing cosmetic genital surgeries on their children. Academic productions by intersex activists^{3,4,5,11,36,62} state that this biomedical practice violates the right to autonomy, since intersex children have their bodies modified without their consent, reducing and/or limiting their options for future choices. Thus, such studies oppose the performance of these procedures and propose that only affected subjects, when they are of appropriate age, should be allowed to consent to the interventions.

Since 1995, the Constitutional Court of Colombia discusses, based on sentence T-477/95¹⁵, what are the limits of parental consent for medical procedures on children, weighing the principles of autonomy and paternalism. It concluded, in the concrete case, that “sex readjustment” is not possible without the direct authorization of the patient, considering that children are not the property of anyone, neither of parents, guardians, nor of society. The Court further established, in this decision, some issues to be considered when analyzing informed consent given by guardians: (a) the urgency and importance of the treatment for the child; (b) the intensity of the treatment's impact on child's current and future autonomy; and (c) the child's age⁶³. In sentences SU-337/99¹⁶ and T-551/99¹⁷, the court advanced the debate and decided that the age limit for substituted informed consent, that is, consent given by guardians, is five years. For children over this age, consent must be given by them^{15,16,17,18,19}.

This decision, however, does not prevent surgeries from being performed on children under five with substituted consent, which can, in practice, bring the procedures forward to before that age as a way to circumvent the need for the child's consent. For this decision, furthermore, consent must be not only informed, but qualified and persistent. In other words, the person and their family must have an interdisciplinary support group to provide them with information about the various treatment options, so that risks and consequences can be understood, and the best alternatives – including the decision not to have procedures – can be chosen. Authorization must also be reiterated, so that the choice reflects a thoughtful and solid choice, and not the result of a momentary state of mind⁶³. In sentences T-1025/02¹⁸ and T-912/08¹⁹, the Colombian Court established that in case of divergent positions between the child, their guardians, and the medical team, the intersex child's opinion should prevail, in respect for the rights to personal and sex identity and to free development of personality and health.

The question we propose here is: how to consider and guarantee the best interest of the child? Despite the discussions proposed by activists about postponing cosmetic procedures on intersex chil-

dren, most physicians believe that surgical changes represent the best interest of the children, arguing that guardians, when well informed about the risks and benefits, should be able to decide ⁶⁴. For these physicians, the best interest of the child involves ensuring that intersex bodies are “normalized” and thus can be read through society’s binary lens, which would prevent future bodily discrimination or discomfort for the child. This discomfort and discrimination are produced by the pathologizing gaze directed at intersex bodies, a perspective that emerges from a social structure that can only see bodies as a binary. In other words, the “best interest of the child” is a principle used by health teams to justify reinforcing the same gender norms that produce the intersex subjects as abnormal. There is, therefore, an inversion in the content of this right: from protecting and prioritizing the child, it becomes the defense of a pre-established bodily standard.

Incorporation into Brazilian law of the Convention on the Rights of Children by *Decree n. 99,710*, of November 21, 1990 ⁵⁹, and the promulgation of the Statute of the Child and Adolescent by *Law n. 8,069/1990* ⁶⁵ established the principle of integral protection, according to which all children and adolescents must be recognized as subjects of rights and protected with absolute priority by the family, society, and the State ⁶⁶, which involves ensuring their physical and mental integrity. Thus, respecting the best interest of children cannot mean discriminating against them in their differences, mutilating their body through unnecessary “normalizing” surgical procedures. On the contrary, it means preserving their physical integrity and protecting it against unconsented discriminatory interventions.

The Yogyakarta Principles ^{13,14}, besides foreseeing the rights to equality and non-discrimination (Principle 2), when addressing protection from medical abuses (Principle 18) and the right to bodily and mental integrity, autonomy and self-determination (Principle 32), also explain, invoking the best interest of the child, that States must ensure children are not subjected to invasive and irreversible medical treatments that alter their sex characteristics, in an attempt to impose a gender identity without their full consent.

Some countries, attentive to the demands of intersex activists and the recommendations of human rights organizations, have already incorporated into their legislation regulations that protect intersex subjects. Malta and Portugal have enacted laws that expressly prohibit surgeries and other unnecessary procedures on intersex children under the age to consent, in respect for the rights to bodily integrity, autonomy, and gender identity. The *Gender Identity, Gender Expression and Sex Characteristics Act* ²³, approved by the Maltese Parliament, provides that treatment can be performed after indication of the interdisciplinary team and consent given by the child’s guardians only in exceptional cases and not socially motivated. If these stipulations are not respected and unnecessary procedures are performed, physicians and other responsible professionals can be punished with fines and up to five years in prison.

Following in the footsteps of Malta ²³, the Portuguese law ²² prohibits bodily modifications in intersex children, except for those performed when there is proven risk to their health. However, it does not specify that the health risk must not involve socially motivated cases. In this regard, the law gives room for interventions in babies and children to take place before they can manifest their gender identity, alleging a risk to their psychological health.

The German law on the protection of children with variants of sex development ²⁰ prohibits surgeries with a purely cosmetic purpose – performed with the intention of adapting the physical appearance to female or male – on children who are incapable of giving their consent. It allows, however, medical interventions in two situations: in health and/or life-threatening situations in which surgery cannot be postponed, or with authorization from the Judiciary, which must submit the matter to an interdisciplinary committee (the child’s physician, a second physician, a child psychologist or psychiatrist, a bioethicist, and, at the request of the child’s guardian, a person with a variant of sex development). In doing so, this law changes the questions to be posed when discussing surgeries on intersex children. Instead of wondering why one should have the surgery, it asks why not postpone it. Despite this important shift, like with the Portuguese law, the German law does not expressly prohibit surgeries motivated by social and cultural issues. On July 19, 2022, the Greek Parliament passed a law similar to the German document, prohibiting medical treatments and procedures on intersex children and adolescents under the age of 15, except with judicial permission and in cases where they cannot be postponed until the minor reaches the age of 15 and do not cause further health complications ²¹.

From a human rights perspective based on epistemic justice, discussions about the right to health cannot be separated from those involving the protection of intersex children's autonomy and agency. This autonomy involves the right to an open future¹², which can only be possible by prohibiting early, invasive, and unnecessary surgical interventions. Only then can we consider the best interest of the child, by valuing and listening to their voice, allowing them to consent or assent about these impactful interventions.

Final considerations

Considering the mappings and discussions carried out throughout this article, we now present proposals to ensure the rights of intersex people in Brazil, in face of the violations produced by an unfair and discriminatory health practice. To avoid epistemic injustice, the various institutions (biomedical, legal, educational, family) that intervene, at different levels, on intersex bodies must base their actions on an ethical responsibility towards the intersex subjects themselves. Listening to and embracing the demands of intersex people is thus fundamental, as well as including them in any decisions that will affect their existence. We propose, therefore, that intersex people be centered in decisions involving their own bodies, which requires their full participation in managing and developing public and institutional policies and promoting the initiatives of social movements.

Regarding health care actions, they should be based on human rights, on epistemic justice, and on an ethics and policy of depathologization, non-discrimination, and respect for the autonomy and self-determination of intersex people. Similarly, such practices must reject binary norms when thinking about bodily differences. Moreover, non-surgical pathways should be discussed with patients and family members, while early, invasive, mutilating, harmful, cosmetic and unconsented surgical interventions on intersex children should be prohibited to protect and support their future capacity for agency. In cases of possible risk to health and life, such as patients with congenital adrenal hyperplasia (CAH) in its salt-losing form, one should intervene to save the child's life, without performing unnecessary and early procedures based on sex and gender stereotypes.

We therefore propose that *Resolution n. 1,664/2003*¹ be repealed and an interdisciplinary committee be created to draft a new resolution that effects the depathologization, non-discrimination, and non-stigmatization policies for intersex bodies, engaging different bioethical and human rights organizations and intersex activists. Besides this reformation proposal within the CFM, a national law must be drafted to protect intersex people, using the Maltese *Gender Identity, Gender Expression and Sex Characteristics Act* as a parameter, given its advances towards depathologization, breaking with binarism, respecting autonomy, and promoting epistemic justice. However, considering the seriousness of the human rights violations presented in this essay, the State officials should promote urgent measures to ban early, invasive, mutilating, harmful, cosmetic, and unconsented surgical interventions on the bodies of intersex children.

Contributors

P. G. C. Leivas designed the study, analyzed and interpreted the data, wrote and revised the manuscript, and approved the final version to be published. A. A. Schiavon designed the study, analyzed and interpreted the data, wrote and revised the manuscript, and approved the final version to be published. A. H. Resadori designed the study, analyzed and interpreted the data, wrote and revised the manuscript, and approved the final version to be published. A. A. Vanin designed the study, analyzed and interpreted the data, wrote and revised the manuscript, and approved the final version to be published. A. N. Almeida designed the study, analyzed and interpreted the data, wrote and revised the manuscript, and approved the final version to be published. P. S. Machado designed the study, analyzed and interpreted the data, wrote and revised the manuscript, and approved the final version to be published.

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References

1. Conselho Federal de Medicina. Resolução nº 1.664, de 13 de maio de 2003. Define as normas técnicas necessárias para o tratamento de pacientes portadores de anomalias de diferenciação sexual. *Diário Oficial da União* 2003; 13 may.
2. Escritório do Alto Comissariado das Nações Unidas para os Direitos Humanos. *Nascidos livres e iguais: orientação sexual e identidade de gênero no regime internacional de direitos humanos*. 2nd Ed. Santiago: Escritório do Alto Comissariado das Nações Unidas para os Direitos Humanos; 2019.
3. Cabral M, editor. *Interdicciones: escrituras de la intersexualidad en castellano*. Córdoba: Anarrés Editorial; 2009.
4. Carpenter M. Intersex human rights, sexual orientation, gender identity, sex characteristics and the Yogyakarta principles plus 10. *Cult Health Sex* 2021; 23:516-32.
5. Vieira AM. Reflexões sobre corpos dissidentes sob o olhar feminista decolonial-queer. In: Dias MB, Barreto FCL, editors. *Intersexo: aspectos jurídicos, internacionais, trabalhistas, registraís, médicos, psicológicos, sociais, culturais*. São Paulo: Thomson Reuters Brasil; 2018. p. 481-92.
6. Machado PS. *O sexo dos anjos: representações e práticas em torno do gerenciamento socio-médico e cotidiano da intersexualidade* [PhD Thesis]. Porto Alegre: Universidade Federal do Rio Grande do Sul; 2008.
7. Lima SAM. *Intersexo e identidade: história de um corpo reconstruído* [Masters Dissertation]. São Paulo: Pontifícia Universidade Católica de São Paulo; 2007.
8. Costa AG. *As (im)possibilidades do desenvolvimento: enquadres da intersexualidade no Brasil contemporâneo* [PhD Thesis]. Rio de Janeiro: Universidade do Estado do Rio de Janeiro; 2018.
9. Pires B. *Distinções do desenvolvimento sexual: percursos científicos e atravessamentos políticos em casos de intersexualidade* [Masters Dissertation]. Rio de Janeiro: Museu Nacional, Universidade Federal do Rio de Janeiro; 2015.
10. Pretes EA. *Intersexualidade e direito ao próprio corpo: garantia à integridade corporal da criança intersexual e direito à autodeterminação na adolescência* [PhD Thesis]. Belo Horizonte: Universidade Federal de Minas Gerais; 2019.
11. Santos TEC. *Educação de crianças e adolescentes intersexo* [PhD Thesis]. Marília: Universidade Estadual Paulista; 2020.
12. Schiavon AA. *Legislando infâncias: coprodução da criança intersexo enquanto sujeito de direitos* [Masters Dissertation]. Porto Alegre: Universidade Federal do Rio Grande do Sul; 2021.

13. Princípios de Yogyakarta. Princípios sobre a aplicação da legislação internacional de direitos humanos em relação à orientação sexual e identidade de gênero. http://yogyakartapriniciples.org/wp-content/uploads/2016/10/principios_yogyakarta-Portugues.pdf (accessed on 15/May/2021).
14. Yogyakarta Principles Plus 10. Additional principles and state obligations on the application of international human rights law in relation to sexual orientation, gender identity, gender expression and sex characteristics to complement the Yogyakarta principles. https://yogyakartapriniciples.org/wp-content/uploads/2017/11/A5_yogyakartaWEB-2.pdf (accessed on 15/May/2021).
15. Colombia. Sentencia T-477/95. Bogotá: Corte Constitucional; 1995.
16. Colombia. Sentencia SU-337/99. Bogotá: Corte Constitucional; 1999.
17. Colombia. Sentencia T-551/99. Bogotá: Corte Constitucional; 1999.
18. Colombia. Sentencia T-1025/02. Bogotá: Corte Constitucional; 2002.
19. Colombia. Sentencia T-912/08. Bogotá: Corte Constitucional; 2008.
20. Bundesministerium der Justiz und für Verbraucherschutz. Gesetz zum Schutz von Kindern mit Varianten der Geschlechtsentwicklung. Bundesgesetzblatt 2021; 21 may.
21. Pikramenou N. Prohibition of intersex genital mutilation (IGM) procedures on intersex children. <https://intersexgreece.org.gr/en/2022/07/25/3449/> (accessed on Jul/2022).
22. Portugal. Lei 38, de 7 de agosto de 2018. Direito à autodeterminação da identidade de gênero e expressão de gênero e à proteção das características sexuais de cada pessoa. Diário da República 2018; 7 aug.
23. Malta. Gender Identity, Gender Expression and Sex Characteristics Act, 14th April, 2015. Valletta: Maltese Parliament; 2015.
24. Fagerholm R, Santtila P, Miettinen PJ, Mattila A, Rintala R, Taskinen S. Sexual function and attitudes toward surgery after feminizing genitoplasty. *J Urol* 2011; 185:1900-4.
25. Binet A, Lardy H, Geslin D, Francois-Fiquet C, Poli-Merol ML. Should we question early feminizing genitoplasty for patients with congenital adrenal hyperplasia and XX karyotype? *J Pediatr Surg* 2016; 51:465-8.
26. Hemesath TP, De Paula LCP, Carvalho CG, Leite JCL, Guaragna-Filho G, Costa EC. Controversies on timing of sex assignment and surgery in individuals with disorders of sex development: a perspective. *Front Pediatr* 2018; 6:419.
27. Jesus LE. Feminizing genitoplasties: where are we now? *J Pediatr Urol* 2018; 14:407-15.
28. Crocetti D, Monro S, Vecchiotti V, Yeadon-Lee T. Towards an agency-based model of intersex, variations of sex characteristics (VSC) and DSD/dsd health. *Cult Health Sex* 2021; 23:500-15.
29. Fricker M. *Epistemic injustice: power and the ethics of knowing*. Oxford: Oxford University Press; 2007.
30. Freitas J, Machado PS. Intersexualidades, bioética e negociações técnico-políticas. In: Facchini R, França IL, editors. *Direitos em disputa: LGBTI+*. Campinas: Editora da Unicamp; 2020. p. 493-510.
31. Machado PS, Costa AB, Nardi HC, Fontanari AMV, Araujo IR, Knauth DR. Follow-up of psychological outcomes of interventions in patients diagnosed with disorders of sexual development: a systematic review. *J Health Psychol* 2015; 21:2195-206.
32. Jones T. Intersex studies: a systematic review of international health literature. *SAGE Open* 2018; 8:2158244017745577.
33. Zeeman L, Aranda K. A systematic review of the health and healthcare inequalities for people with intersex variance. *Int J Environ Res Public Health* 2020; 17:6533.
34. dsd-LIFE. European Union: Multidisciplinary European Consortium dsd-LIFE. <https://www.dsd-life.eu/index.html#> (accessed on 23/Aug/2021).
35. Rosenwohl-Mack A, Tamar-Mattis S, Baratz AB, Dalke KB, Ittelson A, Zieselman K, et al. A national study on the physical and mental health of intersex adults in the U.S. *PLoS One* 2020; 15:e0240088.
36. Bastien-Charlebois J, Guillot V. Medical resistance to criticism of intersex activists: operations on the frontline of credibility. In: Schneider E, Baltes-Löhr C, editores. *Normed children: effects of gender and sex related normativity on childhood and adolescence*. Bielefeld: Verlag; 2018. p. 257-69.
37. King BW. Biopolitics and intersex human rights: a role for applied linguistics. In: Chun CW, editor. *Applied linguistics & politics*. New York: Bloomsbury Publishing; 2020. p. 155-81.
38. Bastien-Charlebois J. How medical discourse dehumanizes intersex people. <https://intersexday.org/en/medical-discourse-bastien-charlebois/> (accessed on 29/Jan/2021).
39. Bastien-Charlebois J. Les sujets intersexes peuvent-ils (se) penser? Les empiétements de l'injustice épistémique sur le processus de subjectivation politique des personnes intersex(u)és. *Socio* 2017; 9:143-62.
40. Carpenter M. The human rights of intersex people: addressing harmful practices and rhetoric of change. *Reprod Health Matters* 2016; 24:74-84.
41. Corte Interamericana de Derechos Humanos. Opinión Consultiva OC-24/17 de 24 de noviembre de 2017 solicitada por la República de Costa Rica. Identidad de género, e igualdad y no discriminación a parejas del mismo sexo. http://www.corteidh.or.cr/docs/opiniones/seriea_24_esp.pdf (accessed on 06/Jan/2023).
42. Comisión Interamericana de Derechos Humanos. *Violencia contra personas lesbianas, gay, bisexuales, trans e intersex en América*. <http://www.oas.org/es/cidh/informes/pdfs/violenciapersonaslgbti.pdf> (accessed on 06/Jan/2023).

43. Comisión Interamericana de Derechos Humanos. Avances y desafíos hacia el reconocimiento de los derechos de las personas LGBTI en las Américas. <http://www.oas.org/es/cidh/informes/pdfs/LGBTI-ReconocimientoDerechos2019.docx> (accessed on 06/Jan/2023).
44. Parliamentary Assembly, Council of Europe. Resolution 2191 (2017). Promoting the human rights of and eliminating discrimination against intersex people. <https://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=24232> (accessed on 06/Jan/2023).
45. Parliamentary Assembly, Council of Europe. Recommendation 2116 (2017). Promoting the human rights of and eliminating discrimination against intersex people. <https://assembly.coe.int/nw/xml/XRef/Xref-DocDetails-en.asp?FileID=24230&lang=en> (accessed on 06/Jan/2023).
46. Organização Mundial da Saúde. Constituição da Organização Mundial da Saúde. Geneva: Organização Mundial da Saúde; 1946.
47. Organização dos Estados Americanos. Protocolo adicional à Convenção Americana sobre Direitos Humanos em Matéria de Direitos Econômicos, Sociais e Culturais – Protocolo de San Salvador. San Salvador: Organização dos Estados Americanos; 1988.
48. World Health Organization. Eliminating forced, coercive and otherwise involuntary sterilization: an interagency statement, OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO. Geneva: World Health Organization; 2014.
49. Office of the High Commissioner for Human Rights. Intersex Awareness Day – Wednesday 26 October 2016. End violence and harmful medical practices on intersex children and adults, UN and regional experts urge. <https://www.ohchr.org/en/2016/10/intersex-awareness-day-wednesday-26-october> (accessed on 06/Jan/2023).
50. Brasil. Decreto nº 98.386, de 9 de dezembro de 1989. Promulga a Convenção Interamericana para Prevenir e Punir a Tortura. Diário Oficial da União 1989; 13 nov.
51. Brasil. Decreto nº 40, de 15 de fevereiro de 1991. Promulga a Convenção contra a Tortura e Outros Tratamentos ou Penas Cruéis, Desumanos ou Degradantes. Diário Oficial da União 1989; 13 nov.
52. Office of the High Commissioner for Human Rights. Special rapporteur on torture and other cruel, inhuman or degrading treatment or punishment. About the mandate. <https://www.ohchr.org/en/special-procedures/sr-torture> (accessed on 06/Jan/2023).
53. Organização das Nações Unidas para a Educação, Ciência e Cultura. Declaração Universal sobre Bioética e Direitos Humanos. 33ª Sessão da Conferência Geral da UNESCO. Paris: Organização das Nações Unidas para a Educação, Ciência e Cultura; 2005.
54. Nunes R. Ensaios em bioética. Brasília: Conselho Federal de Medicina; 2017.
55. Eler KCG, Oliveira AAS. O assentimento ao consentimento das crianças para participar em pesquisa clínica: por uma capacidade sanitária juridicamente reconhecida. *Pensar* 2019; 24:1-13.
56. Brasil. Lei nº 10.406, de 10 de janeiro de 2002. Institui o Código Civil. Diário Oficial da União 2002; 11 jan.
57. Borges RC, Souza ASL, Lima IMSO. A autonomia da criança intersexual: crítica à teoria jurídica das incapacidades. *Espaço Jurídico Journal of Law* 2016; 17:933-56.
58. Perlingieri P. Perfis do direito civil: introdução ao direito civil constitucional. Rio de Janeiro: Renovar; 1999.
59. Brasil. Decreto nº 99.710, de 21 de novembro de 1990. Promulga a Convenção sobre os Direitos da Criança. Diário Oficial da União 1990; 22 nov.
60. Conselho Nacional de Saúde. Resolução nº 510. Dispõe sobre as normas aplicáveis a pesquisas em Ciências Humanas e Sociais. Diário Oficial da União 2016; 24 may.
61. Conselho Federal de Medicina. Recomendação CFM nº 1/2016. Dispõe sobre o processo de obtenção de consentimento livre e esclarecido na assistência médica. Brasília: Câmara Técnica de Bioética do CFM; 2016.
62. Morland I. What can queer theory do for intersex? *GLQ* 2009; 15:285-312.
63. Sánchez PG, Acevedo CV, Quintero SPD. Problemática jurídica de los estados intersexuales: el caso colombiano. *Iatreia* 2010; 23:204-11.
64. Greenberg JA. Health care issues affecting people with an intersex condition or DSD: sex or disability discrimination? *Loyola of Los Angeles Law Review* 2012; 45:849-908.
65. Brasil. Lei nº 8.069, de 13 de julho de 1990. Estatuto da Criança e do Adolescente. Diário Oficial da União 1990; 13 jul.
66. Zapater M. Direito da criança e do adolescente. São Paulo: Saraiva; 2019.

Resumo

No Brasil, crianças intersexo ainda são submetidas a procedimentos para designação de sexo binário no nascimento e a intervenções corporais subsequentes. A Resolução nº 1.664/2003, do Conselho Federal de Medicina, legitima intervenções sobre as corporalidades intersexo, se constituindo como o único instrumento normativo nacional que trata sobre o tema. No entanto, as demandas advindas do ativismo político internacional intersexo vêm expondo o quanto as intervenções precoces na infância para a designação de um sexo binário mutilam os corpos das crianças e violam uma série de direitos humanos. Esta pesquisa visa identificar como os procedimentos precoces, irreversíveis e normalizadores, realizados sem o consentimento da pessoa intersexo, revelam-se violadores de direitos humanos. Sob as lentes do conceito de (in)justiça epistêmica, partimos das disputas em torno da produção de evidências que embasam as práticas médicas. Demonstramos como esses procedimentos violam os direitos humanos à saúde, à integridade corporal e à autonomia e os direitos sexuais e reprodutivos, e analisamos quais têm sido as estratégias para evitar essas violações. Propomos que pessoas intersexo estejam no centro das decisões sobre o próprio corpo e que sejam debatidos, junto a pacientes e familiares, caminhos não cirúrgicos e proibidas intervenções precoces, invasivas, mutilatórias, prejudiciais, cosméticas e não consentidas nos corpos de crianças intersexo. A proposição de mudanças em instrumentos norteadores que deixem de regular esses corpos é necessária para, a partir de uma perspectiva interdisciplinar, incluir instâncias bioéticas e de direitos humanos, assim como pessoas do ativismo político intersexo.

Pessoas Intersexo; Criança; Direitos Humanos; Bioética

Resumen

En Brasil, los niños intersexuales todavía están sujetos a procedimientos de asignación de sexo binario al nacer y a intervenciones corporales posteriores. La Resolución nº 1.664/2003, del Consejo Federal de Medicina, asegura las intervenciones sobre corporalidades intersexuales y es el único instrumento normativo nacional sobre el tema. Sin embargo, las demandas que surgieron desde el activismo político internacional intersexual plantean cómo las intervenciones tempranas en la infancia para la asignación de género binario mutilan el cuerpo de los niños y vulneran una serie de derechos humanos. Esta investigación tiene por objetivo identificar cómo los procedimientos tempranos, irreversibles y normalizadores, realizados sin el consentimiento de la persona intersexual producen violadores de los derechos humanos. Con base en el concepto de (in)justicia epistémica, partimos de las disputas en torno a la producción de evidencia que subyace a las prácticas médicas. Demostramos cómo estos procedimientos vulneran los derechos humanos a la salud, la integridad y autonomía corporales, y los derechos sexuales y reproductivos, además, analizamos qué estrategias se han utilizado para evitarlos. Debatimos que las personas intersexuales deben estar en el centro de las decisiones sobre sus propios cuerpos y que se discutan con pacientes y familiares formas no quirúrgicas e intervenciones tempranas, invasivas, mutiladoras, dañinas, cosméticas y no consensuales en los cuerpos de los niños intersexuales. Los cambios en los instrumentos rectores para que dejen de regular estos cuerpos son necesarios para que, desde una perspectiva interdisciplinaria, se incluyan instancias de bioética y derechos humanos, así como a personas del activismo político intersexual.

Personas Intersexuales; Niño; Derechos Humanos; Bioética

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