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Legal, ethical, and human rights considerations for physicians treating children with atypical or ambiguous genitalia

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ABSTRACT

Some governments, human rights organizations, intersex organizations, and doctors have called for a moratorium on genital and gonadal surgeries for infants born with atypical or ambiguous genitalia. Moratorium supporters believe that the surgeries carry physical and emotional risks, the psychosocial benefits of these procedures have not been proven, and the surgeries violate the patients' fundamental human rights if they are performed before these patients can provide informed consent. Given these calls for a moratorium, treatment teams must determine how to treat their patients and how to counsel their patients' parents. This article examines the treatment teams' ethical and legal responsibilities and provides advice for treatment teams to follow that will protect their patients and their practices.

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Given the differences of opinion regarding early surgeries on intersex infants, treatment teams face challenges in determining the optimal treatment course to enhance their patients' quality of life. This article highlights the ethical and legal issues that may arise when treatment teams counsel parents who are responsible for making treatment decisions on behalf of their intersex children.

Government and human rights organizations' findings regarding early surgery

A number of government entities and human rights organizations have concluded that surgeries performed on intersex infants or young children for what they consider to be cosmetic or psychosocial reasons, as opposed to biological function reasons, should be delayed until the children are old enough to decide for themselves whether they want to undergo any surgical modification.

Government agencies in the United States, Germany, Switzerland, Australia, Chile, Argentina, and Malta have studied the issue. In 2016, the United States Bureau of Public Affairs issued a statement on behalf of the State Department that acknowledged that medical surgeries conducted on intersex children without their free and informed consent "jeopardize their physical integrity and ability to live free."¹ In 2012, the German Ethics Council called for a deferral of these surgeries until the children are old enough to consent and concluded that "[i]rreversible medical sex assignment measures in persons of ambiguous gender infringe the right to physical integrity, to preservation of sexual and gender identity, to an open future and often also to procreative freedom."² A Swiss Bioethics Commission reached the same conclusion and found that these medical practices are incompatible with fundamental human rights, specifically with respect to the patient's physical and psychological integrity and the right to self-determination.³ Similarly, in 2013, the Australian Senate Community Affairs References Committee recommended

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that “medical treatment of people with intersex traits take place under guidelines that ensure treatment is managed ... within a human rights framework ... that favour(s) deferral of treatment until the person can give fully informed consent” and that treatment guidelines should seek to minimize surgical intervention on infants undertaken primarily for psychosocial reasons.⁴ Similar positions have been adopted by Chile⁵ and Argentina.⁶

These government agency and committee recommendations do not have the force of law; they are primarily reports that were commissioned by the legislative bodies of each of these countries. For a legal ban on these procedures to be put in place, legislatures would need to pass a law adopting the committee recommendations or a court would need to rule that these procedures can no longer be performed. In 2015, Malta became the first country to pass a law limiting the circumstances under which these surgeries can be performed.⁷

In addition to these government recommendations, a number of international human rights organizations have examined the current treatment protocols for infants born with intersex traits and have reached the same conclusion. The World Health Organization, in conjunction with a number of U.N. organizations, concluded that medical interventions on infants with intersex traits should be postponed until a child is sufficiently mature to participate in the decision-making and give full, free and informed consent.⁸ The United Nations Special Rapporteur on Torture has called on states to ban genital-normalizing surgery when it is performed without the free and informed consent of the person concerned.⁹ The U.N. Committee on the Rights of the Child (CRC) studied the treatment of intersex infants in a number of states and has called for a ban on these procedures and even suggested redress and compensation for those who have undergone these procedures without their consent. The CRC has directed a number of countries to change their practices “to guarantee bodily integrity, autonomy and self-determination of ... intersex children, by avoiding unnecessary medical or surgical treatment during infancy or childhood.”¹⁰

Informed consent: The legal requirements

No federal or state laws in the United States specifically address the appropriate treatment for children who are born with atypical or ambiguous genitalia. Therefore, as an initial matter, general informed consent requirements must be followed when parents are asked to approve medical procedures for their children.

Before physicians perform a medical procedure, they must obtain the informed consent of the patient or the permission of a surrogate; in this case, the permission of the parents. For consent to be valid, it must be a fully informed consent. Decision-makers must have adequate information to understand the immediate and long-term implications of all treatment options so that they can make an intelligent choice. In addition, they must have enough time to meaningfully weigh the options. In determining the information that must be conveyed, some states apply the test of what a reasonable

decision-maker would want to know, while other states apply a medical community standard.

The United States and many other countries give great deference to parental decisions about the medical treatment of their children. Courts typically do not intervene in a parent's decision if the doctor agrees with the parent. In some circumstances, however, courts have limited the ability of a parent to consent to medical procedures. Courts have ruled that procedures involving constitutionally protected rights (e.g., reproductive rights) and highly invasive and irreversible procedures (e.g., ECT therapy, psychosurgery) can only be performed with a court order authorizing the procedure.¹¹⁻¹³ However, the case law is sparse and states differ on the types of treatments that require a court order.

Application of informed consent rules to the treatment of children with intersex traits

Parental consent to surgeries on intersex infants may be problematic for two reasons. First, it is questionable whether parents by themselves have the legal authority to assent to these surgeries if the surgery affects what may be considered a constitutionally protected right. Second, even if parents have the authority to approve these procedures on their own, current informed consent practices may need to be improved to ensure that parental consent is valid and the fundamental human rights of the children are protected.

Given that surgical alteration of intersex infants may cause irreversible harm and affect the child's fundamental human rights, a court could determine that parental consent to infant genital surgery performed for cosmetic or psychosocial reasons is invalid without a court order.¹² Given the growing international consensus that only the patients should have the power to make the decision whether to undergo surgery when they are old enough to assess the risks and the benefits, some courts may halt or severely curtail the ability of parents to approve these procedures.

Even if a court determines that parents are legally allowed to authorize these procedures, treatment teams need to thoroughly inform the parents, ensure that the parents fully understand the immediate and long-term implications of all treatment options, and provide sufficient time so that the parents can meaningfully weigh all choices.¹⁴

Obtaining a fully informed parental consent to surgery on an intersex infant is more complex than obtaining informed consent for many other types of procedures for a number of reasons. First, parents often know little or nothing about intersexuality before the birth of their child. Second, sex differentiation is a scientifically complex topic and parents need time to learn about the subject. Third, most parents will need time to emotionally adjust to giving birth to a child who some may view as “less than perfect.” Finally, decisions relating to sex, gender identity, and sexual orientation are heavily influenced by stereotypes. Thus, parents require education, emotional and peer support, and time to help them work through their value judgments and emotions.¹⁴⁻¹⁶

A limited number of courts have examined parental consent to genital surgery on their children. In 1999, the Constitutional Court of Colombia, placed severe limitations on

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