

Study recommends that parents, physicians share decisions in sex development disorder surgery

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A shared decision-making process would assist doctors and parents who are facing the extraordinarily complex, challenging and controversial choices presented when infants are born with genetic or anatomical anomalies in sexual development and are being considered for elective corrective surgery, a new research paper suggests.

The paper does not address instances in which infants are born with conditions that pose an imminent threat to their health — such as when children are born without a urinary opening. Instead, the paper is intended to propose guidelines for use when surgery is being considered to make a child's appearance more typical of their sex in order to facilitate their gender-identity development.

"Difficult Decisions: Disorders of Sex Development and [Surgical Intervention](#)" is published online in the August issue of the *Journal of Pediatric Endocrinology and Metabolism*. In it the researchers suggest that a six-step decision-making approach would afford health-care providers the opportunity to clarify the reasons for their recommendations, identify and fill gaps in parents' understanding of their child's diagnosis and treatment options, and explore the values underlying both parents' and clinicians' concerns.

"The big issue that we are addressing is that there is no standard approach or best practice for physicians and family members to follow

to address decision making for infants who are born with disorders of sex development" or with atypical [sexual development](#), said Alexander Kon, senior author of the study and associate professor of pediatrics and [bioethics](#) at the UC Davis School of Medicine.

Study first author Katrina Karzakis, a senior research scholar at the Center for [Biomedical Ethics](#) at Stanford University, agreed.

"There are a lot of gaps in evidence-based medicine regarding these types of procedures that aren't going to be filled any time soon," said Karzakis, who is the author of a book on disorders of sex development called "Fixing Sex: Intersex, Medical Authority and Lived Experience." "But, every day, physicians are seeing patients in the clinic and parents are struggling to make decisions about the best way to care for them."

Disorders of sex development, or differentiation, refer to congenital conditions in which the development of chromosomal, gonadal or anatomical sex is atypical. The disorders include a broad range of conditions such as ones in which infants are born with genitalia having both masculine and feminine attributes, and infants whose genitalia is atypical for their sex because it is over-masculinized for a female or else under-masculinized for a male.

Karzakis said that the overall incidence of disorders of sex development is estimated at 1 in 2,000. But approximately 70 percent of patients experience a family of disorders called congenital adrenal hyperplasia. Most of the conditions involve excessive or deficient production of sex steroids and can alter development of primary or secondary sex characteristics.

Numerous health-care organizations — including the Institute of Medicine and American College of Physicians — have suggested that there is a need for a clearly defined process for medical decision

making. The authors have applied this recommendation to the process for considering elective genital surgery, or genitoplasty, for children born with atypical sex development. In the past, such decisions have been driven by physicians' and parents' personal values and "gut feelings," often with less-than-optimal outcomes, the study says. Health-care providers often report feeling conflicted about whether they have made the right recommendations to families, and parents report feeling rushed into decision making. The researchers said that shared decision making would require clinical caregivers to reveal their reasoning, values and biases and explore their patients' or their surrogates feelings.

"The pediatric literature suggests that about a quarter of families want completely family-driven decision making and another quarter want completely physician-driven decision making," Kon said. "The other half want shared decision making. We tried to develop a process that would allow families to feel comfortable with expressing their feelings and values in a setting that also involves physicians, nurses, chaplains and others in the process."

"We realized," Karzakis said, "that we could help to improve decision making for patients with disorders of sex development just by working on the decision-making process. Part of what we're saying in this paper is that you don't need to know all the answers, and a decision about gender assignment does not have to be a decision about surgery — you don't have to conflate those decisions."

The researchers recommend these six steps for shared decision making:

1. Set the stage and develop an appropriate team, for example, including all of the subspecialists required for such a complex decision and ensuring parents are comfortable with team members.

2. Establish preferences for information and roles in decision making to ensure that parents have access to the amount of information that they want in the manner they want to receive it.
3. Perceive and address emotions associated with the decision-making process to ensure that parents' need for information and their feelings about the decision are acknowledged. Parents who are overly anxious about the child's atypical genitals may not be prepared to effectively participate in the decision-making process and may be unable to offer truly informed permission. To the extent possible, parents who are experiencing strong emotional responses need help addressing these feelings before authorizing elective surgery.
4. Define concerns and values, since how physicians frame discussions with parents can have a significant impact on how a family may perceive the circumstance and their child. If the problem is defined as "abnormal genitals," the response may be different from "challenges of growing up with an atypical body." The discussion, therefore, should shift the discussion away from the choice of whether or not to have surgery to "how do we best address the concerns we've identified?"
5. Identify options and present evidence in an objective fashion presenting the potential choices and the evidence associated with the choices available. Providers should strive for objectivity, conveying what the team believes is the best course of action and why it is supported by evidence.
6. Shared responsibility for making a decision is facilitated by using the six-step process. Parents should have received unbiased information and emotional support to help them make sound

choices. The health-care team will have gained insight into the parents' priorities and the family's circumstances, hopefully leading to a consensus based on trust and understanding.

Provided by University of California - Davis

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