Ambiguous Genitalia Management: It Takes a Team

BY SHERRY BOSCHERT
San Francisco Bureau

It’s one of the first things that parents want to know when a baby is born: girl or boy? When the answer isn’t clear, physicians walk into a mine field of choices that could have lifelong repercussions for the child and the parents. Psychiatrists, psychologists, and social workers today play a much bigger role—and surgeons less of a role—in the care of people with disorders of sex development, compared with past management practices.

“I think the field has revolutionized in the last 10-15 years. The impetus for that largely came from patients themselves,” said Dr. Joel Frader, a pediatrician at Children’s Memorial Hospital and Northwestern University, Chicago.

The revolution is still in progress, with a bit of chaos in the streets. A dearth of research data to inform guidelines leaves clinicians with little to follow besides opinion-based consensus statements and their instincts.

“Because the ultimate outcomes are unpredictable from our standpoint, there is no standard of care. We don’t really know what to do clinically. We’re not sure what to do psychologically. Yet mothers and fathers have to go ahead and raise their child in the context of social situation,” said Dr. William G. Reiner, a psychiatrist and urologist who is director of the psychosexual development clinic at the University of Oklahoma Health Sciences Center, Oklahoma City.

Some key points of agreement, however, inform current practices. Don’t rush to surgery. Integrate psychological care for the family and the child. Consult a multidisciplinary team (preferably at an experienced center) that may include a pediatric endocrinologist, pediatric urologist or surgeon, gynecologist, child psychiatrist or psychologist, geneticist, neonatologist, social worker, nurses, and medical ethicist if needed. Be honest with parents and patients. Emphasize functional rather than cosmetic reasons in any treatment. Make management patient-centered and consider the long-term physical, psychological, and sexual well-being of the patient.

“The single biggest change is our recognition that the infant born with anomalous genitalia is a real, live human being, not a blank slate,” Dr. Reiner said. “We have no idea what that child is going to be like at age 5, or 15, or 50.”

A decade ago, Dr. Frader recalled, training manuals and textbooks for general pediatricians or pediatric endocrinologists reported the problems now called disorders of sex development (DSD) as psychological emergencies.

“That sets a very inappropriate tone. There’s nothing emergent in 99.9% of these cases,” he said. A small minority of babies with congenital adrenal hyperplasia will have life-threatening endocrinologic disturbances that have nothing to do with the appearance of the genitalia. “So there’s never a surgical emergency,” he stressed.

Dr. William Byne, a psychiatrist at Mount Sinai School of Medicine in New York, added, “If there’s a psychosocial emergency in the delivery room, a mental health professional should be brought in. The birth of an intersex child is rarely a medical emergency. We should not rush to make irreversible medical decisions at a time of crisis.”

Unfortunately, he and other experts agreed, there are not enough mental health providers trained to handle DSD.

Dr. Byne, Dr. Frader, and Dr. Reiner contributed to the 2006 Clinical Guidelines for the Management of Disorders of Sex Development in Childhood, which was produced by a consortium of clinicians, patients, and parents and published by the Intersex Society of North America (www.dsdguidelines.org).

Dr. Reiner also was 1 of 50 U.S. and European experts who produced the separate Management of Intersex Disorders from the Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology around the same time (Pediatrics 2006;118:4488-500).

In the past—and sometimes today—intersex newborns would be separated from mothers while a paternalistic cadre of physicians kept parents uninformed until the physicians declared how they would “fix” the child’s problems by surgically altering the genitalia. Most intersex children were never told of their condition.

“The medical model has been that sexual ambiguity is incompatible with their psychological health,” said Cheryl Chase, executive director of the Intersex Society of North America, Rohernt Park, Calif. “There is not a single medical indication for surgery. Not informing patients of their DSD as they grow up can lead to psychiatric crises later on.”

Dr. Byne

Not informing patients of their disorders as they grow up can lead to psychiatric crises later on.

BY SHERRY BOSCHERT
San Francisco Bureau

San Francisco — An anger management intervention that was designed specifically for boys significantly improved their emotional vocabulary, according to preliminary results reported by Arnie Coonerty-Femiano at the annual meeting of the American Psychological Association.

Fourteen eighth-grade boys in a rural school district who were referred by a psychologist or guidance counselor were taking medications for a disorder. One group of seven boys pursued the anger management program, and the other seven waited 8 weeks before starting the program, serving as a control group.

The treatment strategy was to nurture anger secondary to other emotions, and use concepts from cognitive-behavioral therapy to teach about connections between thoughts, feelings, and behavior. The program also raises awareness about emotions and emotions related to thoughts, said Ms. Coonerty-Femiano, a doctoral student at Boston College, and her associates.

The first treatment group significantly improved its emotional vocabulary score from four to eight emotions at the end of 8 weeks, she said. When the delayed-treatment (control) group went through the program, its emotional vocabulary score increased significantly from five to eight emotions.

One of the most successful strategies employed by the intervention was a questionnaire at the start that asked what media the boys consumed, and those media were incorporated into the intervention, she said. Topics and exercises were introduced using examples of emotional experiences and reactions from the “South Park” television cartoon show and movies starting Adam Sandler. These references to the popular culture engaged the boys’ attention and participation.

In one exercise, boys in the intervention group sorted “feeling cards” representing different emotions by categorizing emotions experienced by boys or girls “or not sure.”

In another exercise, cards representing emotions that triggered anger generated discussion of the boys’ thoughts and feelings at the time of the event, how they reacted, and how they felt about their reaction.

Participants in the program had a variety of diagnoses, including depression, attention-deficit/hyperactivity disorder, bipolar disorder, and oppositional-defiant disorder. Half the boys already were in individual therapy, and half were taking medications for a disorder.

Anecdotally after the study, the names of boys in the intervention group came up less often in weekly meetings of school guidance counselors, where the boys initially had been flagged for intervention.

“I’m not sure if that’s due to the group, but we would like to think so,” she said.

Besides increasing emotional vocabulary, the intervention changed awareness of other feelings that accompany anger, and awareness of obstacles faced specifically by boys when expressing anger. Themes from parents’ comments were that boys don’t like being vulnerable, and that strategies are needed to make a safe environment for them to express feelings, she said.

---

Anger Management for Boys Increases Emotional Vocabulary

The program raises awareness about differences between boys and girls related to emotions.

MS. COONERTY-FEMIANO

The program raises awareness about differences between boys and girls related to emotions.

The program raises awareness about differences between boys and girls related to emotions.