Ambiguous Genitalia Management: It Takes a Team

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 Aimee Cooney-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 met weekly for 44-minute group sessions with an anger management counselor for 8 weeks. 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 intervention, which is secondarily to other emotions, and uses concepts from cognitive-behavioral therapy to teach about connections between thoughts, feelings, and behavior. The program also raises awareness about differences between boys and girls related to emotions.

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MS. COONEY-FEMIANO

Our approach in improving emotional vocabulary, the intervention changed awareness of other feelings that accompany anger, and awareness of obstacles faced specifically by boys when expressing emotions. The boys’ 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.

Dr. Byne has treated a number of suicidal adults whose problems included a huge sense of betrayal after discovering their DSD history. Although it is commonly believed that cosmetic surgery on intersex children in the first year of life relieves parental distress and improves the attachment between the child and the parents, there is scant evidence for this. Almost anything a surgeon does to “fix” a young child with DSD will interfere in the long run with the patient’s ability to experience sexual pleasure, said Dr. Frader.

The “vast majority” of patients with DSD do not undergo surgery in the first year of life, said Dr. John P. Gearhart, professor and chief of pediatric urology at Johns Hopkins University, Baltimore. Some surgeries are done for functional reasons (like ensuring proper urinary drainage to avoid infections), and others are done to make the baby “look normal,” he said. Dr. Gearhart called the birth of an intersex child a “true emergency situation” in an article he coauthored that has been criticized by other DSD experts (Urol. Int. 2005;75:291-7).

Dr. Reiner said, “I think most of the children are going to want surgery, but what surgery isn’t clear.” The consortium’s clinical guidelines recommend delaying surgery or hormonal treatment until the patient can participate in the decision, which usually means until puberty.

Others take a middle ground, saying evaluation must include assessment of the parents’ ability to cope with the stress of genital ambiguity in their child. Some parents will demand surgery even when it is not being recommended. “I’ve seen it happen,” Dr. Reiner said.

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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 category. The boys’ emotions experienced by boys or girls or “not sure.”

In another exercise, cards representing events 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 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 emotions. The boys’ 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.

Not informing patients of their disorders as they grow up can lead to psychiatric crises when they discover during puberty or adulthood what their parents and physicians haven’t told them. Dr. Byne has treated a number of suicidal adults whose problems included a huge sense of betrayal after discovering their DSD history.

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