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SCIENCE–IN THE NEWS

Ashley's Case

In October 2006, Gunther and Diekema published a case report concerning treatment of a 6½-year-old girl with "profound developmental disability" at Children's Hospital in Seattle (1). The authors describe and justify use of high-dose estrogen to close long-bone epiphyses, limiting linear growth and overall weight gain. The child also had a hysterectomy, without oophorectomy, and breast bud removal. An accompanying editorial questioned the interventions (2). The medical publications created some controversy, however, and the parents' posting a "weblog," (http://ashleytreatment.spaces.live.com) drew tremendous public and media attention.

The case raises medical, social, and ethical questions. Might the onset of early puberty (as hinted at in the case report) have limited growth, making the risks of pharmacologic estrogen unnecessary? As the patient will always wear diapers, how would menses change her care? What do the parents and doctors mean when they refer to "complications of menses?" Aren't nonsteroidal anti-inflammatory drugs usually adequate treatment for menstrual cramps? How does one balance the risks of elective surgery (hysterectomy and mastectomies) against nonrealized, projected quality-of-life considerations (cramps, uncomfortable examinations for uterine/cervical cancer, weight of full breasts)? What does it say about our responses to persons with disabilities that parents worry that a normal-sized daughter would impede their ability to provide loving care? Can we specify *clear* limits on parental decisions in controversial situations involving patients who cannot speak for themselves? This case demonstrates ethical quandaries when parents request or refuse possible interventions with disputed benefits, such as cosmetic genital surgery for children with disorders of sex development (ambiguous genitalia) or cochlear implants for congenital deafness.

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Pediatricians have been altering patient height for some time by limiting calories, use of estrogen, and growth hormone (GH). The availability of GH has made size modification relatively easy, if expensive. GH use has become routine in children with chronic kidney disease and Turner syndrome, for example, and provokes less controversy than its use in short children without a clear pathologic condition. The goal of increasing adult height is similar and it is not clear that we can more easily justify conferring the social advantages of taller stature on those with a recognized diagnosis.

Ashley will never have any conscious recognition of her own size. With that in mind, altering her linear growth, assuming "treatment" has little risk of harm, raises different questions from giving hormones to otherwise normal, preteenage or early teenage girls because their parents do not want them, for social reasons, "too tall." Ashley's surgery, with speculative benefits and inherent risks of elective general anesthesia, mastectomy, and hysterectomy may fall into a qualitatively different category from the estrogen administration.

The case should stimulate at least three important discussions. First, can we adequately support families of children with serious disabilities in ways that might make growth attenuation unnecessary? Second, how do we define, then weigh, benefits and risks of interventions for patients with permanent, severe cognitive impairments? Third, should we reconsider the relatively free use of elective treatments, medical and surgical, for cosmetic purposes or with only long-term projected impacts, for patients who cannot express their views? − *Joel E. Frader.*

REFERENCES

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