PEDIATRICS®
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Early Genital Surgery to Remain Controversial

Katrina A. Karkazis

Pediatrics 2006;118;814-815
DOI: 10.1542/peds.2006-1067

COMMENTARY

Early Genital Surgery to Remain Controversial

Katrina A. Karkazis, PhD, MPH

Center for Biomedical Ethics, Stanford University, Palo Alto, California

The author has indicated she has no financial relationships relevant to this article to disclose.

In late 2005, 50 international experts spanning multiple medical specialties gathered to revisit treatment guidelines for infants born with intersex diagnoses (see "Consensus Statement on Management of Intersex Disorders"[1] in this month's *Pediatrics Electronic Pages*). It marked the first time that physicians had so thoroughly revisited the medical standard of care for these diagnoses since psychologist John Money and his associates first proposed treatment standards for infants with intersex disorders in the 1950s.[2,3]

Participants agreed to recommend several important changes to care that demonstrate a significant shift in thinking regarding the treatment of infants with intersex disorders. Providing admirable recognition and caution, the guidelines stress that intersex conditions are not shameful, that psychological care should be integral to medical care, and that open communication with parents and patients is essential. Because of the recognition that nomenclature tends to confuse, mislead, and alarm parents, patients, and even clinicians, participants proposed a change in the terminology and diagnostic labels. Suggesting a willingness to think more expansively about gender and its relationship to sexuality, the guidelines note that homosexuality should not be construed as an indication of incorrect gender assignment, and they recommend that the potential for fertility (originally emphasized for female gender assignment only) be an important consideration for male gender assignment as well.

The new guidelines, although commendable, fail to resolve what lies at the center of current controversies: early genital surgery. Acknowledging that there are minimal systematic surgical outcome data about genital surgery (whether on cosmetic appearance or sexual function), that orgasmic function may be harmed by surgery, and that there is little support for the widely held belief that surgery performed in the first year of life relieves parental distress about atypical genitals, the statement nevertheless recommends early surgery for "cases of severe virilization," which would include clitoral reduction and vaginoplasty.

Although surgeons have incorporated increasing anatomic understanding into their techniques, which they hypothesize should preserve sexual sensation and orgasmic capability, the claim that current surgical techniques preserve sensation is unsupported by the available data. There have been very few systematic long-term studies of these procedures. Completed studies have relied on small sample sizes and have often involved surgeons' assessment of their own work, which raises significant concerns about observer bias. Other factors such as age at first surgery, age at evaluation (from immediately postoperation to ≥20 years after surgery), the surgical method used, criteria for success (if detailed at all), and modes of assessing sensation (eg, proxy measures such as blood flow and electromagnetic response) all vary enormously in these studies making their results difficult to generalize.

Until very recently, most studies did not include subjective assessment. If one agrees that such assessment is critical, these studies cannot be conducted until individuals are old enough to participate meaningfully, which means studies would assess techniques and instrumentation that are almost 2 decades old. Surgery, then, will always be a few steps ahead of anyone's knowledge of its efficacy. In the wake of these gaps in knowledge, cred-

www.pediatrics.org/cgi/doi/10.1542/peds.2006-1067

doi:10.1542/peds.2006-1067

Accepted for publication Apr 12, 2006

Address correspondence to Katrina A. Karkazis, PhD, MPH, Center for Biomedical Ethics, Stanford University, 701 Welch Rd, Suite A1105, Palo Alto, CA 94304. E-mail: karkazis@stanford.edu

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

ibility struggles arise, with surgeons arguing that surgery produces good outcomes and some adults with intersex disorders arguing that it does not. Often, the claims and experiences of adults with intersex disorders are dismissed as anecdotal, but the truth is that the only available evidence seems to contradict the widespread belief that early genital surgery either preserves sensation or provides acceptable outcomes.

Although the consensus statement makes many important and laudable recommendations that, if implemented, will undoubtedly improve care for patients and families, it would be premature to assume that it has resolved that which remains most contentious: early genital surgery to normalize atypical genitals.

REFERENCES

1. Lee PA, Houk CP, Ahmed SF, Hughes IA; International Consensus Conference on Intersex. Consensus statement on management of intersex disorders. *Pediatrics*. 2006;118(2). Available at: www.pediatrics.org/cgi/content/full/118/2/e488
2. Money J, Hampson JG, Hampson JL. Hermaphroditism: recommendations concerning assignment of sex, change of sex, and psychologic management. *Bulletin of Johns Hopkins Hospital*. 1955;97:284–300
3. Money J. Hermaphrodism: recommendations concerning case management. *J Clin Endocrinol Metab*. 1956;4:547–556

PATIENTS GET NEW TOOLS TO PRICE HEALTH CARE: TO ENABLE COMPARISON SHOPPING, MORE INSURERS AND STATES REVEAL THE COSTS OF MANY PROCEDURES

"Consumers are finally getting some of the tools they need to comparison-shop for health care the way they do for cars or personal computers, though it's too early to tell whether people will use these new services. . . . The new pricing services are popping up as consumers are being asked to shoulder an ever-greater proportion of their health care costs. Employer-sponsored and other health plans are shifting more of the cost of health care to consumers by raising co-payments and cutting benefits. That dovetails with efforts by the Bush administration to promote so-called consumer-driven health care, mainly through high-deductible insurance policies paired with health savings accounts that offer financial incentives to shop wisely for care. . . . Some tools are available only to an insurer's own enrollees in certain cities. Public Web sites that disclose hospital costs typically focus on 'charges,' which are the undiscounted 'list' prices that don't typically apply to people who have insurance. And while some tools, including Aetna's and Cigna's, are adding information on quality of care, comparative data in that area are still hard to come by. So patients may simply opt for the costlier options in the absence of any other gauge of quality, even though one of the goals of consumer-driven health care is to lower costs."

Rubenstein S. *Wall Street Journal*. June 13, 2006
Noted by JFL, MD

Early Genital Surgery to Remain Controversial

Katrina A. Karkazis

Pediatrics 2006;118;814-815
DOI: 10.1542/peds.2006-1067