

EDITORIALS



Parental choice on normalising cosmetic genital surgery

Between a rock and a hard place

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About 1 in 2000 children are born with genitalia considered atypical enough to prompt medical investigation. Underlying causes include complex genetic and hormonal conditions as well as unexplained anatomical anomalies such as hypospadias. Paediatricians have previously stated that the determining factor in deciding to raise a child as a boy is the “size of the phallus.”^{1,2} Newborn penile size charts were used in the 1960s, and any child with a penis of stretched length less than 2.5 cm was likely to be assigned female regardless of the underlying diagnosis; feminising genital surgery usually followed.¹ Gender assignment has become less simplistic but normalising surgery remains common. As a result, little is known about the physical, psychological, social, and sexual effects of untreated atypical genitalia associated with different diagnoses. It has been impossible to determine to what extent difficulties reported by adults are caused by the anatomical difference, other aspects of the diagnosis, the imperfect results of surgery, poor psychological care, or a combination of these factors.

Paediatricians’ confidence in the ability to construct genital anatomies to meet cultural expectations of appearance and function has not been borne out. The intended outcomes of these interventions can be known only when individuals reach puberty and adulthood, and reliable longitudinal research does not exist. Persistent concerns from adults who have had surgery in childhood have prompted research with adolescents and adults. In a landmark study with 44 adolescent girls born with atypical genitalia, despite multiple feminising genitoplasties in childhood, almost all participants required further surgery to facilitate menstrual flow, vaginal intercourse, or both.³

Subsequent research has identified increased difficulty with orgasm among women who had had clitoral surgery⁴ and diminished genital sensitivity specific to the site of surgery.⁵ Similar doubts have been cast over surgery for hypospadias.⁶ Patient narratives point to the potential harm of multiple operations and repeated genital examinations.⁷ The rate of female assigned and surgically feminised children who reassign as male is of concern.⁸

Surgical techniques for childhood conditions can change long before adult outcomes are known, and experts in surgery have so far been unable to reach a consensus about the best operation. Parents may not realise that they are de facto opting for experimental surgery on their children. Furthermore, their emotional states during decision making may not be optimal. Research suggests that medicalised presentations of genital difference have undue influence on parental decisions⁹ and that parental regret can be high.¹⁰

Credible alternative

In 2012 the law in Germany was changed to allow parents to leave the gender of their baby blank on the birth certificate. The aim was to remove pressure to make premature decisions on irrevocable sex assignment surgery. However, such an aim can be met only if clinical services are able to provide a credible alternative to surgery. There is no evidence that parents are given sufficient time to appreciate their child, effective psychosocial support to manage their emotional reactions, or help to slowly digest the highly complex medical information and implications.

There is no identifiable psychoeducational care pathway to help parents deal with situations that may feel daunting, such as talking to nursery staff and babysitters or discussing with siblings and eventually the affected child about diversity in sex and gender. Skills and confidence will increase with practice, and parents need practical resources and mentoring not verbal instructions that are easier said than done.

Lack of funding is often cited as the reason for the absence of consistent psychosocial follow-up. However, such support may amount to no more than the team nurse and psychologist offering telephone follow-ups and educating community based care providers such as the general practitioner or health visitor to assist the family. The hospital payment structure encourages controversial, invasive, and expensive surgical interventions rather than low cost alternatives. Ongoing contact with tertiary centres, which is part of the surgical trajectory, may seem preferable to parents if the alternative is to be sent home with

no help at all. To improve clinical practice, an additional, non-surgical care protocol is required to enable parents to cope with what may feel like insurmountable pressure to appear normal. Without this, most parents may find it impossible to delay surgery.

In April 2015, the European Union Agency for Fundamental Rights deliberated on the rights of intersex people and recommended that member states “avoid non-consensual sex normalising medical treatments on intersex people,” mirroring earlier recommendations by the European parliament and the United Nations. Earlier this year Malta became the first nation to put a moratorium on “non-vital” childhood genital surgery.

In the UK, genital surgery for children with atypical genitalia remains part of standard medical care.¹¹ Given the contentious scientific issues and in light of recent international recommendations, audit of all such surgery should become mandatory. Furthermore, a credible non-surgical care pathway for affected families should be a performance indicator against which standards of care are judged. Given the increasingly adversarial atmosphere in this field, more of the same is not an option.

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