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Emotionally and cognitively informed consent for clinical care for differences of sex development

Anne Tamar-Mattis[a], Arlene Baratz[b], Katharine Baratz Dalke[c] and Katrina Karkazis[d]*

[a]*Advocates for Informed Choice, Cotati, CA, USA;* [b]*Androgen Insensitivity Syndrome/Disorders of Sex Development Support Group, Pittsburgh, PA, USA;* [c]*Department of Psychiatry, Hospital of the University of Pennsylvania, Philadelphia, PA, USA;* [d]*Center for Biomedical Ethics, Stanford University, Stanford, CA, USA*

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Clinicians who utilise recommended best practices for informed consent may be surprised that families in support groups frequently report that some physicians continue to recommend certain irreversible treatments for children with differences of sex development (DSD) without adequate psychosocial support for cognitive processing of information necessary to decision-making. Such practice is contrary to recommendations in the 2006 Consensus Statement on Management of Intersex Disorders. When psychological preparation is lacking for aspects of DSD such as uncertainty about future gender identity, a false sense of urgency can propel parents to agree to genital surgery or removal of gonads without adequate understanding of the long-term consequences in adulthood. If physicians are uncomfortable discussing gender and sexual issues, they may not explore the feasibility of, or offer support for, alternative approaches towards sex atypicality. Families may draw unrealistic conclusions regarding the extent to which such interventions will relieve their distress and improve quality of life for the child and family. Failing to offer adequate psychosocial support to parents making irreversible decisions about DSD can raise significant ethical and legal concerns. Families may experience regret and anger when they make decisions on the basis of limited or even biased information while in an emotionally vulnerable state. Children's autonomy is violated when they are completely excluded from decision-making. We propose adoption of a holistic approach to emotionally and cognitively informed consent in this setting, with inclusion of psychosocial and peer support from the earliest stages.

Keywords: disorders of sex development; intersex; informed consent; genital surgery

1. Introduction

Ideas about appropriate and beneficent care for individuals with differences of sex development (DSD) have undergone broad change over the last two decades, culminating in the 2006 Consensus Statement on Management of Intersex Disorders (CS) (Lee, Houk, Ahmed, & Hughes, 2006). The CS recommends several significant changes to care, including such areas as surgical decision-making (genital and gonadal), medical examination, medical photography and disclosure of diagnosis. This paper highlights aspects of informed consent that deserve special attention in light of the significant shifts in the CS, including the stated importance of attending to emotional aspects of consent.

*Corresponding author. Email: Karkazis@stanford.edu

A challenge when writing about clinical practice is how to do so without flattening the variability that occurs in the provision of care. Variables such as the individual practitioner, the patient, the institution, the organisation and financing of health care and also the culture in which care is being provided all shape the doctor–patient encounter. In light of these multiple factors influencing clinical practice, we cannot purport to describe 'what is' regarding informed consent practices for DSD, but rather what 'should be'. Our perspective is informed in part by our experiences with the over 200 families in the United States who engage with our support and advocacy work. Given the variability in clinical practice, some physicians and surgeons may not engage in some of the practices we pinpoint for improvement in our discussion and some may already utilise the suggested practices. Based on perspectives in the United States, this paper is a call to action for stakeholders to develop more consistent practices regarding informed consent including involvement of mental health providers and provision of peer support at the earliest stages and where these crucial elements are still lacking.

2. What is informed consent?

The concept of informed consent for clinical care has evolved over the last several decades, but generally rests on the notion that competent patients (or their surrogates) have the right to self-determination, which is understood as an awareness of and choice among treatments. Physicians have a corresponding duty to give their patients adequate information to ensure they can make an informed decision regarding their treatment choices, including the choice of no treatment. A common misunderstanding within and outside medicine is that informed consent consists merely of signing a consent form (often on the day of the scheduled treatment) after a cursory discussion of the procedure and its risks (Jones, McCullough, & Richman, 2005). True and meaningful informed consent, however, is a *process* of communication between the physician and the patient (Karkazis, Tamar-Mattis, & Kon, 2010). Informed consent thus requires physicians to take steps to ensure that patients understand the immediate and long-term implications of medical interventions and alternatives, have time to weigh these considerations, and are able to make decisions with the support of health care providers and free from coercion.

Informed consent is necessary for surgical procedures as well as for many commonplace interventions such as intravenous line placement and administration of contrast for radiology studies. Since the goal of the informed consent process is to enable the patient or surrogate to make an informed decision, the process may be more or less involved according to the complexity of the procedure and the decision. A procedure that is simple, well-understood, uncontroversial and low-risk may require very little discussion. Interventions that are more complex, entail more risks (or unknown risks), are controversial, or that may have significant impact on the patient's life (now or into the future), will require a much more involved process of education. A study of parents' recollections of their early experiences coping with a new DSD diagnosis found that high levels of emotional distress are correlated with increased cognitive confusion (Pasterski, Mastroyannopoulou, Wright, Zucker, & Hughes, in press). When irreversible interventions are proposed, it is essential that parents' emotional distress is addressed to ensure that cognitive impairment does not compromise their decision-making capacity. A useful way of approaching consent in more complex decisions would be to think of these as requiring understanding that is both emotionally supported and informationally complete, what we refer to in this paper as emotionally and cognitively informed consent. In DSD cases, this will include allowing adequate time and support for families to adjust to a DSD diagnosis and to understand the long-term implications of proposed treatments for quality of life.

Laws set minimum standards for informed consent, which may vary by jurisdiction. Legal standards generally require informing the patient of the diagnosis and prognosis; the risks, benefits and unknowns of any proposed treatment; and the risks, benefits and unknowns of any available alternative treatments, including non-treatment. As much as possible, this information should be made specific to the individual for whom the treatment is proposed. A common way of stating the legal mandate in US jurisdictions, for example, is that physicians must provide the patient with 'as much information as [he/she] needs to make an informed decision, including any risk that a reasonable person would consider important in deciding to have the proposed treatment or procedure' (e.g. Judicial Council of California).

However, informed consent is an ethical as well as a legal imperative, and ethical standards may go beyond bare legal requirements (Faden, Beauchamp, & King, 1986). It is a well-accepted principle of bioethics that physicians have a responsibility to respect the autonomy of patients, including the patient's right to complete information when determining whether or not to undergo proposed medical interventions. In order to give fully informed consent, patients must be aware of and understand their condition, and must be able to meaningfully weigh the risks, benefits and alternatives of proposed interventions to ensure that the care they receive reflects their goals, preferences and values.

Emotional distress can impair understanding and decision-making. Making decisions under duress may be unavoidable in emergencies, but in non-emergency situations, providers have a responsibility to help address emotional needs and barriers to informed decision-making. Consent also requires that the patient's decision be voluntary, without influence or prejudice (even if well-intentioned) that might be subtly conveyed by physicians when they believe that a procedure provides a remedy to patient distress (American Academy of Pediatrics, 1995).

In situations where a surrogate, such as a parent, provides consent, respect for autonomy requires the decision-makers to consider the perspective of the patient (the child) across the lifespan. Although competent patients are free to make any decision they like for themselves, caregivers' preferences should not override the focus on the patient's best interest in the long term. Parents may make many medical decisions on behalf of their children, yet there are limitations to parental authority in the medical context (American Academy of Pediatrics, 1995). For example, parents in many US jurisdictions do not have authority to consent to elective sterilisation of a child without court oversight (Tamar-Mattis, 2006).

Even before they are old enough to provide legally valid consent to treatment, children can participate in some medical decisions. Younger children who can understand the basic aspects of an intervention can provide assent (informed agreement) for and may sometimes refuse treatment, and by the age of 14, many children have the cognitive ability (if not the legal capacity) to make medical decisions (American Academy of Pediatrics, 1995). Respect for children's developing autonomy requires involving them in medical decisions to the extent of their capacity, which means explaining even complex treatments in terms they can understand and respecting their right to refuse treatment when appropriate. It also means a progression to children's greater involvement in their health care decisions as they develop.

3. Why is informed consent a particular concern with DSD?

The history and cultural meaning of DSD, with its complex entanglement of ideas about sex, gender and sexuality, creates special challenges for informed consent. Many of these challenges result from long-standing beliefs about the necessity and benefit of interventions aimed at making a child's body more sex-typical. The theory of gender development

put forth in the 1950s posited that gender identity development depended, in large part, on the child having a body typical for the assigned sex, and traces of this theory persist. Although sex atypicality per se is not a medical condition requiring treatment (though the underlying factors causing it can be), some physicians have been concerned that variance from sex (biological) and gender (social) norms is socially and psychologically harmful to patients. Historically, the traditional treatment paradigm for DSD suggested health care providers wishing to help the child with a DSD focus the treatment on 'fixing' sex ambiguity or incongruity, believing this was the best way to remove the stigma associated with sex atypicality and thus to improve a child's adjustment and quality of life. Because some physicians have perceived interventions intended to give the child a more 'normal' appearance (or congruous sex traits) as wholly beneficial, they may have not recognised that there is a decision to be made regarding treatments such as genital and gonadal surgery (Hester, 2004). Parents who agreed to such procedures following what they perceived as a truncated consent process have expressed decisional regret about approving irreversible treatments for their children (Karkazis, 2008).

The importance of being truthful with patients about their condition and prognosis took hold in medicine by the late 1970s. In DSD care, honest and full disclosure has not yet been universally implemented (Austin, Tamar-Mattis, Mazur, Henwood, & Rossi, 2011). Despite recommendations from as early as the 1950s that children be given age-appropriate information about their condition (Money, Hampson, & Hampson, 1955), the treatment of DSD was based on concealing the diagnosis and even its treatment from families and children to avoid the psychological and emotional trauma believed to be caused by such knowledge. 'Sparing' parents and the child difficult information and making efforts to reduce sex atypicality via surgical intervention were believed to give children the best chance at an otherwise unattainable normal life. In many cases, physicians in the past made unilateral decisions regarding irreversible treatment. In others, parents approved such treatment without psychosocial support or complete and honest disclosure about the child's anatomy, condition and risks and the hoped-for benefits of treatment. There is also evidence some children were not told what procedures were being performed or why (Austin et al., 2011; Dreger, 1999; Karkazis, 2008).

In 2006, some patients' dissatisfaction with medical decisions made on their behalf, as well as physicians' acknowledgement of poor outcomes, led to the new standard of care articulated in the CS (Lee et al., 2006). This document called for the end of the concealment model and highlighted the importance of the sharing of information; recognised the need for parents and patients to be partners in decision-making; argued for full disclosure and for age-appropriate participation by children; called for a more conservative approach to genital surgery; and acknowledged the lack of evidence base for, and harm from, excessive genital exams and photography (see also Creighton, Alderson, Brown, & Minto, 2002). It is now more widely recognised that the ultimate goal of care is not that the child be made to look 'normal', however well-intentioned that goal might have been, but that the child and family flourish; this necessitates implementation of many strategies to enhance quality of life and child and family functioning.

In the wake of CS recommendations for openness, full and honest disclosure and collaborative decision-making, we continue to hear from some families of instances where physicians have advised against telling adolescents and children with DSD about their condition, anatomy or treatment out of a desire to protect children from the perceived stigma associated with having sex atypical anatomy. Families have also described situations in which physicians abdicate responsibility to parents for disclosure without providing psychosocial support for them to do so. Perhaps thinking it kinder or easier for families,

some physicians, including those who believe that honesty and disclosure are critical to good patient care, may still withhold information they believe to be stressful or challenging. As a result, psychologically and emotionally overloaded parents may make decisions about genital surgery without a discussion of future sexual function and some teenagers may be under- or uninformed about their diagnosis, anatomy or treatment history (Austin et al., 2011; Karkazis, 2008; Liao, Green, Creighton, Crouch, & Conway, 2010).We advocate a path of realism that recognises the limits of medical intervention, maximises sharing of information with families and recognises the developing autonomy of the child (Daaboul & Frader, 2001; Greenberg, 2006).

4. Emotionally and cognitively informed consent for differences of sex development

Given the particular stressors parents face in making decisions on behalf of a child with DSD, the many unknowns that surround these conditions and their treatment, and the history of treatment without full adequate disclosure, there is a great need for focus on improving the quality of informed consent in DSD cases. Below, we outline some components of informed consent that warrant particular attention.

4.1. Psychological and peer support

Psychosocial support is an essential initial element for creating an emotional environment in which families can make informed decisions. Parents who have just discovered that their child has a DSD are often ashamed, frightened and grieving (Karkazis, 2008). Families significantly distressed by genital or sex atypicality can be further traumatised by the isolation and uncertainty they often experience during the clinical information-gathering stage. Distraught parents are especially challenged to make decisions in the child's best interests, as is legally required for meaningful informed consent. Families need psychosocial support for processing intense and often-conflicting emotions in order to make clear-headed, considered decisions. It takes time for parents to process their feelings even with mental health assistance – without such help, some never do.

Although children with DSD may have life-threatening medical illnesses, in some recent instances, families tell us that they have been treated as if the physical atypicalities were the paramount consideration driving intervention. The biopsychosocial model of healthcare – a holistic and patient-centred approach to wellness – recognises that biological, psychological and social factors equally shape a child's health and well-being in the context of illness. Recognising the limitations of earlier, narrowly-focused approaches to the long-term well-being of children with DSD, the CS is consistent with a biopsychosocial approach to care for children with DSD and their families (Maharaj, Dhai, Wiersma, & Moodley, 2005).

The CS calls for improving the biomedical care of DSD, including an expansion of the evidence base and provision of care at specialised DSD centres. The CS also points to the benefits to families of being treated as equal members of the care team, with support from mental health care providers and peer networks; it also explicitly acknowledges long-neglected psychosocial issues, such as the psychological harms to both the child and family of concealing information and of medical photography. Its suggestions are oriented towards the longer-term care of children with DSD; however, these same values and considerations are essential to an emotionally and cognitively informed consent process, both at the outset of care and at various decision-making points throughout the duration of care.

When contemplating irreversible interventions for a child with a DSD, an extensive informed consent process is necessary simply to ensure appropriate cognitive assimilation through provision of information tailored to each family's level of health literacy. Equally important, however, is that anguish over a diagnosis does not preclude the family from grasping basic concepts about the child's body and condition before making decisions about interventions that are permanent. Parents need time and emotional support to process any uncertainty about the best course of action, understand what outcomes treatment such as genital surgery is meant to improve and form realistic expectations about the degree to which and how proposed interventions can achieve desired goals. Families must also understand specific issues such as surgical risks to sexual function; the known likelihood of gender discordance/incorrect sex assignment; controversies over surgery and reports of patient dissatisfaction; likely cosmetic and functional results; and the options of, and strategies for, deferring surgery temporarily or indefinitely.

Both gonadectomy and surgical treatment for genital ambiguity are felt by some clinicians and parents to avert future psychological distress for families and children. Input from mental health professionals is crucial to clarify whether this reasoning is in line with current knowledge about child development. Other interventions may also be aimed at alleviating presumed psychosocial harms associated with having a DSD. Where there may be psychological risks *resulting from* treatment, as described by some who have undergone those treatments, parents also need to be aware of these possible outcomes and risks.

Understanding future sequelae of childhood treatment is complicated for families because contemplation of a child's adult sexuality can be difficult. DSD can unconsciously evoke feelings about culturally-loaded and potentially stigmatised topics such as sex, sexuality and genitalia, clinicians and families may struggle to fully discuss these topics (e.g. Karkazis, 2008). The notion that sex atypicality is a difference no one would want to contemplate or endure has been used as a justification for withholding key aspects of health information from parents and children. The treatment of DSD as exceptional – medical 'disorders like no other' (Feder, 2009) – has led at times to under-informed medical decisions and subsequent parental decisional regret. Without professional mental health support for acknowledging and considering future sexuality, discomfort discussing sex-related matters can create ongoing barriers to the full exploration of these issues necessary for emotionally and cognitively informed consent.

Physicians can do much to ease parents' understanding and acceptance of a DSD by presenting information in a compassionate and non-alarming way. Still, support for the entire emotional process of coping with such unexpected and challenging information can be greatly improved by the involvement of mental health specialists. Even when physicians are willing to refer families to psychosocial support, mental health services are not available to families at many US institutions (Karkazis, 2008). To help fill this gap, medical caregivers have a responsibility to identify, refer to and coordinate psychosocial care for families with other local mental health professionals. Where mental health care providers experienced with DSD are unavailable, there is a role for "patient navigators" to help parents negotiate the complexities of the medical system especially when they are experiencing grief and uncertainty.

In our experience, quality peer support is very effective for helping parents through both the early days and the long-term challenges of raising a child with a DSD. Many families have been grateful for peer support, and clinicians should direct parents to peer support groups (monitored by experienced parent educators and expert clinicians), where they can learn about the lived experience of families. High-quality peer and psychosocial support can prove invaluable for helping parents to make treatment decisions by clarifying

the ways in which DSD and its treatment may impact a child's friendships, school experiences, adolescent development and intimate romantic and sexual relationships. Contrary to some providers' concerns, US privacy laws such as the Health Insurance Portability and Accountability Act of 1996 (HIPAA) allow referral to support groups or other parents.

Clinicians are sometimes excessively pessimistic about families' ability to raise a child with a genital or gonadal difference. Some may assume that parents cannot handle the possibility of uncertainty regarding sex assignment and eventual gender identity. Although the notion that genital surgery will prevent gender confusion or dysphoria has historically dominated the management of DSD, such intervention may actually complicate gender identity development during childhood and adolescence by creating genitalia, for example, that may not match the child's eventual gender identity (Meyer-Bahlburg, 2011). It is helpful for families in this situation to share real-life perspectives offered by both affected adults and other families who have had successful experiences in helping children with atypical genitalia develop and flourish.

With so few studies evaluating the outcome of various treatments or practices (such as genital exams and photos) on quality of life, and existing evidence disputed, clinicians who treat these children must share a common understanding that DSD require *more* psychological exploration, disclosure and careful sharing of information, not less. Above all, parents must understand that there is no medical or surgical cure for the complex realities of rearing a child who has a physical difference.

4.2. Respecting parents' role and children's autonomy

Current guidelines for care emphasise that the uncertainty surrounding the management of DSD makes it imperative that families are fully informed before making decisions (Lee et al., 2006). The physician's duty to the child as patient means that doctors cannot abdicate their responsibility to share in decision-making. Doctors should not provide an intervention if they do not agree that it is in the child's best interest, for example, simply because 'the parents want it'. We have previously outlined a shared decision-making process for genital surgery in which parents and doctors (and the child, when possible) share responsibility for making emotionally and cognitively informed decisions (Karkazis et al., 2010). Such a process is widely accepted as the ideal in medical decision-making (e.g. Barry & Edgman-Levitan, 2012).

Limited attention has been directed at the participation of children with DSD in medical decisions that will shape their lives. In some instances, physicians and families may be inclined to focus on the fear that the child will suffer emotionally without early physical interventions. They may also hesitate to have conversations with the child about the DSD, and may underestimate children's capacity and need for input into decisions about their bodies. Irreversible decisions made without a child's input, however, can lead to problems later in life. Rates of gender variance dissatisfaction with assigned sex remain high in DSD. In 46, XX congenital adrenal hyperplasia (CAH) with androgen effects, a physician interview series shows 11% gender dissatisfaction (Slijper, Drop, Molenaar, & de Mulnck Keizer-Schrama, 1998). Moreover, rates of self-reassignment can be as high as 63% in conditions like 5-alpha reductase-2 deficiency (Cohen-Kettenis, 2005). Whether or not they accept their sex assignment, some adults with DSD deeply regret the surgical decisions that were made on their behalf in childhood and adolescence (Dreger, 1999; Karkazis, 2008; Preves, 2003).

In forming a treatment plan, it is vital to consider which decisions can be postponed until the child is old enough to participate meaningfully. Giving children the chance for

involvement in their care shows respect for their dignity as persons and allows them a sense of control over their bodies and treatment (American Academy of Pediatrics, 1995). When a significant elective procedure, such as genitoplasty, is contemplated before the child is old enough to participate in the decision, the potential harm from loss of dignity and autonomy must be balanced against any potential benefits of early intervention. Ethical treatment of DSD over the course of childhood, therefore, requires constant assessment of a child's competence to participate in health care decisions. Because most physicians do not have expertise in assessing childrens' competence, the participation of specialists in paediatric and adolescent mental health as full and involved members of the health care team can help ensure that children's autonomy is respected, that children are prepared for participation in their own health care and that their input is solicited and respected as developmentally appropriate.

Involving children in decisions requires sharing information. The thought of explaining a DSD to a child has at times proven daunting to some parents and physicians. Nonetheless, providing the child with understandable and truthful information has many benefits. It makes informed assent possible, facilitates trust in the parents and medical providers and protects the child from unplanned discovery of the condition. Some parents may assume that they will protect their child from stigma by concealing information, but studies of other stigmatised conditions have shown that children benefit from knowing the truth (Austin et al., 2011). Specialists in children's cognitive and psychosocial development can help maximise their ability to assimilate complex information. Excellent materials have been developed to assist parents and doctors with sharing difficult information with paediatric patients, some of which may be adaptable for use with DSD (see Austin et al., 2011). Other parents who have successfully discussed DSD with their children are the ultimate experts, and peer support enables families to compare and combine diverse strategies for unique solutions to disclosure.

4.3. Giving complete, accurate and balanced information

In order to fully weigh the potential risks and benefits of treatment, the family must have access to complete, accurate and balanced information. For surgical decision-making, families must be notified of provider factors that may influence the outcome of treatment, such as whether the child might have a better outcome in a centre of excellence. Additional relevant information includes specifics about a provider's specialty training, how many of the proposed procedures she has performed, to what age those children were followed and whether teenagers and adults express satisfaction with a proposed treatment. Complete and accurate information about effects over the life cycle may require input from multiple specialists. For example, a mental health expert may have insight into whether a procedure might help or harm psychological functioning, and an adolescent or adult gynaecologist may have insight into longer-term appearance and functional outcomes of genital surgery.

Procedure-specific information must also be provided. If a treatment is intended to improve cosmesis, parents should be invited to view photographs depicting appearance during and after healing and at long-term follow-up. This is standard practice in cosmetic surgery as it allows the decision-maker to have realistic expectations of outcomes and to understand the scope of possibilities for post-operative appearance and scarring. Knowing the range, not just the mean number, of how many surgical procedures on genitalia may be required can influence decisions. For example, if multiple procedures with long recovery periods might be necessary for a boy with DSD to urinate in a standing position, parents

might place more value on preserving a child's time at school and with friends. A shared decision-making approach can elicit such values.

In proposing treatment plans, it is important to consider that clinicians' and families' cultural assumptions may differ. Moreover, clinicians in some encounters may misunderstand or fail to probe parents' assumptions or real concerns. Some parents report, for example, being given information based on stereotyped notions of sex and gender. Two of the authors recently consulted with a parent of a boy with a DSD from a European country. Her child's urologist emphatically told her that masculinising surgery was necessary because 'a boy has to be able to pee in a pond' in order to be psychologically healthy. When she asked for a referral to a psychologist, she was told that such referral was not necessary because the boy would not have psychological issues once the surgery was complete. The mother was distressed at having been denied the information she needed to make a fully informed decision about how, and indeed whether, masculinising surgery could benefit her son.

Some parents and physicians have felt that such surgery will relieve parental distress and address a host of other concerns and fears about the child's atypicality. One problem with performing surgery to allay parental anxiety is that the surgery cannot destigmatise the condition; it can only reshape the genitals. Some clinicians and parents may regard surgery as a panacea for a variety of concerns – such as fears about homosexuality or a girl's XY chromosomal type – that have very little to do with the child's genital configuration and that often persist despite genital surgery. Moreover, parents may have unstated and unrealistic assumptions that some physicians and surgeons must explicitly dispel, for example, that surgery can create genitals with no sign of the original atypicality. It is important to address such misconceptions during decision-making so parents base their decision on the actual benefit of the proposed intervention to the child.

It is generally agreed that evidence for both physical and psychosocial outcomes in DSD remains incomplete, uncertain and disputed. Some fundamental questions about whether genital surgery harms sexual sensation, produces acceptable cosmetic and functional results or improves well-being are still deeply contested. How these issues interplay in individual situations may never be resolved definitively because the answer will always be dependent on too many variables: the surgeon's skills and judgment, the techniques used, the child's individual anatomy and physiology, the quality of post-operative care, the psychosocial resources available, relationships within the family and the deeply subjective nature of satisfaction with sexual sensation and function as well as cosmetic outcomes. Physicians must remain vigilant that the absence of high-quality evidence concerning results of current techniques does not lead to a lack of accountability when discussing interventions with families: it may be tempting to attribute any negative outcome to earlier, less technically sophisticated techniques, and not to harm which might be intrinsic to procedures involving disruption of nerves and erectile tissue.

According to some parents, the risks of genital surgery on sexual function and sensation are sometimes minimised with statements acknowledging 'we know that people had nerve damage in the past, but modern surgical techniques preserve the nerves'. Over the years, however, expected improved sexual outcomes from successive refinements in technique have not always materialised. Although some parents can be uncomfortable discussing sex and gender, and physicians may feel sensitive to this discomfort, parents need accurate information about the risks and unknowns of various treatments on the child's future gender identity and sexual function in order to make informed decisions. Physicians must thus ensure that parents understand the limitations in the quality of existing data. As new data

are gathered, physicians will need to adjust their recommendations accordingly (Houk & Lee, 2010).

In our experience, the potential risks of tragic health and psychosocial outcomes if surgery is deferred are often magnified in discussions with parents. The overemphasis on cancer risk in testes of girls with complete androgen insensitivity syndrome (CAIS) is an example of how parents may be swayed by intensely emotional information. If parents are presented with a statement such as 'your baby's testes may turn cancerous if they are not removed', they may not question the need for early gonadectomy. If they hear 'there is a 2% risk of testicular cancer, which is unlikely to occur before puberty' (Lee et al., 2006), they may take a more measured approach. Although it may be hard for some physicians to believe, we have heard, over the last year, of some cases where physicians have pressured parents of girls with CAIS who resist immediate gonadectomy. One mother, for example, was physically prevented from leaving a doctor's office until she agreed to surgery. Another mother who refused infant gonadectomy was told that her daughter would grow a penis at puberty. In the face of such catastrophising, can we consider the consent uncoerced and 'informed'?

Finally, just as informed consent for transplant surgery would require an explanation of the need to take immunosuppressants and the risks of those medications, so too must the need for and risks of follow-up after genital surgery be clearly stated. For example, some clinicians feel that post-operative management requires frequent genital examinations and photography. Although exams may provide the physician with important information about the development of the child and may guide future treatment (such as subsequent surgery or hormone therapy), repeated displays of the child's body can cause psychological trauma. In our experience, patients often describe childhood genital examinations conducted by groups of white-coated strangers as traumatic, at times employing the language of sexual assault and rape to describe their feelings of exposure and violation of bodily integrity (Karkazis, 2008). One of the authors knows a woman who was diagnosed with post-traumatic stress disorder as a result of frequent genital examinations in the immediate post-operative period after her vaginoplasty and who experienced flashbacks every time she tried to be sexually intimate with a partner as an adult.

It is thus important not only that providers are aware of risks so that they minimise genital exams of children with DSD, but that parents are also alerted to these risks so they can give informed consent for those exams. Furthermore, since parents are best positioned to keep track of how often their children are exposed to such exams, they may also be in the best position to judge whether the benefits of a particular exam justify the risks. Providers must also explain to parents whether a given exam is medically necessary or useful, or if it is being performed for other reasons, such as for research, or for the education of trainees. Parents may assume that any requested exam is medically necessary – if this is not the case, then they must be so notified before they can make an informed decision. The special risks of repeated genital exams are not covered by blanket consent forms that parents sign in teaching hospitals authorising involvement of medical trainees in their child's care.

5. Conclusion

DSD necessitate a careful and thoughtful process of education to help parents make truly emotionally and cognitively informed decisions. When families deal with DSD without adequate psychosocial and peer support, a crisis atmosphere can develop, with the initiation of irreversible interventions before parents can integrate complex information to develop an adequate understanding of their potential effects in adulthood. Distraught

families are least able to process the complex information necessary to make thoughtful choices. Ethical and legal requirements may be further compromised when children do not participate in these decisions, challenging their recognised right to autonomy and self-determination.

In an ideal process for informed consent in DSD, medical caregivers will refer parents for psychosocial support and assessment by mental health professionals to ensure their emotional readiness to absorb information about the diagnosis and its implications. Continued support from these practitioners and high-quality peer support groups allows frank discussion of many issues, both with the family and with the child, and includes information about the lived experience of affected adults and families. While an ideal situation will not always be possible, it is incumbent on care providers to do all they can to ensure an adequate process for emotionally and cognitively informed consent. Mental health providers can also take a role in initiating such support in their systems. A thoughtful process of shared decision-making includes psychosocial support and input from affected adults and families as well as clinicians, and permits ongoing exploration to provide balanced, complete and accurate information about any proposed intervention and its eventual effects on the child as an adult.

Notes on contributors

Anne Tamar-Mattis, JD, is the Executive Director of Advocates for Informed Choice, the first organisation in the country focused on legal advocacy on behalf of children with DSD. She is also an adjunct professor at the University of California, Berkeley, School of Law.

Arlene Baratz, MD, is the mother of two adult daughters with CAIS and a medical adviser and board member for multiple advocacy groups including Androgen Insensitivity Syndrome/Disorders of Sex Development (AIS/DSD) Support Group, Advocates for Informed Choice (AIC) and Accord Alliance.

Katharine Baratz Dalke, MD MBE, is a resident in Psychiatry at the Hospital of the University of Pennsylvania, is affected by CAIS, acts as Co-President of the Board of Directors of Advocates for Informed Choice, and is a member of the medical advisory group to the AIS/DSD Support Group.

Katrina Karkazis, PhD, MPH is a Senior Research Scholar at the Stanford Center for Biomedical Ethics and the author of *Fixing Sex: Intersex, Medical Authority, and Lived Experience* (Duke University Press, 2008).

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