

A Call for Fertility and Sexual Function Counseling in Pediatrics

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During a pediatric endocrinology clinic visit, a 16-year-old boy presented with his family for evaluation of his endocrine axes due to history of bone marrow transplantation. He had previously been followed elsewhere; transfer records stated his family had been told that his fertility was likely to be impaired, but his parents had not shared this with him. It was also unclear from review of the notes whether any discussions regarding sexual function had occurred.

Historically, reproductive health in pediatrics has focused primarily on contraception and prevention of sexually transmitted infections. However, there is now a growing body of literature discussing the long-term impact of many pediatric conditions and treatments on fertility and sexual function, such as oncologic therapy, hematologic or autoimmune conditions requiring bone marrow transplantation, renal and rheumatologic disorders in which alkylators are used, cross-sex hormonal therapy used in the care of transgender youth, disorders of sex development, and other genetic syndromes such as galactosemia. Pediatric providers face dilemmas about the optimal approaches for assessing and discussing fertility and sexual function with patients and families, the type of guidance to give to parents about related communications with their children at each developmental stage, and ethical obligations regarding disclosure when parents are opposed to sharing sensitive information with their children.

Decades ago, the nondisclosure approach to sensitive topics in pediatric care was commonly accepted. As young individuals matured, however, it became clear that secrecy resulted in increased distress. Since then, extensive literature in adoption, HIV, cancer, and other illnesses has highlighted the importance of age-appropriate information sharing. The American Academy of Pediatrics (AAP) published recommendations in 1999 encouraging disclosure of HIV status to children.¹

The AAP and several other groups have published guidelines encouraging providers to refer patients at risk for fertility loss (primarily focusing on childhood cancer) for fertility preservation before gonadotoxic therapy.² In a 2006 Consensus Statement addressing care of youth with disorders of sex development, disclosure to individuals about their conditions, including counseling about fertility and sexual function, was encouraged

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to occur in a “collaborative, ongoing” manner.³ However, specific guidelines about which specialists on an interdisciplinary care team should initiate discussions about fertility and sexual function, at what age/developmental stage, and how information should be shared (eg, with the patient directly, parents and patients together, or each separately) are lacking.

Current studies show that both fertility and sexual function are major areas of concern for adolescents and young adults whose reproductive and sexual function/anatomy may be affected; these individuals are frequently unaware of their fertility status and desire more communication from providers on these issues.⁴⁻⁶ With more pediatric providers continuing to follow patients into adulthood, addressing these gaps in reproductive health counseling is now of utmost importance. Uncertainty regarding fertility status has reportedly led to unplanned pregnancies in certain instances.⁶ Patients may also feel dissatisfaction or anger if there was a missed window of opportunity for fertility preservation, or for interventions aimed at improving sexual function outcomes. For instance, new fertility preservation options are emerging, such as cryopreservation of oocytes as well as testicular and ovarian tissue; shared decision-making about these choices can occur only when patients are fully informed.

In addition to these medical implications, there are psychological implications of incomplete disclosure. Unclear or delayed information sharing about these topics may create a dissonance between parenthood and intimacy goals, and actual fertility and sexual function status, and risks potential negative impacts on intimate relationships and quality of life. Without proper counseling, these individuals are likely to obtain information from other sources,

including the Internet. They may experience discomfort and confusion regarding perceived reproductive and anatomic differences, and harbor unexpressed concerns regarding sexual performance potential. Patients can also benefit from professional guidance about how to disclose their fertility status and body/sexual differences to others, to help mitigate shame and/or fears of rejection from potential intimate partners, a process that is limited when there are minimal discussions about these topics. Further, withholding information from patients can lead to insensitive or even harmful disclosures from a new provider, who may assume that the patient is fully informed. This concern becomes even more salient as pediatric patients approach the transition to adult care.

BARRIERS TO DISCLOSURE

Similar to discussions about other sensitive topics, such as adoption or HIV-positive status, there are parental challenges to disclosing fertility concerns to their child. It may be devastating for parents to learn their child’s future parenting opportunities are limited, and they may grieve for their children as well as their inability to have biological grandchildren. Additionally, many parents are uncomfortable discussing sexual function with their children.

There are also challenges from the provider’s perspective. Fertility and sexuality have not traditionally been considered routine components of pediatric care, and are thus not included in training curricula for most pediatric specialties. Studies among pediatric cohorts at risk for infertility have revealed inadequate provider knowledge and inconsistent fertility counseling practices.⁷ Even providers who routinely screen for sexually transmitted infections and prescribe contraception, such as adolescent medicine providers,

may have limited knowledge about the risk of infertility and sexual dysfunction in various conditions, fertility preservation and/or management options, and optimal surveillance methods. Further, it is unclear whose responsibility it is to provide this counseling. Because providers from several disciplines are often involved in these patients’ care, the assumption that “someone else will talk about it” risks an actuality of no provider taking responsibility, and/or inconsistency in the information that is imparted.

A NEED FOR GUIDELINES

Once thought of as “adult issues,” it is now clear that many childhood disease survivors are affected by infertility and sexual dysfunction, which significantly impact quality of life. Although the guidelines about fertility preservation have helped in the overall goal to improve reproductive outcomes, providers lack knowledge, training, and guidance about how to assess and discuss fertility status and management options with adolescents and young adults on an ongoing basis. Guidelines on counseling regarding sexual function are also absent, and providers may lack requisite fundamental knowledge about this issue, an obstacle to initiating discussions.

We recommend the formation of an interdisciplinary task force to develop specific guidelines regarding fertility and sexual function counseling in at-risk pediatric populations. This panel could include experts from the AAP, American Society for Reproductive Medicine, Society for Adolescent Health and Medicine, North American Society for Pediatric and Adolescent Gynecology, Society for Pediatric Urology, Pediatric Endocrine Society, American Society of Clinical Oncology, and the American Psychological Association. In addition

to highlighting the time-sensitive nature of making referrals for fertility preservation before gonadotoxic therapy, guidelines should specify key points to cover at different developmental stages, including anticipatory guidance about reproductive capacity, therapeutic options for impaired fertility and sexual function, alternate options for parenthood, and strategies for disclosure to peers and romantic partners. Additionally, guidelines should discuss which providers should take responsibility for such counseling, how to balance the goals and wishes of parents and patients, and how to approach these situations with appropriate sensitivity. Ultimately, to achieve optimal outcomes, we must acknowledge the significant impact of reproductive and sexual function on patients' long-term quality of life, and integrate routine counseling about these issues into the treatment of a multitude of pediatric diseases.

ABBREVIATION

AAP: American Academy of Pediatrics

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