CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

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Counseling in Pediatric Populations at Risk for Infertility and/or Sexual Function Concerns

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abstract

FREE

Reproductive health is an important yet often overlooked topic in pediatric health care; when addressed, the focus is generally on prevention of sexually transmitted infections and unwanted pregnancy. Two aspects of reproductive health counseling that have received minimal attention in pediatrics are fertility and sexual function for at-risk pediatric populations, and youth across many disciplines are affected. Although professional organizations, such as the American Academy of Pediatrics and the American Society of Clinical Oncology, have published recommendations about fertility preservation discussions, none of these guidelines address how to have ongoing conversations with at-risk youth and their families about the potential for future infertility and sexual dysfunction in developmentally appropriate ways. Researchers suggest many pediatric patients at risk for reproductive problems remain uncertain and confused about their fertility or sexual function status well into young adulthood. Potential infertility may cause distress and anxiety, has been shown to affect formation of romantic relationships, and may lead to unplanned pregnancy in those who incorrectly assumed they were infertile. Sexual dysfunction is also common and may lead to problems with intimacy and self-esteem; survivors of pediatric conditions consistently report inadequate guidance from clinicians in this area. Health care providers and parents report challenges in knowing how and when to discuss these issues. In this context, the goal of this clinical report is to review evidence and considerations for providers related to information sharing about impaired fertility and sexual function in pediatric patients attributable to congenital and acquired conditions or treatments.

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INTRODUCTION

Reproductive and sexual health are important yet often overlooked topics in pediatric health care; when addressed, the focus is generally on prevention of sexually transmitted infections (STIs) and unwanted

TABLE 1 Examples of Pediatric Populations at Risk for Infertility and/or Sexual Dysfunction (1 or Both May be Affected)

Discipline[a]	Condition or Treatment
Hematology, oncology, and/or immunology	Gonadotoxic chemotherapy
	Gonadotoxic radiation
	Genitourinary surgery
	Genitourinary cancer
	Sickle cell disease
	Hemochromatosis
	Any condition treated with chronic transfusions
	Any condition treated with stem cell transplantation
Genetics	Galactosemia
	Turner syndrome
	Klinefelter syndrome
	Down syndrome
	Fragile X
	Cystic fibrosis
Rheumatology and/or nephrology	Lupus and/or mixed connective tissue disease
	Vasculitis
	Steroid-dependent nephrotic syndrome
	Rheumatoid arthritis
	End-stage renal disease
Gastroenterology, cardiology, and/or pulmonary	Inflammatory bowel disease
	End-stage liver disease
	End-stage cardiac disease
	End-stage lung disease
Urology, gynecology, and/or anatomic	Spina bifida
	Cerebral palsy
	Disorders of sex development
	Bilateral cryptorchidism
	Anorchia and/or testicular regression
	Prune Belly syndrome
	Hypospadias
	Mayer-Rokitansky-Küster-Hauser
	Bladder exstrophy-epispadias complex
	Spinal cord injuries
	Anorectal malformations
	Endometriosis
	Fibroids
Endocrinology	Hyperprolactinemia
	Thyroid dysfunction
	Diabetes mellitus
	Hypogonadotropic hypogonadism
	Polycystic ovarian syndrome
	Autoimmune ovarian insufficiency
	Transgender
Infectious diseases	Mumps
	HIV/AIDS
	STIs

[a] Some conditions may be associated with >1 category.

pregnancy.[1,2] An expanding body of literature has highlighted other important aspects, such as puberty, sexuality, and healthy relationships, in addition to emphasizing specific populations for whom extra guidance may be needed, such as lesbian, gay, bisexual, transgender, and questioning youth.[3,4] However, two aspects of reproductive health counseling that have received minimal attention in pediatrics are fertility and sexual function for at-risk populations, and pediatric patients across many disciplines are affected (Table 1).

Fertility is the ability to produce offspring from one's genetic material. Sexual function refers to the physical and emotional ability to experience sexual pleasure and satisfaction when desired.[5] Multiple medical conditions (eg, disorders of sex development) and treatments (eg, chemotherapy and radiation, hormonal treatments for transgender youth) occurring in childhood and/or adolescence may impair future fertility and sexual function (Table 1). Some patient populations may benefit from technologies developed to preserve gametes for future use, known as fertility preservation. (The American Academy of Pediatrics [AAP] has a technical report forthcoming on fertility preservation for pediatric and adolescent patients with cancer.) Briefly, established forms of fertility preservation include sperm cryopreservation for pubertal boys and oocyte cryopreservation for postmenarchal girls; experimental options, such as testicular and ovarian tissue preservation, may be considered for prepubertal boys and premenarchal girls, respectively. Although professional organizations such as the AAP and the American Society of Clinical Oncology have published recommendations about fertility preservation discussions for at-risk children and adolescents,[6–8] none of these publications address how to have ongoing conversations with children and adolescents and their families about the potential for future infertility and sexual dysfunction in developmentally appropriate ways.

Researchers suggest many pediatric patients at risk for reproductive problems remain uncertain and confused about their fertility or sexual function status well into young adulthood. Potential infertility may cause distress and anxiety, has been shown to affect formation of romantic relationships, and may lead to unplanned pregnancy in those who incorrectly assumed they were infertile.[9,10] Sexual dysfunction is also common in otherwise healthy and at-risk adolescents, leading to problems with intimacy and self-esteem[11,12]; young adult cancer

survivors consistently report inadequate guidance from health care providers in this area.[11] Health care providers and parents of childhood cancer survivors, as well as other populations facing intellectual or physical disabilities affecting reproductive health, report challenges in knowing how and when to discuss these issues.[9,13,14]

In youth with conditions such as congenital adrenal hyperplasia and androgen insensitivity syndrome, critical decisions affecting fertility and sexual function were historically made in infancy, with adolescents and young adults later relying on their families and health care providers for ongoing counseling.[15] Individuals with these conditions report distress when information about their potential infertility or sexual dysfunction is kept from them and frequently ask their health care providers for guidance in how to share information about these sensitive topics with intimate partners.[16] Whenever relevant, families should be counseled about risks and controversies surrounding medically unnecessary surgeries without patient involvement in decision-making and be informed about fertility and sexual function implications on an ongoing basis.[15]

Some health care providers managing conditions that affect fertility and sexual function, such as pediatric rheumatologists, nephrologists, and oncologists, may lack knowledge and inconsistently provide counseling or referrals to reproductive health specialists.[17–20] A recent national survey revealed the majority of pediatric endocrinologists, urologists, and gynecologists felt inadequately trained in fertility and sexual function and desired additional guidance in these areas; many providers were unsure whose responsibility it was to provide such counsel to patients and families.[20] As a result, although at-risk patients may be seeing many different care providers, they may not be counseled about fertility or sexual function in any of these encounters.[11,21] In this context, our goal with this clinical report is to review evidence and considerations for providers related to information sharing about impaired fertility and sexual function in pediatric patients resulting from congenital or acquired conditions or medical treatments.

ASSESSING RISK

In preparation for the clinical encounter, the first step is to become educated about fertility and sexual function concerns on the basis of a given patient's condition and/or treatment history. Initial questions to consider may include the following: (1) Is there a medical or surgical intervention taking place that may affect the patient's future fertility and/or sexual function? (2) Is there an opportunity now to protect or preserve fertility and/or sexual function? (3) What type of information can be shared about future fertility and/or sexual function implications?

Obtaining information about these topics may be challenging at times because there is little empirical evidence on reproductive and sexual health outcomes in many conditions, and there may not be an easily accessible source. Some medical conditions or groups of conditions have disease-specific guidelines and literature in which infertility risk, sexual function concerns, and interventions (see Resources) are discussed, but in other cases, one would need to research the specific condition or treatment agent itself. Ultimately, providers may need to work with parents to determine optimal approaches to care and communication, even in the absence of known information. Beyond fertility and sexual function, there may be concerns about pregnancy because of implications for the mother or teratogenicity of certain medications. In such cases, involving a maternal-fetal medicine specialist may be of benefit.

INTERDISCIPLINARY APPROACH TO CARE

When possible, an interdisciplinary approach to care is helpful to incorporate expertise regarding (1) the primary medical conditions and treatment plan (oncologist, rheumatologist, geneticist, or other treating provider) and (2) optimal approaches for assessing gonadal function in male and female patients of different ages and pubertal stages (such as general and/or reproductive endocrinologist, gynecologist, or urologist). In addition, although team physicians may understand the relevant medical issues for a child or adolescent, a behavioral health professional will be best equipped to appreciate issues accounting for culture, child development and/or developmental limitations, family psychosocial issues, and the best way to engage a child in decision-making. The interdisciplinary team (including the primary care provider) should communicate before the patient encounter to share information and designate which members of the team are best suited to counsel the child and family about various aspects of fertility and sexual function. It is important to document the discussion and send it to all members of the health care team as a shared guide for future reproductive health planning.

Although a team approach is optimal, challenges occurring within interdisciplinary frameworks can impede care and ultimately result in suboptimal practices. Difficulties sometimes occur when encounters are rushed, precluding optimal communication between team members, and/or if consensus cannot be reached because of fundamentally different beliefs and approaches. Other challenges

include inadvertent transmission of conflicting information by different team members, models in which some members may not be equally comfortable disagreeing with team leaders or across disciplines, and lack of clarity regarding parameters and/or responsibilities across members. Finally, poor access to pediatric specialists who are trained and comfortable counseling about fertility and sexual function or lack of insurance coverage for certain subspecialists, such as mental and/or behavioral health professionals, may pose barriers to establishing optimal interdisciplinary care. Communication about these sensitive issues should be well documented so that all current and future providers (eg, in the transition to adult care) are informed about what has been discussed. Finally, when a comprehensive team cannot be established, a variety of disciplines could take the lead in providing counseling about fertility and sexual function.

ASSESS WHAT THE CHILD AND PARENTS KNOW AND INTERVENTIONS THAT MAY HAVE BEEN PERFORMED

Studies reveal families may not be aware of potential threats to fertility and/or sexual function or may not feel comfortable broaching the topic and thus rely on health care providers to initiate these conversations.[8,15] It is important to assess what parents and patients understand about previous medical or surgical interventions (eg, exposure to gonadotoxic therapies, fertility preservation attempts, and/or surgery involving the genitalia or gonads) and their fertility and/or sexual function implications. In many cases, information about fertility and sexual function may have initially been shared in the context of a new medical diagnosis that is life altering or life-threatening or when there is a pressing urgency to initiate treatment, which can affect retention of information. Additionally, years may have passed, the child may have been too young to participate in the initial discussions or decisions, and there may be new information that has emerged since initial counseling occurred.

In some cases, parents may express a desire to withhold information about their child's condition and/or infertility risk. Families should be counseled that although nondisclosure was previously common in pediatric care, the literature on a vast array of subjects, from HIV[22] to adoption or informing offspring of their conception by gamete or embryo donation,[23] reveals the importance of developmentally appropriate disclosure at the earliest possible age. Studies in women with Turner syndrome reveal that an absence of communication about the condition can create tremendous distress later in life when infertility is discovered.[24] Researchers suggest many families desire the health care provider's input and support in decision-making about disclosure.[25] The health care provider may find it helpful to start the conversation about disclosure with families by addressing common misconceptions. For instance, a parent may believe the child is too young for such discussions. However, literature reveals that parental lack of disclosure does not mean the child is unaware, and the child may have unexpressed anxiety. Another common misconception is that if the child is not asking questions, he or she is not interested or concerned. However, the child may simply be following the emotional tone that has been established in the home when talking about the condition and its effects; if the child notices parental discomfort or anger when the condition is discussed, he or she may not feel safe to ask questions. A lack of information or living in uncertainty may also lead to inaccurate beliefs (eg, "I must not have a problem because no one is talking to me about it"), or looking to suboptimal sources for information, such as the Internet.

COUNSELING CONSIDERATIONS

Time

Discussions about the decision-making process affecting fertility and sexual function most optimally occur when sufficient time is allotted. Often, these topics are discussed along with other complex health-related information, making them difficult to comprehend and digest. When possible, it is important to plan for ongoing counseling with families as they absorb information and continue to formulate questions and generate concerns. Patients old enough to be involved in the decision-making process (described in the next section) should have time to consider options, with ongoing discussions as the patient-provider relationship is solidified. Compensation for time spent on counseling should be provided by insurers as an integral component of managing the underlying condition.

Normalize the Stress of Ambiguity

Many families find it difficult to manage stress and decision-making when medical issues are unknown and unpredictable, as is frequently the case with fertility and sexual function concerns. It is important to acknowledge the stress and help the family and youth plan to manage it and build positive coping skills while giving guidance in avoiding catastrophizing.

Recognize and Acknowledge Stressors and Strengths

Family stressors, such as a patient's or parents' psychosocial issues or financial constraints, can affect a family's ability to make decisions or engage in discussions about fertility and sexual function. Parents and children with cognitive limitations

or acute mental health issues may lack the ability to comprehend fertility and sexual function. Parents of children with limited survival may also experience difficulty considering future fertility or sexual function. Health care providers can help families navigate these issues, identify their strengths, and facilitate general means of coping.

Address Cultural, Linguistic, and Health Literacy Factors

Cultural factors, including religious beliefs, may affect a patient and caregiver's comfort in discussing or considering interventions related to fertility and/or sexual function, but these should not be barriers to sharing relevant information. It is also important to secure interpreter services when language proficiency may hinder communication, and the interpreter needs to be comfortable speaking directly about issues of a sensitive nature. In addition, health literacy may be low, and both parents and their children may need concise and simple explanations of risks and options.

Facilitate Connections With Others for Support

Youth may benefit from connecting with older adolescents and adults with similar conditions for support and guidance regarding fertility and sexual function. Parents may also benefit from peer advice about how to support their children and initiate age-appropriate discussions.

Talking Points Based on Age or Developmental Stage

Children, even at a young age, may begin to envision future parenthood. Even parents of infants may envision them as future parents and hope to be grandparents. However, pediatric patients may struggle to think about future fertility when facing life-threatening illnesses, such as cancer, or when uncomfortable in their own bodies, such as those with gender dysphoria. The health care provider can offer guidance about developmentally appropriate levels of information with more detail as the child matures.

TABLE 2 Overview for the Clinician

Before encounter
Assess the patient's fertility and sexual function risk and/or implications
Develop a framework for counseling by using an interdisciplinary approach when possible
During the initial encounter
Assess what the parents and child have been told and what interventions (if any) have been offered
Consider cultural factors, ethical issues, and other special circumstances that may impact communication
Plan initial talking points for both the parents and patient on the basis of age or developmental stage
Ongoing care
Plan future talking points for both the parents and patient on the basis of age or developmental stage

Although health care provider–initiated discussions about fertility with both children and parents are appropriate starting at a young age, sexual function counseling generally takes place with adolescents and young adults without parents present. However, some youth may develop concerns at a younger age regarding body image and future romantic relationships, and parents may share these concerns as well, necessitating these discussions with families early in a child's life. It is important to emphasize to parents that the youth's fertility and sexual function are only 2 aspects of their child, and that families should foster positive development and relationships at every developmental stage. Suggestions for specific talking points by age or developmental stage are as follows (summary provided in Table 2):

Parents of Infants or Young Children

Inform parents about known and unknown fertility or sexual function outcomes relevant to the particular condition or treatment and when decisions about medical or surgical interventions are being made. Assess family supports and, when possible, connect families with others who have had similar experiences. Inform families about current fertility preservation (explain that options for prepubertal children are experimental) and treatment strategies and that new fertility-related technologies may emerge. Inform families that medical and surgical approaches may evolve to preserve and/or improve sexual function. Even young children may show interest and curiosity about their bodies, and the topic of future parenthood can and should be discussed in an age-appropriate manner.

School-Aged Children

Developmentally, children's levels of cognitive maturity and self-awareness increase as they age; however, there is some variability from child to child, making it difficult to define an exact age at which different information should be shared with a child. In clinical research, assent is typically required at 7 years of age on the basis of assumptions of decision-making capacity in typically developing youth,[26] but younger children should be involved and provided with information. It is important to be sensitive to the changing perspectives of school-aged children, modify discussions accordingly to provide information geared toward a child's cognitive and emotional readiness, and set the stage for open communication. It can be helpful to give children permission to ask any questions of interest and let them know they have a right to all information they want to know about their bodies and medical conditions.

Talk with the parents to see whether they would prefer to start these discussions at home and provide guidance accordingly for these discussions. Children may be told "there are many different ways to become a parent and have a family." Check in periodically with children to assess their understanding and encourage continued conversation both with parents and providers. Although detailed discussions about sex may not be appropriate at this age, children should feel comfortable asking about their bodies regarding appearance and function at home and at doctors' visits; open-ended prompts, such as "How are you feeling about your body?" may be helpful. As children approach adolescence, they will have an increasing awareness of their sexuality, and counseling should be tailored accordingly.

Adolescents and Young Adults

Starting around 14 to 16 years of age in typically developing youth, pediatric patients should begin to take more responsibility for their own reproductive and sexual health in preparation for future transition to adult care.[27] Adolescents may feel more comfortable engaging in conversations with their health care providers than with their parents, and establishing patient-provider relationships at this stage provides an opportunity for recurring conversations over time. Optimally, counseling should take place with parents present and also with the youth alone. Asking open-ended questions is helpful, although being specific with regard to fertility, family building, and sexual function and health is important. Relevant topics may include anatomy, masturbation, erections, nocturnal emissions, sexual fantasies, sexual orientation, orgasms, sensation, and performance.[1] Adolescents and young adults may struggle with future thinking and long-term decision-making yet wonder and worry about the impact of fertility and sexual impairment on dating and the formation of romantic relationships. Female adolescents may wonder whether carrying a pregnancy is an option regardless of ability to have a biological child. It is also critical to emphasize that even if an individual is likely to be infertile, barrier methods need to be used with every sexual encounter to prevent STIs, including human papillomavirus infection, and contraception should be used to prevent an unwanted pregnancy. These can be awkward conversations, and efforts should be made to create a safe and comfortable environment to facilitate discussions. It is also important to inquire where patients are getting their information (ie, friends, media) to better understand their level of knowledge and potential misconceptions.

SUMMARY AND RECOMMENDATIONS

Infertility and sexual dysfunction have a significant effect on quality of life. Given that numerous pediatric conditions and treatments impair reproductive capacity and sexual function, general pediatricians and pediatric medical subspecialists should provide ongoing counseling about these risks and potential management options as well as psychosocial support. Considering the sensitive nature of these topics, clear communication between health care providers and inclusion of youth in discussions and decisions are paramount. In summary, the AAP recommends the following:

- Counseling about fertility and sexual function for at-risk pediatric populations is essential and should begin with parents in infancy or at the earliest time point a patient may be affected.
- All children should have access to full information about their conditions using developmentally sensitive approaches as they mature, understanding that perspectives, comprehension, and patient concerns are not static and can change with maturity.
- Treatment-specific fertility and sexual function risks and potential interventions and recommendations should be evidence-based; when evidence is unavailable, this information needs to be transmitted to families in the context of information sharing and decision-making.
- Interdisciplinary teams must develop a strategy to address issues of fertility and sexual function in a direct but sensitive manner, allotting enough time for questions and considerations and ensuring that a consistent message is relayed. Teams should also identify which provider will discuss each aspect of the risk and potential intervention and at what time point.
- Clear documentation about the content and outcomes of discussions is imperative to optimize communication among health care providers and also facilitate a smooth transition to adult care.

RESOURCES

The Children's Oncology Group. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Available at: http://www.survivorshipguidelines.org/

American Society for Reproductive Medicine, Ethics Committee. Fertility preservation and reproduction in patients facing gonadotoxic therapies: a committee opinion. *Fertil Steril*. 2013;100(5):1224–1231. Available at: http://www.fertstert.org/article/S0015-0282(13)03007-0/fulltext

Oktay K, Harvey BE, Partridge AH, et al. Fertility preservation in patients with cancer: ASCO clinical practice

guideline update. *J Clin Oncol*. 2018. Available at: http://ascopubs.org/doi/abs/10.1200/JCO.2018.78.1914

International Society for Sexual Medicine. Sexual function in childhood cancer survivors: a report from project REACH. Available at: http://www.issm.info/news/research-highlights/research-summaries/sexual-function-in-childhood-cancer-survivors-a-report-from-project-reach/

Hembree WC, Cohen-Kettenis PT, Gooren L, et al. Endocrine treatment of gender-dysphoric/gender-incongruent persons: an Endocrine Society Clinical Practice Guideline. *J Clin Endocrinol Metab.* 2017;102(11):3869–3903

Lee PA, Nordenström A, Houk CP, et al. Global disorders of sex development update since 2006: perceptions, approach and care. *Horm Res Paediatr*. 2016;85(3):158–180. Available at: https://www.karger.com/Article/FullText/442975

The Oncofertility Consortium (overview of fertility preservation, includes information on some nonmalignant conditions as well). Available at: http://oncofertility.northwestern.edu/

Johnson EK, Finlayson C, Rowell EE, et al. Fertility preservation for pediatric patients: current state and future possibilities. *J Urol*. 2017;198(1):186–194. Available at: http://www.sciencedirect.com/science/article/pii/S0022534717302239

Alberta (Canada) Health Sciences. Sexuality and disability. Available at: https://teachingsexualhealth.ca/wp-content/uploads/sites/4/Sexual-and-Development-Disablity-Guide-2016.pdf

Advocates for Youth. Sexual health education for young people with disabilities: research and resources for parents/guardians. Available at: http://www.advocatesforyouth.org/publications/publications-a-z/2560

Wilson GN, Cooley WC. *Preventive Health Care for Children With Genetic Conditions*. 2nd ed. Cambridge, United Kingdom: Cambridge University Press; 2006

Cassidy SB, Allanson JE. *Management of Genetic Syndromes*. Hoboken, NJ: John Wiley & Sons; 2010

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ABBREVIATIONS

AAP: American Academy of Pediatrics
STI: sexually transmitted infection

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REFERENCES

1. Breuner CC, Mattson G; Committee on Adolescence; Committee on Psychosocial Aspects of Child and Family Health. Sexuality education for children and adolescents. *Pediatrics*. 2016;138(2):e20161348
2. Hagan JF, Shaw JS, Duncan PM. *Bright Futures for PDA: Guidelines for Health Supervision of Infants, Children, and Adolescents*. 3rd ed. Elk Grove Village, IL: American Academy of Pediatrics; 2008
3. Ott MA, Sucato GS; Committee on Adolescence. Contraception for adolescents. *Pediatrics*. 2014;134(4). Available at: www.pediatrics.org/cgi/content/full/134/4/e1257
4. Burke PJ, Coles MS, Di Meglio G, et al; Society for Adolescent Health and Medicine. Sexual and reproductive health care: a position paper of the Society for Adolescent Health and Medicine. *J Adolesc Health*. 2014;54(4):491–496
5. American Sexual Health Association. Sexual functioning. 2017. Available at: www.ashasexualhealth.org/sexual-health/sexual-functioning/. Accessed January 10, 2017
6. Ethics Committee of American Society for Reproductive Medicine. Fertility preservation and reproduction in patients facing gonadotoxic therapies: a committee opinion. *Fertil Steril*. 2013;100(5):1224–1231
7. Fallat ME, Hutter J; American Academy of Pediatrics Committee on Bioethics; American Academy of Pediatrics Section on Hematology/Oncology; American Academy of Pediatrics Section on Surgery. Preservation of fertility in pediatric and adolescent patients with cancer. *Pediatrics*. 2008;121(5). Available at: www.pediatrics.org/cgi/content/full/121/5/e1461
8. Oktay K, Harvey BE, Partridge AH, et al. Fertility preservation in patients with cancer: ASCO clinical practice

guideline update [published online ahead of print April 5, 2018]. *J Clin Oncol*. doi:10.1200/JCO.2018.78.1914

9. Ellis SJ, Wakefield CE, McLoone JK, Robertson EG, Cohn RJ. Fertility concerns among child and adolescent cancer survivors and their parents: a qualitative analysis. *J Psychosoc Oncol*. 2016;34(5):347–362
10. Nilsson J, Jervaeus A, Lampic C, et al. 'Will I be able to have a baby?' Results from online focus group discussions with childhood cancer survivors in Sweden. *Hum Reprod*. 2014;29(12):2704–2711
11. Frederick NN, Recklitis CJ, Blackmon JE, Bober S. Sexual dysfunction in young adult survivors of childhood cancer. *Pediatr Blood Cancer*. 2016;63(9):1622–1628
12. Zebrack BJ, Foley S, Wittmann D, Leonard M. Sexual functioning in young adult survivors of childhood cancer. *Psychooncology*. 2010;19(8):814–822
13. East LJ, Orchard TR. Somebody else's job: experiences of sex education among health professionals, parents and adolescents with physical disabilities in Southwestern Ontario. *Sex Disabil*. 2014;32(3):335–350
14. Murphy C, Lincoln S, Meredith S, Cross EM, Rintell D. Sex education and intellectual disability: practices and insight from pediatric genetic counselors. *J Genet Couns*. 2016;25(3):552–560
15. Lee PA, Nordenström A, Houk CP, et al; Global DSD Update Consortium. Global disorders of sex development update since 2006: perceptions, approach and care [published correction appears in *Horm Res Paediatr*. 2016;85(3):180]. *Horm Res Paediatr*. 2016;85(3):158–180
16. Sutton EJ, Young J, McInerney-Leo A, Bondy CA, Gollust SE, Biesecker BB. Truth-telling and Turner syndrome: the importance of diagnostic disclosure. *J Pediatr*. 2006;148(1):102–107
17. Goodwin T, Elizabeth Oosterhuis B, Kiernan M, Hudson MM, Dahl GV. Attitudes and practices of pediatric oncology providers regarding fertility issues. *Pediatr Blood Cancer*. 2007;48(1):80–85
18. Miller SD, Li Y, Meyers KE, Caplan A, Miller VA, Ginsberg JP. Fertility preservation in paediatric nephrology: results of a physician survey. *J Ren Care*. 2014;40(4):257–262
19. Nahata L, Sivaraman V, Quinn GP. Fertility counseling and preservation practices in youth with lupus and vasculitis undergoing gonadotoxic therapy. *Fertil Steril*. 2016;106(6):1470–1474
20. Nahata L, Ziniel SI, Garvey KC, Yu RN, Cohen LE. Fertility and sexual function: a gap in training in pediatric endocrinology. *J Pediatr Endocrinol Metab*. 2016;30(1):3–10
21. Nahata L, Quinn GP, Tishelman A. A call for fertility and sexual function counseling in pediatrics. *Pediatrics*. 2016;137(6):e20160180
22. Delaney RO, Serovich JM, Lim JY. Reasons for and against maternal HIV disclosure to children and perceived child reaction. *AIDS Care*. 2008;20(7):876–880
23. Ethics Committee of American Society for Reproductive Medicine. Informing offspring of their conception by gamete or embryo donation: a committee opinion. *Fertil Steril*. 2013;100(1):45–49
24. King JE, Plamondon J, Counts D, Laney D, Dixon SD. Barriers in communication and available resources to facilitate conversation about infertility with girls diagnosed with Turner syndrome. *J Pediatr Endocrinol Metab*. 2016;29(2):185–191
25. Gallo AM, Angst DB, Knafl KA, Twomey JG, Hadley E. Health care professionals' views of sharing information with families who have a child with a genetic condition. *J Genet Couns*. 2010;19(3):296–304
26. Hein IM, De Vries MC, Troost PW, Meynen G, Van Goudoever JB, Lindauer RJL. Informed consent instead of assent is appropriate in children from the age of twelve: policy implications of new findings on children's competence to consent to clinical research. *BMC Med Ethics*. 2015;16(1):76
27. Cooley WC, Sagerman PJ; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011;128(1):182–200

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