Mini-Review

Adolescents with Special Needs: Clinical Challenges in Reproductive Health Care

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A B S T R A C T

Adolescents with special needs have unique reproductive health care needs related to their physical and cognitive issues. This review discusses some of the most common concerns that are encountered in clinical practice, as the clinician will partner with the adolescent and her family to guide her through the pubertal transition and to help navigate the risks and rights of reproduction. Families often seek anticipatory guidance before menarche on menstrual hygiene, abuse risk and sexuality and can be reassured that most teens with special needs do very well with menstruation. The clinician needs to evaluate the teenager's reproductive knowledge as well her risk for abuse and coercion and her ability to consent to sexual activity, if she requests contraception. Menstrual management is mostly based on the impact of the menstrual cycles on the teenager's life and activities. The adolescents may have a decreased ability to tolerate menses or pain, or experience changes in seizure pattern or altered mood. Hormonal treatment is often used to assist with menstrual hygiene, cyclical mood changes or dysmenorrhea. The goal of treatment can be complete amenorrhea, alleviate pain or regulate and decrease menstrual flow. The unique risks and benefits of hormonal treatment for this special population are highlighted.

Key Words: Adolescents with special needs, Disabilities, Menstrual management, Sex education, Abuse

Introduction

The reproductive health of teenagers and women with special needs brings about an interesting dichotomy. Teens with special needs have a known increased risk of abuse and exploitation, so every effort is made to minimize that threat. However, these adolescents are less likely to be allowed to express sexual feelings or contemplate sexual relationships, if they desire to do so. It is these rights and risks of reproductive health for teenagers with disabilities that primary care clinicians and adolescent health specialists are often called upon to help navigate: the complex issues of the healthy and safe transition to young adulthood.

In 2012, 12.1% of the overall US population reported a disability; ambulatory disabilities were the most common (6.9%). In the age group of 16 to 20 years the overall disability rate is 5.5% with cognitive disabilities being reported most frequently (3.9%).[1] The reported rate of children with developmental disabilities from 2006 to 2008 was approximately 1 in 6 children with the largest increases in autism spectrum disorder and attention deficit hyperactivity disorders.[2] Therefore, most clinicians will encounter teenagers with a wide range of abilities in their practice. When these girls with special needs, whether the limitations are physical, developmental or both, become adolescents, many unique challenges are experienced by the teenagers and their caregivers (in this communication the term, "caregiver," will include parents, guardians or other caregivers). In this report we address some of the clinical challenges in reproductive health care for adolescents with disabilities. Some will apply for all teens with special needs; others will be more applicable for teens with physical or developmental disabilities only.

Anticipatory Guidance

Parents are often so worried about the onset of menses and associated symptoms that they will come in with their daughter before menarche, when breast development has started. They are searching for guidance on menstrual cycles, either to discuss the possibility of complete menstrual avoidance or to become aware of options to treat if indicated. In a large Canadian study 31.7% of parents came to a gynecologist before their affected child reached menarche.[3] Although there is great fear and anticipation of menstrual issues, most teens with disabilities and families report doing fairly well with menstruation without intervention.[4,5] Because it is difficult to predict how menses will affect a teenager's life before it starts and whether intervention is indicated, pubertal events should be allowed to advance naturally. The tolerance and effect of the menstrual cycles can then be evaluated, which will lead to the most natural growth and development.[3,6] Young women with physical disabilities might wonder how to deal with menses and hygiene products and how that might affect their (in)dependence. For the clinician this is an opportunity for validation of these concerns, have an open discussion with the parents and the (pre)teens about sexuality, and

The author indicates no conflict of interest.

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1083-3188/$ - see front matter © 2016 North American Society for Pediatric and Adolescent Gynecology. Published by Elsevier Inc.
http://dx.doi.org/10.1016/j.jpag.2015.05.003

emphasize the normalcy of menstruation and sexual feelings as a part of growing up.[7] Most teens with disabilities will have normal pubertal development, although there are some situations in which an earlier puberty can be anticipated, as in adolescents with cerebral palsy.[8]

Sexual Education and Abuse Prevention

Sexual abuse and unwanted attention is a major concern for parents of teenagers, especially those who are more vulnerable. Although the overall rate of sexual abuse has decreased in the past 10 years, children with disabilities are 2 to 3 times more likely to be sexually abused than children without disabilities.[9] Teenagers with physical disabilities are dating at the same rates as their peers, but report more dating violence (25.9% vs 8.8% for teens without disabilities).[10] In a national survey female high school students who reported a physical disability or long-term health problem were more likely to report having been physically forced to have sexual intercourse than those who did not (19.6% vs 9.4%).[11] Persons with certain disabilities might be dependent on others for many activities of daily living, including private activities and might have difficulty distinguishing appropriate from inappropriate touch. They are often praised for cooperation and following orders, which can make them more vulnerable to exploitation. Teenagers with physical or intellectual disabilities (ID) are often considered to be asexual[12] and are not provided the same access to education about sexuality, sexually transmitted infections, and pregnancy prevention, either at school or at home. One recent study tested sexual knowledge of 60 young people (ages 16-21 years); 30 with mild ID and 30 peers without ID. The overall knowledge was lower in teens with ID, as was anticipated. However in the study group men with ID were more knowledgeable than women with ID, as opposed to the control group in which women had better knowledge.[13] Clinicians should bring up sexuality as part of general health care, and acknowledge the family's concerns and values and help them educate their daughters. The provider can assess knowledge, safety, and the ability to consent to any sexual activity. Any changes in behavior, like regression, social withdrawal, or self-injurious behavior might be indicative of abuse. On physical examination bruises in unusual places and pain, trauma, or itching in the genital area raises concern for maltreatment. A confidential interview with the teen starting at approximately the age of 12 to 14, recommended by the American Academy of Pediatrics in their general guidelines for pediatric care[14] and the American Congress of Obstetricians and Gynecologists (ACOG) guidelines for adolescent health care,[15] might help to get a conversation started, dependent on the individual situation, the teen's level of development, and her interest. After evaluation the clinician can make an educational plan with the family to be followed through at home.

Dependent on developmental level, the education can start with basic aspects of sexuality, including anatomical parts of both sexes and what activities are appropriate and inappropriate for private and public places. The next level of discussion is around sex, pregnancy, contraception, and sexually transmitted infections, including voluntary and nonvoluntary activities. Abuse prevention should be part of this education, based on the developmental level. One relatively easy technique to teach is "NO-GO-TELL" abuse prevention (exercise: in an uncomfortable situation the adolescent says NO clearly, tries to GO away, then TELLs a trusted adult; families can practice this at home). Support groups and agencies that care for individuals with cognitive impairment might be able to offer useful resources.

Menstrual Management

The Decision

Menstrual management requests are evaluated like any other request for medical care. If the adolescent herself asks for menstrual management, then the clinician can discuss the effect of the menstrual periods, including heaviness, frequency, and length and normalcy of initial irregular bleeding in adolescence.[7] This is followed by an assessment for contraceptive needs and the ability to have a consensual relationship. If the request is made by caregivers, it is important to address the reasons that prompted the parents or care providers to ask for this. Consider the effect of the cycle on the life of the teen or the caregivers and the possible fear of pregnancy in a teen who cannot articulate her desires in that respect. Address the safety of the teenager at school or at home. If the request is done because of caregiver discomfort with menstruation then education of all of the adolescent's caregivers, including aides at school, might help the family adapt more easily.

General Concerns for Teens with Disabilities

When the decision has been made to manage the menses, outcomes goals are set with the patient and her caregivers. These might include lightening flow of regular heavy cycles, regulation of irregular periods, or suppression of all or most bleeding and the need for reliable contraception. There are several areas to consider in discussions with the adolescent and her caregivers[6,16]:

- Complete amenorrhea is difficult to obtain with any method, especially initially. For some teenagers, unpredictable bleeding is worse than predictable infrequent periods. This is especially true for teens who have to rely on others for their hygiene needs.[17]
- Weight gain can be a major issue for teens who use mobility devices, because this might affect their ability to do their own transfers and therefore change their independence level.
- For teens with seizures or receiving seizure medication, there might be cross interference with certain hormonal medications.[18]

Challenges of the Specific Methods

Decisions on the method of menstrual management to use for a specific patient can be complicated and an overview of the methods and the special consequences for teens with disabilities are provided in Table 1. A shift has been

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