Menstrual and Reproductive Issues in Adolescents With Physical and Developmental Disabilities

Elisabeth H. Quint, MD

(Obstet Gynecol 2014;124:367–75)

Question 1:

Discussing sexual health seems to be awkward for all teens. Considering the additional communication barriers for adolescents with disabilities, are there any recommendations or resources that you have found to be particularly helpful for assessing their understanding of reproductive health and abuse?

Response from Dr. Quint:

It all is really dependent on the level of disability and developmental delay of the teen. For adolescents with physical disabilities only, the discussion is focused on making sure their sexual knowledge is adequate. We also discuss potential adaptive techniques (eg, position changes) to be able to have sexual intercourse if they desire and to start that conversation with the families if the patients need help to facilitate that.

If the patient is mildly to moderately delayed, we will start with assessment of gender knowledge. We use questions like: What is the difference between boys and girls? We discuss private and public body parts as well as private and public activities with the body parts. The use of drawings or dolls can really help with that talk. The next step is discussing behaviors appropriate for girls, boys, and other people in their lives. “Circles” is a good tool to discuss the people in the patient’s life with whom she can hug, shake hands, wave to, and who she should not talk with.

With mildly delayed patients, we focus on safety, abuse prevention (NO-GO-TELL), sexual activity that could be appropriate, assessment of ability to consent, need for birth control, and sexually transmitted infections.

With more delayed patients, we discuss with the patients and caregivers safety, actions to prevent abuse, hygiene measures, and appropriate private expression of sexuality.
Question 2:
You mention that teens with neurodevelopmental disabilities experience earlier sexual development while teens on the autism spectrum tend to be delayed. What is the speculated mechanism for this?

Response from Dr. Quint:
For teens with neurodevelopmental disabilities, central precocious puberty is found more often than in the general populations and is likely due to brain insult (see Knickmeyer et al, Dev Med Child Neurol 2006;48:1007–8 and Whitehouse et al, J Autism Dev Disord 2011;41:1125–30).

In terms of autism, two studies showed a delayed menarche and the speculated mechanism has been proposed as prenatal androgen exposure as a common contributor, both for autism spectrum conditions and later onset of menarche.

Question 3:
I usually tell my adult patients with daughters to send them to me for their first visit “before they actually need me.” This way I have the opportunity to review sexually transmitted infections and contraception prior to them becoming sexually active. Do you recommend that special needs teens come even earlier to have more time to educate them? When should the teenager with disabilities begin visits to the obstetrician–gynecologist?

Response from Dr. Quint:
A lot depends on the family and how open they are in educating their kids on these topics. Teens with disabilities tend to miss out on the sexual education at school and at home because they are often considered “asexual.” As the mother of a 15-year-old told me: “I just tell her: boys can never touch you.” Clearly, the parents need help with this issue, they often do not know where to begin, and they are very worried about abuse and vulnerability. Soon after menarche is a good time to start the discussion on the effect of periods on the teenager’s life and the assessment of knowledge on health and sexuality. Discuss with the parents and team up with them to develop an educational plan that fits with their comfort level and philosophy.

Question 4:
After reading this article, I feel that your take-home point is to treat teens with disabilities similarly to teens without disabilities. The critical difference seems to be focusing on communication and education. Would you agree with this?

Response from Dr. Quint:
I totally agree. The more we attempt to treat all teenagers the same, the more we focus on their abilities and not their limitations. Sexuality is a part of everyone’s life and should be given the proper attention, with an adapted focus for each individual and special attention to education and communication.
Question 5:
You mention drospirenone-containing combined oral contraceptive pills (OCPs) for menstrual related mood disturbances. Do you recommend a specific progestin-containing combined OCP for more effective cycle control? Dysmenorrhea? With what dose do you begin?

Response from Dr. Quint:
As we are trying to practice evidence-based medicine as much as possible, there unfortunately is not great evidence about what combined OCP gives the best cycle control.

A 2013 Cochrane review showed that the 20 microgram ethinyl estradiol combined OCP has worse cycle control than the higher ethinyl estradiol preparations for most progestins used (see Gallo et al, Cochrane Database Syst Rev 2013;1:CD003989). There is also some evidence that the 30 microgram ethinyl estradiol level pills are better for bone mineral density in adolescents than the lower ethinyl estradiol combined OCP. So overall, my preference is to start with a 30 microgram combined OCP.

Which progestin will give the best suppression is unclear. The dysmenorrhea literature does not clearly favor one over another.

Question 6:
When you discuss combination oral contraceptives, you mention supplementing with intermittent estrogen for breakthrough bleeding. What type of estrogen and dose do you recommend and on what schedule?

Response from Dr. Quint:
Studies have shown that the continuous regimen leads to endometrial atrophy and that may lead to persistent spotting. After pregnancy has been ruled out, the two solutions that have been proposed in the literature are to take a 3–4 day break, then restart, or to use low-dose estrogen supplementation. I usually recommend my patients to take the 4-day break and have found that to be helpful. There is no study that has looked at the low-dose estrogen supplementation per se, so it is hard to give a solid recommendation. Getting an ultrasonogram to document a thin endometrial lining and then a trial of 1–2 weeks of an estradiol patch is certainly something that could be tried. Trials using 10 microgram ethinyl estradiol in the 7 days “off” in the 84/7 contraceptives show promise at long-term decrease in breakthrough bleeding.

Question 7:
Given the greater chance of undiagnosed expulsion in teens with disabilities, do you recommend more frequent assessment of intrauterine device (IUD) location with exams or ultrasonograms, or do you rely on the caregiver’s observations?

Response from Dr. Quint:
There is not a lot of experience yet about IUD expulsions in teens with disabilities. Ultrasonograms are often suboptimal if the patients cannot tolerate a transvaginal approach or cannot reliably hold their urine for a good transabdominal scan. I recommend thorough education of the patient and all her caregivers about concerning bleeding pattern changes that could possibly predict IUD expulsions and would warrant notifying the provider. I also encourage keeping a bleeding calendar that the provider can then evaluate yearly and notice changes that may prompt an investigation of IUD location.
Question 8:
You mention there are some concerns with teens and use of selective serotonin reuptake inhibitors (SSRIs). What concerns should we be aware of? Increased suicide rates? Polypharmacy and drug interactions?

Response from Dr. Quint:
Those are exactly the two main concerns with the use of SSRIs in teenagers. The U.S. Food and Drug Administration has placed a black box warning on the use of SSRIs in young adults under age 24 years for an increased risk of suicide in the first few months of use, as well as with dose changes. Also noticeable is that premenstrual dysphoric disorder (PMDD) is not an approved indication for SSRI use in adolescents; therefore, if the PMDD is so severe that this treatment is contemplated as off-label use, discussion with a psychiatrist is recommended. In teens on multiple medications, I also consult with their other providers.

Question 9:
Since antiepileptic drugs are known for decreasing effectiveness of systemic hormonal contraceptives, do you think the levonorgestrel-containing IUD would be better for contraception or menstrual suppression for teens with seizure disorders?

Response from Dr. Quint:
Since the IUD is one of the most effective forms of birth control, I would highly recommend it. However, combined OCPs can be used based on the antiepileptic drug the patient is on. The medical eligibility criteria for contraception from the Centers for Disease Control and Prevention (CDC) give us guidance. Any contraceptive in patients using the non-enzyme inducing antiepileptic drugs are CDC category 1, including combined OCPs and both IUDs. In teens on the enzyme-inducing antiepileptic drugs, depot medroxyprogesterone acetate as well as the IUDs are category 1, but the combined OCPs are category 3 and alternatives are usually indicated.

Question 10:
Apart from the weight gain seen with depot medroxyprogesterone acetate, are there any special considerations for choice of contraception for the obese teen with disabilities?

Response from Dr. Quint:
The contraceptive choices for obese teens with disabilities are similar to obese adolescents without disabilities. In the Medical Eligibility Criteria from the CDC, all methods are category 1 or 2 for obesity. However, the side effects of the contraceptives may have a different effect on the lives of these teens. Examples of this are the already mentioned weight gain of depot medroxyprogesterone acetate and how that may affect independence if adolescents do their own transfers. Breakthrough bleeding on any form of contraception may be much more difficult to manage if the teen is dependent on caregivers for changing of menstrual products and may lead to missing school and therefore affecting the teenager’s life.