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4-1-2016

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Recommended Citation

Acharya, K., Lantos, J. D. Considering Decision-Making and Sexuality in Menstrual Suppression of Teens and Young Adults with Intellectual Disabilities. *AMA J Ethics* 18, 365-372 (2016).

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American Medical Association Journal of Ethics

April 2016, Volume 18, Number 4: 365-372

ETHICS CASE

Considering Decision Making and Sexuality in Menstrual Suppression of Teens and Young Adults with Intellectual Disabilities

Commentary by Kruti Acharya, MD, and John D. Lantos, MD

Dr. Jones is a gynecologist who has been seeing Amy for the past few years to help with menstrual suppression. Amy was diagnosed with cerebral palsy at birth; she experienced some global developmental delay as a child and was in special education in school. Now 25, Amy works part-time at a local grocery store. Amy's mother currently holds her medical power of attorney, but she makes a concerted effort to include Amy in her medical care decisions, as she can express many of her wants and needs.

Dr. Jones remembers that Amy is a healthy young woman overall but has struggled with heavy and painful periods since her first menses at 13. Hygiene has also been difficult for Amy; she often forgets to change her pads, which results in staining of her clothes. Continuous-use oral contraceptive pills were successful at suppressing her periods for several years; then she switched to the medroxyprogesterone shot so she would not need to take any daily medications. Last year, however, bothersome breakthrough bleeding prompted Dr. Jones to order a pelvic ultrasound, which revealed that Amy had several small uterine fibroids. Subsequently, he recommended a hormonal IUD for menstrual suppression, which was placed under anesthesia. Amy and her mother arrive for a follow-up visit six months after its placement, and Dr. Jones is eager to hear how things have been going.

Dr. Jones quickly learns that Amy has been doing very well at work and has recently started dating. Her new boyfriend, David, also has cerebral palsy. Amy proudly explains that she and David have been dating for three months.

Dr. Jones asks, "What do you and David like to do together?"

Amy grins and says, "We like to go to the movies. Our parents go with us, but we make them sit a few rows back."

Dr. Jones goes on to ask, "Amy, I wanted to see how your periods have been. Has the IUD helped?" Amy replies, "I don't have cramps anymore but I still am bleeding a small amount almost every day. I try to wear a pad but I sometimes forget and bleed on my clothes."

Amy's mom confirms, "Unfortunately, she is still struggling with the bleeding and it's really hard for her to stay clean, especially at work."

Later, speaking privately with Dr. Jones, she asks, "I have wondered about the possibility of having Amy's uterus taken out. Her bleeding has still not stopped and we know that she has fibroids. I am happy that Amy has been able to find such a nice boyfriend, but I really don't anticipate that she will ever have children. She has gone through sex education classes, but I don't think she really understands 'the birds and the bees.'"

Dr. Jones nods and replies, "I know Amy is pretty capable of expressing her wants and needs. What do you think she would say?"

Amy's mom sighs and says, "I haven't brought up the idea with her yet. I'm concerned about how she might respond. She probably would not be happy to hear that she would never be able to have children. However, she doesn't understand what having a child is really like. At least as things are now, I do not anticipate her being able to care for a child independently. She still lives with us and requires a lot of support herself."

Dr. Jones then says, "I understand your concerns and certainly empathize with your difficult situation. I would like to take time to consider this more."

Commentary

This case raises ethical issues about the treatment of young adult patients with intellectual disabilities: distinguishing caregiver convenience from patient benefit, respecting the desires of patients who might not have decision-making capacity, and appropriate counseling and teaching regarding sexuality for adults with intellectual disabilities.

According to the 2010 US Census, 1.7 million children and adolescents aged 6 to 15 years have developmental disabilities [1]. For most teenagers with disabilities, puberty occurs at the same age as in peers without disabilities, although some neurodevelopmental disabilities are associated with early puberty [2]. Teens with autism spectrum disorders might experience slight delays in the onset of menarche [3].

Hygiene

Menstrual flow, whether normal or increased, can be difficult to manage for patients with disabilities, and some teens with disabilities might require assistance from a caregiver (e.g., to properly place a menstrual pad or remember to wear or to regularly replace it). Other teens with disabilities might remove pads or not dispose of them properly [4].

The American College of Obstetrics and Gynecology recommends pharmacological menstrual suppression for teens (or adults) with disabilities who need significant help with menstrual hygiene [5]. There are a variety of treatments that can reduce menstrual flow, but complete amenorrhea is difficult to achieve with any hormonal treatment. In this case, despite trying increasingly invasive pharmacological and physical interventions to suppress her menses, Amy still has continued bleeding, and her problems with hygiene persist. An ethical and clinical question confronting her parents and Dr. Jones is how to respond to these facts.

Ethical considerations. All treatments have side effects, including some that are quite severe. Ethical issues in hormonal or surgical suppression of menstruation have to do with balancing potential risks and benefits. In order to assess the benefits of a given treatment course, two things are necessary: the first is an accurate characterization of the problem. Objective data about the number of days of bleeding and the number of days of adequate and inadequate menstrual hygiene would be helpful to quantify the magnitude of the problem. The second is an understanding of the reasons offered by [the person who is requesting the treatment](#) to suppress menstruation (i.e., the person with the disability and the caregiver might have different reasons). If the caregiver is making the request, it is important to tease out whether the primary motivation is to decrease caregiver burden (i.e., convenience) or whether it is to improve quality of life for the person with the disability. If the primary motivation is to decrease burdens to the caregiver, then it would be appropriate to consider solutions other than medication for the patient. If the focus is on the teen's quality of life, then medication might be a more ethically appropriate choice.

Menstrual suppression. Although the benefits of hormonal therapy are mainly psychosocial and hygienic, the risks are physical, including potentially life-threatening complications such as thromboembolism [6]. Medroxyprogesterone can also decrease bone density [7]; limited ability to bear weight is of particular concern for patients with cerebral palsy because they are already at increased risk of osteopenia and osteoporosis [8]. Hormonal treatments can also affect the metabolism of drugs, particularly antiepileptic drugs [9] and antiretroviral medications [10], so physicians will need to carefully monitor doses of other medications the patient might be taking. Generally, a satisfactory treatment regimen can be developed and maintained [11]. Behavioral interventions can be important therapeutic adjuncts to hormonal treatments for menstrual hygiene. Visual or audio alarms on mobile apps or programmable watches, for example, can help remind a patient to place or replace a pad. Procedures under general anesthesia, as was the case with the IUD insertion, also carry their own risk. The risks of general anesthesia have been well described in the anesthesia literature [12].

Sterilization. The request for a hysterectomy is an ethically complex option because it would mean permanent and irreversible sterilization. Of note, the fibroids in this case are

a classic red herring. Fibroids, alone, are not an indication for hysterectomy [13]. Thus, there does not appear to be a bona fide medical indication for hysterectomy in this case at this time. If there were a bona fide medical indication for hysterectomy and all other medical and behavioral options had been exhausted, then the need to get Amy's consent for surgery would decrease; instead, considerations of her best interest would become more important than respecting her autonomy.

Even in that case, however, involuntary sterilization would not be ethically acceptable. Involuntary sterilization has a long and sordid history in both the United States and other countries. In the early twentieth century, involuntary surgical sterilization was part of a nationwide eugenics program designed to prevent persons with intellectual and other disabilities from having babies. In 1927, these eugenic practices were upheld by the Supreme Court decision in *Buck v. Bell*. That ruling upheld a Virginia law that allowed states to forcibly sterilize residents in order to prevent "feeble-minded and socially inadequate people from having children" [14]. After the ruling, more than 60,000 involuntary sterilizations were performed in the United States [15]. After World War II, forced sterilization of individuals with disabilities gradually lost favor. In 1942, the Supreme Court declared procreation to be a fundamental human right [16], and the United Nations Convention of the Human Rights of People with Disabilities recognizes fertility as an inherent human right [17].

Today, it is illegal to use federal money to pay for involuntary sterilization [18]. Many states have statutes that ban involuntary sterilization or require judicial approval. However, as the American Academy of Pediatrics notes, "The complexities of federal rules, state laws, and judicial rulings have created a confusing and contradictory array of restrictions on surgical sterilization of persons with developmental disabilities" [19].

As the possessor of medical power of attorney, Amy's mother has been legally designated as Amy's [proxy decision maker](#), but it is not ethically justifiable for her to make decisions based solely on her own values and judgment. As discussed above, it is benefit to the patient, not to the caregiver, that must balance or outweigh the risks to the patient. Furthermore, these decisions should be made following the practice of shared decision making, that is, by considering and prioritizing Amy's personal values and preferences and ensuring she has an active, strong voice in her future planning. Perhaps a next step would be for Dr. Jones to facilitate a discussion that includes Amy. Her mother's concerns about Amy's decisional capacity and future independence are appropriate, but even if Amy might not be able to fully assess the consequences of her options to make an informed choice, her desires can help guide her mother's decision-making process.

There is no way to assess Amy's understanding of a hysterectomy and its implications without having a discussion with her. In evaluating her ability to make such a decision, it

is important to distinguish two key concepts: decisional capacity and competence. Decisional capacity is determined by a physician after a clinical assessment of a patient's ability to make an informed decision [20], whereas the presence or absence of competence is determined by judges after reviewing medical information and testimony. Decisional capacity varies with the specific task or decision under discussion, whereas competence is a global assessment. To have decision-making capacity, one must be able, among other things, to understand the implications of a particular decision.

Many women with intellectual disabilities can give informed consent [21]. People with intellectual disabilities should be assumed to have capacity to make decisions unless there is good evidence to question their capacity. In this case, a decision about sterilization requires some understanding of contraception, pregnancy, childbirth, fertility and infertility, and parenting [22]. Amy might, as her mother fears, not be happy with a plan that curtails the possibility of having children. On the other hand, she might accept that she would never be capable of caring for children herself. In either case, hysterectomy should not proceed unless she agrees to it with some understanding of the implications of her decision and of the risks of the surgery.

Amy's Sexuality

In this case, both Dr. Jones and Amy's parents seemed to welcome and accept her relationship with her boyfriend, but there is no indication that they have talked to her about sexuality. For example, it is unclear whether Amy is aware that the medications she has been taking for menstrual suppression are also contraceptive agents. In the case as presented, it is unclear whether Amy understands the implications and possible consequences of sexual activity. According to her mother, she did receive some sex education, but we do not know the content of that education or whether it was adequate. Parents might avoid bringing up sexuality with their children with disabilities—as Amy's mother seems to have done—because they are uncomfortable with the topic (and perhaps fearful that the child has experienced sexual abuse), have little knowledge themselves about sexuality and disability, or are concerned that such a conversation might encourage sexual intercourse [23].

Amy's parents and caregivers should know that people with intellectual disabilities can have intimate social relationships, including friendships and romantic and sexual relationships. For example, Chamberlain et al. found that 51 percent of a sample of 41 11- to 23-year-old women with mild intellectual disabilities had engaged in intercourse, and 32 percent continued to be sexually active [24].

Typically, developing teens learn about social boundaries and limits of touch through repeated everyday peer interactions. Their peers with disabilities can experience more social isolation, which might limit their exposure to natural learning environments in which physical interactions occur.

Therefore, formal education about sexuality and sexual health is critical for people with disabilities. Many people can be taught what is or is not appropriate and healthy sexual behavior and how to engage in sexual behavior within socially appropriate limits. However, people with disabilities tend to be viewed as either incapable of understanding these issues or as asexual [25]. As a result, they might not receive appropriate sex education. To ensure understanding, curricula need to be explicit and adapted to an individual's level of health literacy. Plain but accurate terms should be used to describe body parts, for example. Visual material and models can be helpful, particularly for participants with limited verbal skills.

Sexual education should not be confined to school settings, however; it must be reinforced at home by parents and professional caregivers. By discussing sexuality and sexual health with their teens and young adults with disabilities, parents can equip their children with necessary tools to navigate emerging intimate relationships.

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ISSN 2376-6980**