

Ethical Controversy About Hysterectomy for a Minor

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One of the most complicated ethical issues that arises in children's hospitals today is the issue of whether it is ever permissible to perform a procedure for a minor that will result in permanent sterilization. In most cases, the answer is no. The availability of good, safe, long-acting contraception allows surgical options to be postponed when the primary goal of such surgical options is to prevent pregnancy. But what if a minor has congenital urogenital anomalies or other medical conditions for which the best treatment is a hysterectomy? In those cases, the primary goal of therapy is not to prevent pregnancy. Instead, sterility is an unfortunate side effect of a medically indicated treatment. Should that side effect preclude the provision of a therapy that is otherwise medically appropriate? We present a case that raises these issues, and asked experts in law, bioethics, community advocacy, and gynecology to respond. They discuss whether the best option is to proceed with the surgery or to cautiously delay making a decision to give the teenager more time to carefully consider all of the options.

abstract

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THE CASE

A 15-year-old teenager with complex urogynecologic anomalies presents to adolescent gynecology for a second surgical opinion.

She was born with vaginal atresia and a uterine duplication. Now, after puberty, she has menses, but a noncommunicating upper vaginal segment. This leads to ongoing pain from retention of menses. In a previous surgery at age 10 years, a nonfunctioning pelvic kidney, a nonfunctioning left uterine horn, and an ectopic ureter were removed.

A urologist has recommended complex reconstruction of her vagina and remaining uterine horn, with the hope for potential gestation of a fetus in the future. Preparation for this surgery requires using gonadotropin-releasing hormone (GnRH) analogs and daily vaginal dilation. The patient finds the dilations very painful.

A gynecologist is consulted for a second opinion. She believes that the chances of successful uterine and vaginal reconstruction are low, and that it is unlikely the patient will ever be able to carry a pregnancy in a small, scarred uterine horn. If she were to get pregnant, the risk of uterine rupture is high. The gynecologist recommends a hysterectomy, with retention of the ovaries for possible egg harvesting (if the patient so desires) later in life.

After reflection on the serious consequences of complex reconstruction against those of hysterectomy, the patient and her mother request a hysterectomy. The patient's father, who has not been present for the patient's appointments, worries that a hysterectomy might limit her options in the future.

The gynecologist consults the ethics committee, asking if concerns about

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sterilization of a minor would make it ethically unacceptable to perform a hysterectomy.

Alyssa M. Burgart, MD, MA, Arlene B. Baratz, MD, and Katrina Karkazis, PhD, Comment

This young woman, born with a difference of sexual development causing retention of menses, has experienced severe menstrual pain since puberty. Because she is a legal minor and treatment may variably affect her reproductive capacity, a particularly reasoned approach to her treatment options is required. Specific considerations include: (1) irreversibility, (2) future fertility options, and (3) the role of parental consent.

The patient's options for pain management are either noninvasive and reversible, or invasive and irreversible. Pharmacologic management with menstrual suppression, the sole noninvasive, reversible option, is the preferred treatment, even as a temporizing measure to delay a decision for surgery until she is of legal age to consent. However, she has already found GnRH analogs unacceptable. It would be cruel to leave her intractable pain unaddressed until she is 18 years of age solely to delay other treatment options that might compromise potential fertility.

Invasive, irreversible options include hysterectomy or a highly complex, novel procedure to establish a path for menstrual egress by surgically creating a vaginal conduit to the uterine horn. Both options could provide pain relief.

A urologist proposed surgery to create a neovagina, which would permit evacuation of menses while potentially preserving fertility. Congenital urogynecologic differences develop uniquely, requiring tailored interventions with unpredictable rates of complications. This experimental procedure is being considered to facilitate

gestational parenthood. At the time of presentation, the young woman can tolerate neither the proposed surgery's requisite regimens of menstrual suppression nor vaginal dilation.

The patient sought a second opinion from an adolescent gynecologist who recommended a hysterectomy. There are extensive data on the risks and benefits of hysterectomy showing it to be safe; it is the option that is most likely to provide comprehensive pain relief, the primary treatment goal.¹

Although hysterectomy precludes gestational capability, the experimental procedure would not ensure a safe and successful term delivery either. The patient and her mother have agreed that hysterectomy is the desired option; the patient's father reserves support for this decision.

Fifteen-year-old adolescent women are theoretically able to give consent for many kinds of reproductive decisions, but for procedures that irreversibly affect aspects of potential fertility, assurance of competence and comprehension is imperative. The patient's informed consent requires full discussion and understanding of the options for fertility preservation with assisted reproductive technologies, in addition to the risks and benefits of hysterectomy or other surgery. She should explore her values regarding menstruation, fertility, and sexuality, which will also influence her decision. If aversion to dilation is part of the decision for hysterectomy, she should understand that dilation remains an open option for the future when she is emotionally ready and motivated to become sexually active.²

The limited pregnancy outcome data on extensive experimental reconstruction suggest its fertility benefits are hypothetical. Even if her anastomoses heal without complication, endometriosis associated with obstructive

anomalies limits the likelihood of conception. Any pregnancy in a small uterus risks rupture or preterm delivery. In the presence of a neovagina, cesarean delivery is more likely than vaginal delivery. Given the patient's stated aversion to the required preoperative and postoperative dilation, the prospects of successful neovagina construction are limited.

The father has valid concerns about his daughter's future fertility. The risk that an irreversible fertility decision, such as tubal ligation, taken at a relatively young age will lead to regret later in life is well documented.³ Both offered procedures carry a risk of regret, which might be reduced with an open family discussion of how the patient and her parents engage with various aspects of fertility. Parenthood, the implied consequence of fertility, includes the conception, gestation, birthing, and rearing of children. Even if she does not carry a fetus, this young woman may become a parent in various other ways, either via adoption or through assisted reproductive technology using her eggs and a gestational carrier. Ideally, the father will respect his daughter's procreative values and understand that her choice of a hysterectomy may best serve her medical and emotional needs. The prospect of conventional fertility is important, but should not be prioritized above all else.

Much of the discussion on fertility here is theoretical, because this woman was born with unusual anatomy precluding typical fertility. A case might be made for the experimental surgery if the patient hopes to conceive a child through coitus and carry a pregnancy to term. The procedure proposed by the urologist offers a potential but slim chance to accomplish those goals, albeit with significant subsequent obstetrical risk. Given the poor prognosis of reconstruction

at facilitating a term pregnancy, the complex and invasive procedure leaves the patient as unlikely to be fertile as she was before. A hysterectomy does not preclude the patient from creating an embryo with an egg from her ovary if she desires. Using a gestational carrier may be a safer and more reliable alternative than attempting pregnancy and delivery with an atypical uterus and vagina. Uterine transplantation is another experimental approach that may become an option for this patient in the future if the therapy advances.⁴

Because this patient has no known mental incapacity and is old enough to provide consent for many reproductive services, she may be legally competent to make this decision herself, regardless of her parents' preferences. If her father does not consent to a hysterectomy, the patient and her mother may pursue a court order authorizing the procedure or allowing the patient to proceed as a minor. It is highly unlikely that the father could force uterovaginal conduit construction over the daughter's objections, especially while the mother is in agreement with the daughter.

Even if all stakeholders agree on the best course of action, sterilization law may influence the selection of treatment options. Given our country's history of eugenics, existing laws focus on preventing the involuntary sterilization of people with intellectual disabilities, rather than securing the rights of individuals choosing a procedure whose secondary effect also prevents pregnancy.⁵ There are legal prohibitions on involuntary sterilization of minors because the US constitution protects the right to reproduce, especially that of vulnerable groups, including those with difference of sexual development. Any relevant statutes, probate codes, and case law varies by state.⁵ In California, the patient

may not need parental consent, her hysterectomy would not be involuntary, and the "secondary" sterilization does not necessarily limit her fertility.

Court review of such decisions is feasible and would protect both doctors and parents from future liability. Physicians should consider a legal consult in any case of elective sterilization and in cases such as this one, which land in a legal gray area.⁶

Julie L. Strickland, MD, MPH, Comments

Any nonemergent therapy that produces irrevocable, life-altering changes to a teenager's ability to have an infant requires careful consideration. Such decisions can cause moral distress for the teenagers, their parents, and the professionals who care for them. This case gives cause to examine several issues of consent and assent of minors to both treatment and the cessation of treatment. It also highlights the emotionally charged issues involving medically indicated sterilization and the uncertainties about surgical outcomes.

Complex uterovaginal reconstruction is possible for patients born with vaginal atresia, but long-term management and frequent reoperation and revisions are often required. Vaginal reconstruction for patients with such anomalies remains imperfect and stenosis and fistula formation are common problems.⁷ This patient will need painful and disruptive surgeries and dilation treatments directed toward a distant future presumptive goal (vaginal competency and possible fertility). There is no guarantee of a favorable outcome. Thus, a hysterectomy might be considered a reasonable alternative to a long course of painful procedures with an uncertain outcome.

The concern regarding sterilization of this patient should be contrasted to general concerns about the

sterilization of minors and those with developmental disabilities.⁸ The American College of Obstetricians and Gynecologists discusses the use of hysterectomy regardless of consent status for those cases when indications meet the standard criteria and the benefits of surgery clearly outweigh the surgical risks.⁹ A hysterectomy for sterilization alone or for menstrual management is never indicated. But definitive surgical treatment of complex malformations may be considered in some cases, even though it may result in sterilization. In this case, a hysterectomy may be appropriate because the benefits might be judged to outweigh the harms. The suggestion of ovarian preservation maintains the principle of minimal harm to the patient and allows the patient to maintain some link with reproductive choice, although these are often practically limited due to logistical, scientific, and financial complexities. Larger concerns remain about the necessity of this choice in the maintenance of the overall health and well-being of the child and the medical necessity of proceeding with an irreversible procedure before the legal age of consent.

Although, in this case, the child has given assent, no mention has been made of the professional assessment of her maturity and understanding. This remains an important aspect of consent. Irrespective of that assessment or that she verbalized a unified opinion with her parent caregiver regarding a desire for a hysterectomy, complexities regarding the ability of parents to make nonemergent reproductive choices for their child loom large. The maintenance of reproductive organs and fertility carries special significance. Parental consent is adequate when limitation of reproduction is urgently necessary to preserve life or health. But that is not the case for this patient. The validity of parental consent to a sterilizing

procedure can be challenged when “the procedure could be safely postponed until the child can consent, or where less-invasive alternatives are available.”⁵

Menstrual suppression with the cessation of other therapies, such as dilation, remains an attractive option for this case, allowing the minor to mature and reach the age of consent. GnRH analogs are widely used for this purpose and, with add-back hormonal therapy, have a high level of medical safety.¹⁰ This approach combined with cessation of dilation would allow a reasonable chance for this adolescent girl to return to a relatively asymptomatic state and preserve fertility considerations until she can give legal consent to treatment. At that time, it will be easier to ensure that she is making an informed decision.

Reproductive integrity remains an emotionally charged issue. Psychological stress and feelings of isolation and loss are often expressed by women who have complex uterine anomalies, such as uterine agenesis.¹¹ Sexual identity and gender roles can be threatened. Sterilization at a young age often leads to powerful regrets later in life.¹² The best course of action in this case might be cautious delay, giving this young girl time and support to live with her condition and consider all the options carefully. This approach may lead to the best long-term psychological outcome. Research suggests that with such an approach, many women can deal with the feelings of regret and loss that accompanies an early hysterectomy.

Complex uterovaginal anomalies require an individualized approach. Treatment programs in general are more successful when they allow for adult decision-making for reproductively limiting surgical procedures.

Dena S. Davis, JD, PhD, Comments

Concerns about sterilization of a minor do not make it ethically unacceptable to perform a hysterectomy on this young woman, if that is her decision.

Faced with a difficult decision, the patient and her parents are making a reasonable choice. Although the urologist has held out some hope for a successful pregnancy in the future, the young woman finds the vaginal dilations painful. Thus, even if her reproductive capabilities were preserved, her sexual health might be compromised. The gynecologist believes that a successful pregnancy is unlikely and that attempting a pregnancy would be dangerous. She additionally believes that the chances of successful reconstruction are slim. Given the young woman’s ongoing problems with pain from retained menses, it appears that a hysterectomy is a good option. The young woman should understand the consequences and should also understand that this is not a decision she needs to make quickly.

Of course, a hysterectomy for a 15-year-old is certainly the sterilization of a minor, and there are good reasons why law and ethics have built strong safeguards around such actions. Sterilization of incompetent persons has a long and sad history, and even today, parents or institutional caregivers may be thinking of their own convenience rather than of the minor’s best interests. Decision-makers may underestimate the capacity of developmentally disabled persons to make their own decisions. If the primary reason for sterilizing females is to prevent pregnancy, other reversible modalities are available instead.

However, these historical objections are not relevant in this case. No one is trying to impede this young woman’s opportunity to reproduce, for eugenic or other reasons; nor is

anyone attempting to control her sexuality. Sterility is an unfortunate byproduct (the double effect, if you will) of a medical procedure aimed at enhancing this young woman’s health. Most importantly, although the patient is “incompetent” because she is a minor, and thus appropriately in need of extra protection, she is not incompetent to understand and to make decisions.

Legally, depending on the jurisdiction, it might be necessary to get court approval for this procedure, but there are no ethical barriers.

John D. Lantos, MD, Comments

In his essay, “Self-Reliance,” Emerson famously wrote, “a foolish consistency is the hobgoblin of little minds.”¹³ The essay advocates attention to the details of each moment and each situation, rather than the mindless application of rules. The issues raised by this case illustrate the dangers that led to Emerson’s diatribe. Surgical sterilization without the consent of the patient is a terrible thing. It was widely practiced and even more widely advocated by many people in the United States and throughout the world.¹⁴ This is a shameful history and one that we should be vigilant and diligent to not repeat. But that is not what this case is about.

There are cases in which the goal of treatment is not eugenic sterilization, but in which sterilization might be an unfortunate side effect.¹⁵ Technology now allows the preservation of fertility in such cases through the preservation of gametes in sperm and egg banks.¹⁶ The discussion of these cases needs to change from one of reactive abhorrence to the horror of involuntary eugenics toward an approach that emphasizes the medical indications of treatment, the patient’s preferences, and a process of shared decision-making.

ABBREVIATION

GnRh: gonadotropin-releasing hormone

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