Sterilization as last resort in women with intellectual disabilities: protection or disservice?

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Women with intellectual disabilities have been defined by the American Congress of Obstetricians and Gynecologists (ACOG) as women "whose ability to participate in the informed consent process is, or might be, limited, and whose autonomy is, or might be, thereby impaired."[1] The intellectual disabilities category covers a wide range of conditions and abilities, including patients with mild to severe mental retardation, Down syndrome, autism spectrum disorders, and congenital abnormalities. It is well known that the gynecologic management of patients with intellectual disabilities presents many challenges. Many women with intellectual disabilities do not receive any care or receive treatment that is below the standard of care, particularly regarding sexuality, sexual abuse, and contraception counseling.[2,3] One complex issue that has not been addressed within the literature is the question of sterilization as a form of contraception. This commentary revisits the issue of sterilization in women with intellectual disabilities, asking whether the field's stance of sterilization as a last resort is best viewed as a protection of this vulnerable population or one that actually does significant harm. After reviewing the arguments against sterilization as a first-line treatment, we defend the controversial position that, in some cases, sterilization should be presented as an equally viable choice to reversible contraceptives.

Sterilization as a last resort

Consider the following case, which highlights the needs and complexities of contraception options for women with intellectual disabilities: Emily is a 24-year-old woman with cerebral palsy and epilepsy, who is severely physically and intellectually disabled, nonverbal, and wheelchair bound. Her mother, Emily's caregiver, brings her to her primary care physician with nausea and vomiting. Her vital signs are within normal limits, physical examination is unremarkable with the exception of chronic spasticity at baseline, and the physician diagnoses her with a gastrointestinal virus. Two weeks later, the patient continues to have persistent nausea and vomiting. Her mother brings Emily to the emergency department, where she is found to have tenderness to palpation in her right lower quadrant on examination, and an elevated white blood cell count. An abdominal computed tomography scan is performed to rule out appendicitis, but instead reveals an early intrauterine pregnancy. Despite her age, Emily has never had routine gynecologic care nor has she had contraception counseling because her mother and physicians presume she is not sexually active. In fact, Emily had been repeatedly sexually assaulted by an attendant at her daycare, where she spends 5-6 hours a day during the week. As she is nonverbal and severely intellectually impaired, she has been unable to express what has been happening to her.

With regard to a case like this, the current professional view is that sterilization, particularly via surgical intervention, should only be considered under extraordinary circumstances in patients with intellectual disabilities. One example of the prevalent view in the United States is that although sterilization may be the appropriate option for some people with intellectual disabilities in treating medical conditions, it should be considered a last resort, used only if less invasive options have been exhausted.[4] This view of sterilization as a last resort is shared on an international level as well, with the United Nations Human Rights Commission "[recommending] against sterilization of girls with disabilities, and [recommending] that nations develop systems of protection."[5] Surgical sterilization by any means is regarded as potentially harmful and abusive, but hysterectomy is considered especially drastic. ACOG acknowledges that "disabled women with limited functional capacity may sometimes be physically unable to care for their menstrual hygiene and are profoundly disturbed by their menses" but maintains that "hysterectomy for the purpose of cessation of normal menses may be considered only after other reasonable alternatives have been attempted."[1] Even Paransky and Zurawin,[6] some of the only openly supportive proponents of the option of sterilization, agree that "surgical intervention should be considered when [alternative medical contraceptives] are contraindicated or are unsuccessful." Diekema[7] lays out specific circumstances under which sterilization of a patient who permanently lacks capacity is justified. He argues that sterilization should be performed only if it is urgently necessary, it serves the best interest of the patient, other less invasive/less permanent methods cannot serve the patient's best interest, and a fair and good decision has been made on behalf of the patient.[7] According to Diekema,[7] sterilization of a patient who lacks capacity ought never be performed for the sole purpose of contraception. In summary, even among authors who consider the possible benefit of sterilization in women with intellectual disabilities, the general consensus in the field of obstetrics and gynecology is that sterilization should be reserved as a last resort, when all else has failed.

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Received Aug. 23, 2014; revised Oct. 4, 2014; accepted Oct. 9, 2014.

The authors report no conflict of interest.

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0002-9378/$36.00 • © 2015 Elsevier Inc. All rights reserved.
http://dx.doi.org/10.1016/j.ajog.2014.10.016

Given the long and sordid history in this country of involuntarily sterilizing women with intellectual disabilities, our subsequent extremely protective attitude towards this population is understandable and necessary. During the eugenics movement of the early 20th century, 17 states allowed, and in some cases mandated, involuntary sterilization of men and women with disabilities.[7] The infamous 1927 Supreme Court case of Carrie Buck v Bell[8] ruled in favor of sterilizing a 17-year-old institutionalized "feeble-minded" woman, the daughter of a "feeble-minded" woman. The Supreme Court argued that Carrie Buck was the "probable potential parent of a socially inadequate offspring" and that her involuntary sterilization would be "better for all the world." Justice Holmes famously wrote: "Three generations of imbeciles are enough."[7,8] But the current situation is summarized nicely by Paransky and Zurawin[6] when they write that "there is a backlash against the atrocities of the past to the extent that some patients are prohibited from accessing a medically beneficial service." By limiting access to sterilization, one of the most effective means of pregnancy prevention, we may be violating the reproductive rights of some women, rather than protecting them.

The antisterilization stance as disservice

In contrast to the prevailing view, we argue that the antisterilization stance is, in some contexts, a disservice to intellectually disabled women. To see how sterilization could be understood as an important benefit to women with intellectual disabilities that they are currently being denied, we return to our case. Emily is nonverbal, incompetent to make her own medical decisions, incapable of sexual consent, and the victim of repeated sexual abuse. Clearly, the most pressing clinical concern in this case is Emily's susceptibility to sexual abuse. Women with cognitive impairments are up to 4 times more likely to be sexually abused than women without intellectual disabilities, making vulnerability to abuse tragically common in this population.[9] But although the highest priority in this case is to implement safeguards to protect such vulnerable patients from abuse, clinical providers cannot ensure the absolute safety of anyone in Emily's situation, even with protective interventions. A secondary responsibility to Emily, then, is to protect her health. Sexual abuse poses 2 threats to Emily's health: sexually transmitted infections and unwanted pregnancy. While only the cessation of abuse can prevent the sexually transmitted infections, pregnancy can and must be prevented even as other protections are attempted to be put in place. Any pregnancy would cause Emily further emotional and physical trauma, and it can be permanently prevented through sterilization.

The first objection to the argument for sterilization in Emily's case is that it robs her of the right to reproduce, a right we sometimes view as universal and inviolable. But as Paransky and Zurawin[6] point out, "[T]he assumption often made for all people is that they have an interest in procreating…Women who cannot consent to sex do not have an interest in procreating because they cannot even willingly participate in the act that will fulfill the reproductive interest." We agree with this argument. While the Paransky and Zurawin[6] approach to sterilization in women with intellectual disabilities requires "that appropriate reversible alternatives have proven unworkable or inapplicable," we argue that this is an unnecessary step that is inconsistent with their rationale for permitting sterilization at all. For Emily, the fact that she can never participate in consensual sexual activity is the only criteria needed to justify permanent protection from pregnancy. That said, we urge caution in deeming an individual with intellectual disabilities incompetent to consent to sexual activity: many women with intellectual disabilities are not incompetent and can consent.

A second justification for stipulating that reversible alternatives always be tried first in a case like Emily's is that sterilization compromises a woman's bodily integrity and dignity, given that this involves an invasive procedure to which the patient cannot consent. But this argument only makes sense if a woman's dignity and bodily integrity is violated by sterilization procedures and not by other methods of contraception that would be offered in this kind of case. It is hard to see why an intrauterine device (IUD), for example, would be less of a violation than tubal ligation. A woman in Emily's situation cannot consent to either the procedure of IUD placement or to contraceptive injections. Sterilization is only a violation of bodily integrity if fertility is a desired possibility. There are also additional concerns about confining sterilization to an option of last resort, namely, that they expose Emily to the risks of multiple invasive, potentially traumatizing trials of other contraceptive methods. Consider an IUD: to safely insert an IUD, Emily will need sedation for the procedure, either conscious sedation in an office setting or general anesthesia in an operating room. Since hormonal IUDs are only effective for 5 years and the copper IUD for approximately 10 years, Emily will require multiple replacement IUDs over the course of her reproductive lifetime. Repeated insertion means repeated exposure to conscious sedation or general anesthesia. There is also a risk of uterine perforation with each insertion, failed insertion, expulsion, and displacement.[10] Expulsion or displacement may even go unrecognized for a significant period of time, as Emily may be unable to express her discomfort or pain, further exacerbating her risks.

Additionally, with every invasive procedure, there is the real, yet unquantifiable, risk of what we call "treatment trauma." Women with intellectual disabilities who undergo procedures like IUD placement will very likely experience them as uncomfortable, awkward, and possibly even humiliating or assaultive. When we calculate the risk/benefit ratio for any procedure, we almost invariably fail to consider the perspective of the patient who experiences it. While for providers, the lithotomy positioning, speculum examinations, and IUD placements are routine and not seen as invasive or painful, for even the average woman the clinical experience of gynecological care is unpleasant at best. For a woman with intellectual disabilities, these potentially painful and