

Surgical Challenges

Management of Menstrual Problems and Contraception in Adolescents with Mental Retardation: A Medical, Legal, and Ethical Review with New Suggested Guidelines

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Abstract. The controversial history of the reproductive rights of the mentally retarded has led to the formulation of laws in the past century designed to protect women from forced sterilization. Significantly, however, in their official ethical guidelines, The American College of Obstetricians and Gynecologists states that “sterilization should not be denied to individuals simply because they also may be vulnerable to coercion” (Int J Gynaecol Obstet 1999; 65:317). Recent advances in medical and surgical methods of contraception and control of menstrual abnormalities have led to a re-evaluation of the management of adolescents with special needs. Physicians, the courts, parents, and caretakers need to be aware of the latest medical and surgical options available, the current applicable laws in each state if such exist, and the ethical guidelines to determine what treatment option is in the best interests of the patient. This review examines the history of the sterilization of the mentally retarded, the latest surgical and pharmacologic treatments available, and the current legal environment and proposes an algorithm to facilitate the management of menstrual hygiene and contraception.

Key Words. Contraception—Sterilization—Adolescents—Medical ethics

Definitions

As defined by the DSM-IV,¹ mental retardation is characterized by significantly subaverage intellectual functioning (an IQ of approximately 70 or below) with onset before age 18 years and concurrent deficits or impairments in adaptive functioning in at least two of the following skill areas: communication, self-care,

home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety. This definition is helpful in that it emphasizes the need for the physician to examine both IQ and adaptive functioning. Those who may be considered mildly or educably retarded, with an IQ of 50–55 to 70, may be capable of a grade school reading level and are capable of performing semiskilled labor. They may be interested in sexual activity and need careful contraceptive planning.² Those with an IQ range of 35–40 to 50–55 are considered trainable or moderately retarded. In the past, these women lived in sheltered situations, but now with increasing efforts at “normalization,” the possibility for their becoming pregnant has increased.² The severely retarded, with an IQ of 20–25 to 35–40, or profoundly retarded, with IQ below 20 or 25, are frequently unable to cope with personal hygiene² and often are not even interested in sexual activity.³ Approximately 1% of the general population is mentally retarded.¹ As young women with mental retardation have varying levels of understanding of reproduction, contraception, and sexuality, and varying levels of ability to care for themselves and to make informed decisions, this paper will focus on developing an approach for women who are not able to make decisions for themselves, because they are more frequently severely and profoundly retarded and have been determined by medical specialists to be incompetent or by a court to be incapacitated.

Reproductive Physiology of the Mentally Retarded

There are few series in the literature that report data concerning the physiologic difference in menstruation in females with mental retardation as compared with women with normal intellectual functioning, with regard to time of menarche and flow. Goldstein et al⁴,

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in a survey of 15 adolescents with Down syndrome and 33 female controls, reported no statistically significant differences in menarche, duration of bleeding, and cycle length between the groups. However, Salerno et al⁵ in a study comparing 97 females with mental retardation caused by multiple etiologies with the normal curve plotted by Kinsey based on data from 8,000 women, showed that menarche presented with a delay of two or three years in brain damaged and undifferentiated retardation groups and a delay of three to four years in patients with Down Syndrome. Of the women who were menstruating, 65% had irregular periods and none had menometrorrhagia. Sixty-two percent of the women ovulated, indicating potential fertility. Thus, the few studies found in the literature present conflicting observational data concerning any physiologic differences in women with mental retardation that might relate to fecundity. These women, like others, also suffer from other processes that affect menstruation, such as thyroid dysfunction and obesity.

Specific Menstrual Concerns of Adolescents with Mental Retardation

The initial task in helping a young woman with mental retardation with her menstrual problems is to categorize the nature of her and her family's concerns. Three major concerns have been reported in the literature: menstrual hygiene, premenstrual disorders ranging from premenstrual syndrome to premenstrual dysphoric disorder, and concern for contraception in cases where there is risk of sexual abuse.

Elkins et al⁶ described that the two most common gynecologic concerns for women with profound or severe retardation are menstrual hygiene and premenstrual-syndrome-like symptoms, such as behavioral changes and cramping. The management of menstrual hygiene in this population is challenging because it balances the patient's ability to take care of her bleeding with the demands on her caretaker. One of the concerns particular to this group is that excessive self-stimulation is seen in the severely and profoundly retarded and they can masturbate during menses and smear blood on nursing staff. In the profoundly retarded, menstrual hygiene problems often coexist with other physical handicaps and incontinence.⁷ As mentioned earlier, many women with mental retardation suffer from obesity and thyroid disease which can affect the amount and frequency of bleeding, frequently causing menorrhagia and metrorrhagia. Women with less severe retardation can be trained to use sanitary napkins. Behavior modification programs have been successful in women with mild, moderate, and even severe retardation, but they are rarely successful in the profoundly retarded.⁸ This is supported by Chamberlain et al's study of 87 patients of varying degrees of mental retardation, which showed that 15/17 mothers

of severely retarded women had difficulty training daughters to handle periods, while these problems in higher functioning patients were mostly temporary.⁹ Thus menstrual hygiene is a real concern for mothers and caretakers of women with severe and profound retardation. A striking finding is that many parents sought sterilization in the form of hysterectomy for elimination of menses in the severely retarded.¹⁰ For this reason, parents and physicians alike must work together to determine an appropriate management strategy while protecting the integrity of the patient. Many clinics have shown that an effective algorithmic approach to helping with problems of menstrual hygiene includes first and foremost behavioral education and secondarily hormonal control and finally consideration of endometrial ablation or hysterectomy for those women who continue to suffer from severe menstrual problems.

Premenstrual syndrome is another primary concern of parents, as seen by 32% of patients referred to Elkins. Symptoms in this population include an increase in behavior problems, seizures, aggression, tantrums, crying spells, and self-abusive behavior in the week before and first few days of menses.⁶ Patients with severe and profound retardation are often unable to express their discomfort verbally. As the physician realizes that the problem is one of behavioral changes associated with cycling, the algorithmic approach may then include reducing cycling with hormonal agents. Selective serotonin reuptake inhibitors have been shown to be highly effective in this disorder, especially in combination with hormonal regulation, and should be considered if they do not conflict with any other psychotropic medication the patient is taking.

Parents of the severely and profoundly retarded are also concerned about preventing pregnancy in their daughters. While mildly retarded people show as much interest in marriage and sexual interaction as most other people, most severely retarded people show little sexual interest in the opposite sex.³ Thus, it is fortunate that those women who are so disabled that they cannot participate in meaningful decision-making are also those with low interest in sex. Their parents, however, are legitimately concerned about sexual abuse taking place in an institutional environment where supervision is not always consistent. Forty percent of the first 104 patients in Elkin's clinic were victims or thought to be victims of sexual abuse.¹¹ In another model clinic, ten of 37 patients had been abused and eight had unwanted pregnancies.⁶ In Chamberlain's population, 25% of the patients had been sexually assaulted. Ten percent of the total sample had been victims of incest.⁹ Contraception was first begun in severely retarded females for menstrual suppression, but parents were also concerned about vulnerability to pregnancy.

Non-surgical Treatment Options

Table 1 reviews the benefits and risks of medical and surgical treatment options with additional specific information about reports of their effectiveness in this population. Each treatment option must address the concerns of the parents with regard to compliance and side effect profile. One study reported that 43% of sexually active mentally retarded youth became pregnant, which suggests that their methods of birth control were not appropriate.¹⁶

Counseling

The most important task in the initial visit with a patient and her family is to delineate their concern. This may include speaking with caretakers, school teachers, and other family members. For each concern, management should involve behavioral techniques such as socialization training, menstrual hygiene training, sexual abuse avoidance training, family counseling, and sexual education. In the management of menstrual hygiene problems, most mild to moderately retarded adolescents can master use of sanitary napkins and cope with periods, especially with educational aids and repetitive materials.¹⁶ Several studies have shown that even severely retarded women can be taught to deal with their periods with intensive training if they have been successfully trained to use the toilet.⁶

Oral Contraceptives

Oral contraceptives can be given cyclically to regulate dysfunctional menstrual bleeding or continuously to reduce menstrual flow on a chronic basis. Oral contraceptives received low satisfaction ratings from parents because of problems with daily administration.¹⁶ This would remain a problem even with the recent release of Seasonale® (Barr Laboratories, Pomona, NY) which administers continuous combined oral contraceptives for three months at a time resulting in only four menstrual periods per year. While long-term oral contraceptives have been proven safe in the general population, one must consider the unknown consequences of life-long hormonal therapy from menarche to menopause on the development of breast cancer and cardiovascular disease.^{17,18}

Contraceptive Patch/Injectable

Ortho Evra (Norelgestromin/ethinyl estradiol transdermal system, Ortho-McNeil, Raritan, NJ), the transdermal contraceptive patch, might solve problems in administration with its once-weekly application. The transdermal route encourages better compliance and, by minimizing fluctuations in hormone levels, has the potential to minimize the behavioral problems associated with estrogen withdrawal, although this remains

to be proven in clinical trials. A monthly contraceptive injection is also available (Lunelle—medroxyprogesterone acetate and estradiol cypionate injectable suspension—Pharmacia and Upjohn, Kalamazoo, MI), but the injection may not be well accepted.

Depot-medroxyprogesterone Acetate

A survey in 1992 showed that the highest use of Depot-Medroxyprogesterone acetate (DMPA) was in females with mental retardation.¹⁹ Parents averaged a rating of 4/5 for satisfaction of DMPA injections.²⁰ This form of contraception has been favored because it creates amenorrhea and reduces cycling in many patients while simultaneously serving as highly effective contraception. While some have thought that DMPA causes depression in patients, one study reports no significant difference.²¹ The hormone does cause significant weight gain.²¹ Unlike oral contraceptives, which have been studied for over 40 years and have been proven to be relatively safe, no large randomized controlled studies have shown the effects of DMPA when taken over the entire reproductive lifetime as would be the case in the mentally retarded patient. Berenson et al¹⁴ showed that users of DMPA experienced a mean bone marrow density loss of 2.74% over 12 months compared with controls and women taking birth control pills, who gained bone marrow density. These findings have been challenged in subsequent studies^{22,23} but supported in others. That DMPA specifically is the culprit of bone loss and whether or not this effect is reversible is beyond the scope of this paper, but it is postulated that the bone loss is due to the potent action of DMPA on estrogen receptor downregulation, an effect not seen with other progestins such as norethindrone acetate which tend to have an opposite, bone-forming effect.²⁴ One must also question the effects of long term hormonal therapy with or without DMPA in light of the findings of the Women's Health Initiative²⁵ study which challenged long-held beliefs in the safety of all hormone replacement therapy in the menopause. Once again, the safety of DMPA has been challenged by the unfavorable cardiovascular and breast cancer effects of hormone replacement therapy containing both conjugated equine estrogen and medroxyprogesterone acetate. As a result of all of the above concerns a lower dose of DMPA for contraceptive purposes is now being tested. The essential point to consider is whether the risks of DMPA outweigh the significant contraceptive benefits of an injectable and highly effective contraceptive that needs to be administered only four times a year.

Table 1. Comparison of Treatment Options for Women with Mental Retardation

Type of contraception	Indications	Menstrual hygiene benefits	Other benefits	Difficulties	Risks	Sterilization
Oral contraceptives (OC)	Menstrual hygiene, premenstrual syndrome, contraception	Decrease in dysmenorrhea and mittelschmerz, decrease menstrual flow by 60% or more, reduced cycle length, can schedule fewer periods per year if taken three months continuously without inactive pills	Reduce risk of ovarian, endometrial and colorectal cancers, ameliorate acne, improve bone mineral density	parents have to administer daily, cannot verbalize common side effects on nausea, mood swings, breast tenderness, and headache	venous thromboembolism, increased risk of breast cancer with women on OCs but no increased life risk, ¹² (and among healthy nonsmoking women who use OCs with less than 50 meg estrogen, no increased risk of MI or stroke). Gall bladder disease Same as OCs. May have reduced efficacy in women with body weight > 198 lb. Studies suggest reduce bone mineral density ¹⁴ Adverse lipid changes Risk of infection with sexual activity	No
Contraceptive patch	Menstrual hygiene, premenstrual syndrome, contraception	Like birth control pills, trials yet to be done in this population	Weekly dermal administration	Cutaneous reactions, patients with problems picking might not be able to use patch		No
Depot Medroxyprogesterone acetate (DMPA)	Menstrual hygiene, premenstrual syndrome, contraception	Amenorrhea in 50% of women within first year of use ¹³	Highly effective, ease of administration, induce amenorrhea	Heavy breakthrough bleeding in first 6 months, fluid retention, weight gain average 4 lbs per year		No
IUD-nonhormonal	Contraception	Most increase menstrual bleeding ³	Passive contraception, no hormonal side-effects	Might need to use general anesthesia to insert, difficult to check string regularly, more difficult insertion in nulliparous women		No
Levonorgestrel intrauterine system	Menstrual hygiene, contraception	Progressive reduction of menstrual duration and menstrual blood loss, relief of menstrual pain ¹⁵	Effective for 5 years	Might need to use general anesthesia to insert, difficult to check string regularly, more difficult insertion in nulliparous women	Risk of infection with sexual activity	No
Endometrial ablation	Menstrual hygiene	Amenorrhea, hypomenorrhea, improvement in dysmenorrhea	Outpatient procedure	Dilatation of the nulliparous cervix, which can be overcome with insertion of prostaglandin analogue such as gemeprost ²⁷	Pregnancy complications if contraception not used, surgical risks of perforation	Suggested
Tubal ligation	Contraception	No change	Relatively low surgical risk outpatient procedure, no incision required	Requires general anesthesia	Surgical and anesthetic risks	Yes
Hysteroscopic tubal occlusion	Contraception	None		General anesthesia may be needed, but may be performed under conscious sedation	At present, FDA requirement for three month postoperative hysterosalpingogram	Yes
Hysterectomy	Menstrual hygiene, contraception	Absolute amenorrhea	Cessation of bleeding and sterilization	May not affect premenstrual symptoms	Invasive surgery, operative and anesthetic risks	Yes

Progestin Intrauterine Device

While the traditional intrauterine device (IUD) has met with disfavor because it can create heavy bleeding or facilitate ascending infection, the levonorgestrel intrauterine system has been shown to reduce in blood loss compared to controls. The number of days of bleeding was found to decrease and some women also reported relief of menstrual pain.¹⁵ A significant compliance-related advantage for mentally retarded patients is that the IUD needs to be changed only once every 5 years. By the same token, the nature of these patients' disability requires that they frequently need sedation for the IUD to be inserted. The favorable impact of passive contraception and improved bleeding profile makes the progestin IUD worthy of further study in this population.

Surgical Treatment Options

Surgical intervention should be considered when the above approaches are contraindicated or are unsuccessful. Grover²⁶ reports that in her clinic only 2/109 patients required surgical intervention; both of these patients tried and failed medical approaches.

Endometrial Ablation

Endometrial ablation has not been particularly popular until recently because the traditional method, using a hysteroscopic roller-ball technique, required technical facility and was associated with complications such as hyponatremia and hemorrhage. The development of a number of non-hysteroscopic global endometrial ablation devices has revitalized this surgical treatment of menorrhagia and makes it a very attractive alternative. This surgical technique has gained popularity as an elective procedure in women with dysfunctional uterine bleeding, as it has been shown to successfully induce results ranging from eumenorrhea to amenorrhea. Few case reports have described its successful use in younger women with mental retardation. Wingfield et al²⁷ reported a series of seven patients with mental retardation who underwent endometrial ablation. All were satisfied with the results, as one woman was amenorrheic at 38 months, two at 27 months and one at 16 months. Endometrial ablation offers markedly reduced morbidity and operative risk when compared to hysterectomy and can usually be performed as an outpatient procedure. Studies in older women have shown that the procedure must sometimes be repeated to achieve ideal results and that it must be repeated more often in younger women. In extrapolating the findings of endometrial ablation to young women with mental retardation, it is essential to remember that in older women endometrial ablation is performed to correct an underlying disorder that

causes menorrhagia. Its use in young women with normal menses has not been studied though it has been used successfully to treat abnormal bleeding in young women with chronic diseases causing life-threatening blood loss.²⁸ Fertility is impaired, and in fact any pregnancy subsequent to ablation is considered high risk such that a concomitant tubal occlusion procedure should be performed.

Special attention must be given to the fact that in the young, mentally retarded population the cervix is usually nulliparous. All endometrial ablation requires some degree of cervical dilatation. A traditional resectoscope has a 9 mm sheath although some are 7 mm. A number of the new global ablation devices require at least 7 mm dilatation, which presents a challenge in the young nulliparous patient.²⁹ In our experience the ThermaChoice (Gynecare, Somerville, New Jersey) balloon system requires the least cervical dilatation and has not met with insertion failure, as has been the case with other devices. Several pharmacologic agents, vasopressin and prostaglandins, are useful aids to preoperative dilation, as are laminaria.

Finally, the family must be counseled that endometrial ablation does not guarantee amenorrhea and that until data for nulliparous adolescents is gathered, the adult experience that amenorrhea is achievable somewhat less than 50% of the time should be used as a guideline. Nevertheless, endometrial ablation unquestionably offers a valuable adjunct in the management of menorrhagia and can reduce normal flow to a few days of spotting. For optimal results, pre-treatment with a gonadotropin-releasing hormone agonist is preferred.

Sterilization

190 million couples worldwide have chosen sterilization as their contraceptive method. It is the most prevalent contraceptive method in the United States, used by 39% of reproductive-aged couples who practice contraception.³⁰

Tubal Ligation

Female tubal sterilization represents 72% of all sterilization, male and female in the United States.²⁵ Most studies report the incidence of major operative complications of 0.5%.²⁵ Complications are mainly secondary to general anesthesia and laparoscopic injuries and include respiratory compromise, hemorrhage, injury to uterus, cervix, bowel or bladder, subfascial and subcutaneous emphysema, and death. Rare complications in the weeks after surgery include hematoma, infection, delayed active bleeding, unrecognized intraoperative bowel, bladder, ureteral, injury to the peroneal nerve from the use of stirrups, or uterine injury.²⁵ A new, less invasive method of blocking the fallopian tubes

has been approved in the United States. Essure (Conceptus, San Carlos, CA) are micro-inserts consisting of a stainless steel inner core, a nitinol outer coil and polyethylene fibers placed hysteroscopically that cause the tubes to become fibrotic and block passage of ova and sperm. The procedure requires no incisions and can be performed under local anesthesia and conscious sedation as an outpatient, effectively eliminating the complications listed above. The avoidance of abdominal incision and general anesthesia makes this procedure particularly attractive especially when mental retardation is accompanied by multiple other medical problems. At the present time the FDA requires a hysterosalpingogram to be performed three months after the procedure to confirm tubal occlusion, but as more data is collected, this requirement will most likely be waived. Finally, the hysteroscopic approach to sterilization allows simultaneous endometrial ablation, thus addressing both sterilization and menstrual hygiene. The safety of endometrial ablation using electrosurgery in conjunction with the hysteroscopic implants has not been determined, so at the present time only the thermal balloon and free saline methods are recommended.

Tubal ligation/blockage can be considered for two different groups of young women. The first group is those women who concomitantly need endometrial ablation for intractable bleeding. Secondly, as sterilization procedures are used around the world for women who do not want to have any more children, parents may consider this option for sterilization, especially because it is far less invasive than hysterectomy.

Hysterectomy

The American College of Obstetrics and Gynecology opinion on sterilization of women in 1999 states, "Hysterectomy solely for the purpose of sterilization is inappropriate. The risks and cost of the procedure are disproportionate to the benefit, given the available alternatives."³¹ In the past century, hysterectomy has been used in the mentally retarded population both to control menstruation and serve as contraception. Small trials have reviewed the success of different types of hysterectomies in this population. In a 1975 report of 152 hysterectomies in mentally retarded women, Wheelless³² reported that a majority of parents and guardians were pleased with the results. Kaunitz et al³³ report a series of five hysterectomies, four of which were vaginal, done in women with severe and profound mental retardation. None of the patients was felt to have the intellectual function consistent with responsibility for sexual consent or menstrual hygiene. They, too, suggest hysterectomy should be done for women with problems with menstrual hygiene, not only for contraception. Sheth et al³⁴ reported the success and advantages of doing vaginal hysterectomy in a group

of 60 mentally retarded women. It offers a shorter hospital stay with easier postoperative recovery, no abdominal wound and dressings, fluids for 6–8 h, and fewer complications. However, since the vast majority of these patients are nulliparous and may even be virginal, vaginal hysterectomy is more technically challenging. Physicians may consider doing supracervical laparoscopic hysterectomies in this population when needed. This approach may be performed in an outpatient setting, it offers preservation of endopelvic fascial support by not disrupting the uterosacral-cardinal ligament complex, and it may reduce the incidence of future pelvic organ prolapse.

A Cochrane review demonstrated that women preferred hysterectomy in the improvement of heavy menstrual bleeding as compared with endometrial destruction techniques. Thirteen percent of patients undergoing endometrial ablation did not have reduced bleeding at one year follow-up. Rates narrowed after longer follow-up and after re-treatment of the ablation group.³⁵ Boujida et al³⁶ found that younger women were more likely to require second ablation. The decision for or against hysterectomy is in large part related to the invasiveness of the procedure in a population that cannot consent.

Parental Attitudes towards Sterilization

In Passer's study of parents in Cincinnati, 10 65% of parents of severely retarded women had thought of sterilization as had 63% of parents of moderately retarded women. Two thirds of these parents had difficulty dealing with menstrual hygiene. Parents of mildly retarded women were three times more likely to consider tubal ligation than hysterectomy. Parents of severely retarded were three times more likely to choose hysterectomy. The most common primary reason given by sterilization seekers was protection from pregnancy, but 60% of parents seeking hysterectomy gave "elimination of menses and related problems" as the primary reason. In another clinic at the University Of Tennessee College Of Medicine, 43% of patients presented seeking hysterectomies. Fifty percent of those were for menstrual hygiene.⁶ This data shows that parents have historically sought hysterectomy more readily in patients with more severe retardation and perhaps wrongly overlooked other medical treatment options.

Legal History

The history of sterilization of the mentally retarded has gone through three major legal phases in the past century. Current laws represent the attempt to

correct the injustices of the past.³⁷ At the turn of the century, American eugenicists, inspired by social Darwinism, argued that forced sterilization was in society's best interest because social ills could result from characteristics passed down genetically. Society actively discouraged retarded people from procreating because of the belief that the children would usually end up as wards of the state, or as criminals. In 1907, reflecting this mentality, states began enacting laws allowing involuntary sterilization of the developmentally disabled.³¹ In 1927, the Supreme Court upheld this rationale in *Buck v. Bell* which argued that forced sterilization was constitutional under certain circumstances. Justice Holmes's opinion stated that "[t]hree generations of imbeciles is enough."³⁸ Between 1907 and 1963, more than 60,000 Americans, mostly women, were sterilized without their consent.³⁹

The second legal phase occurred as sterilization based on eugenic rationale lost support and women gained personal control over reproductive decisions. In 1942, *Skinner v. Oklahoma* held that procreation is "one of the basic civil rights of man." *Griswold v. Connecticut* made contraceptive choices private, and *Roe v. Wade* gave women the right not to procreate. In the 1960s, some states repealed sterilization laws. Finally a scandal involving sterilization of a developmentally disabled girl without her consent in a federally funded clinic resulted in 1978 guidelines from the Department of Health, Education, and Welfare forbidding use of federal funds for sterilizing anyone younger than 21, incompetent, or institutionalized.³¹

We are in the third phase, where some would argue 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.³¹

Current Sterilization Laws

The laws in the 50 states vary considerably on the topic of sterilization in many respects: the form of the law, the content of what criteria should be used to determine eligibility, who carries the burden of proof, all of which ultimately give patients in the different states different access to the same medical procedure.

Some state legislatures have passed clear clauses into statutes: some granting a court permission to allow for a sterilization procedure and some delineating criteria in regards to the petition, representation, and criteria needed to be proven by the petitioner. Other states use case law as judges rule based on previously decided cases; no specific guidelines exist in the statutes. And finally, some states have never heard a case on the topic, and a judge would base the decision on other laws that could apply. A review of state laws (Table 2) is helpful to the physician who can then know to search for a specific statute or look up the recent case that is considered the standard in their state.

Table 2. State Laws Regarding Sterilization^{40,41}

States with Statutes about Sterilization of Persons with Mental Disabilities	States with Only Case Law	No Statutes or Case Law	Per Statute, Surrogate May Not Authorize Sterilization
Arkansas	Alabama	Arizona	Maryland
Colorado	Alaska	Illinois	
Connecticut	California	Louisiana	
Delaware	Colorado	Montana	
Florida	Indiana	Nebraska	
Georgia	Iowa	Nevada	
Hawaii	Kentucky	New Mexico	
Idaho	Massachusetts	Oklahoma	
Kansas	Michigan	Rhode Island	
Maine	Missouri	Virginia	
Minnesota	New Jersey	Wyoming	
Mississippi	New York		
New Hampshire	Ohio		
North Carolina	Pennsylvania		
North Dakota	Texas		
Ohio	Washington		
Oregon	Wisconsin		
South Carolina			
South Dakota			
Utah			
Vermont			
West Virginia			

The content of the laws, both statutes and case law, varies considerably. Most courts first determine the competency of the patient and might appoint a guardian ad litem to represent the patient. Ultimately, the judge, acting as *parens patriae*, will determine what is best for the patient based on some of the criteria listed in Table 3.

Table 3.

Judicial Criteria for Determining "Best Interest"
The individual is physiologically sexually mature
No evidence of infertility
The individual has the capability and a reasonable opportunity for sexual activity
The individual is unable to understand reproduction or contraception and there exists the likely permanence of that inability
Lack of ability to consent is likely persistent
The person's opinion was solicited and considered
Physical or emotional inability to care for the child
Procreation would endanger the life or severely impair the physical or mental health of the individual
Less drastic alternative contraceptive methods have proved unworkable or inapplicable
Method of sterilization is consistent with standard medical practice
No imminent breakthrough would improve functioning or make sterilization reversible
Proponents of sterilization are seeking sterilization in good faith and primary concern is for best interest of the respondent rather than their own convenience or the convenience of the public. ^{40,42}

Some courts use some of the criteria listed in Table 3, while other courts use others. The parental interest in protecting a child from unwanted pregnancy, avoiding the inconvenience of menstrual hygiene, and promoting family stability by reducing stress associated with care are not considered.³⁵

The criteria that guide the decision maker are organized into four types of legal decisions. When “mandatory criteria” must be shown, the burden is with the petitioner to prove specific criteria in order to establish the desirability of sterilization. This type of rule implies a strong presumption against sterilization and a conflict between the interests of the parents and the patient as the parents are removed from the decision making process and a judge makes the decision for the daughter. The “discretionary best interest” rule is more flexible as it allows the decision maker to weigh the criteria to determine whether sterilization is in the best interest of the incompetent person. Few states use the “substituted judgment” criteria, which weigh the criteria above to determine what the patient would have chosen for herself. This type of decision making has been criticized by the argument that no one can possibly decide what the incompetent person would choose for herself if she has been incompetent her entire life. Finally, some jurisdictions prohibit the sterilization of incompetent patients entirely.³⁵

Texas Law

Whereas a comprehensive analysis of the laws of all fifty states pertaining to sterilization is beyond the scope of this paper, we have chosen to examine the laws in the State of Texas. Unlike other state statutes, which delineate both the guardian’s process for request of permission of the court and the rules governing what the court should weigh in making its decision, Texas statute never addresses this specific issue. A search through the Texas statutes points to three applicable sections of the law.

The current Texas Family Code Chapter 151.001 Rights and Duties of Parents reads

(a) A parent of a child has the following rights and duties:

(6) the right to consent to the child’s marriage, enlistment in the armed forces of the United States, medical and dental care, and psychiatric, psychological, and surgical treatment;⁴³

The current Texas Probate Code 767 Powers and Duties of Guardians of the Person reads

The guardian of the person is entitled to the charge and control of the person of the ward, and the duties of the guardian correspond with the rights of the guardian. As guardian of the person has:

(4) The power to consent to medical, psychiatric, and surgical treatment other than the in-patient psychiatric commitment of the ward.⁴⁴

An interpretation of these codes would suggest that parents and guardians can consent to medical and surgical treatment. However, The Texas Health and Safety Code Chapter 597 Capacity of Clients to Consent to Treatment outlines the process for obtaining consent for medically invasive procedures when the patient is incapacitated. The chapter specifically excludes sterilization from applying to the laws described in the chapter.⁴⁵ This exclusion would suggest another chapter would delineate a different legal process for the excluded procedures, but none exists. The Texas Health and Safety Code Chapter 551.041 states that a state facility may not request a sterilization procedure or frontal lobotomy when they cannot obtain consent from the guardian, whereas other medical procedures would be permitted.⁴⁶ This also implies that the procedure is important enough that normal permission is inadequate.

In addition to using the statutes, one must look to previous court cases to figure out what the common law would be based on decisions of judges in the past. In the 1969 case *Frazier v. Levi*, 440 SW 2d 303, an appellate court ruled that Texas law did not specifically authorize the court to make a decision regarding sterilization of a person who is incapacitated and the decision would be “in excess of the power delegated by the statutes of Texas and would be invalid.”⁴⁷ At the time of the decision, the probate code read differently than above in that it did not specifically delineate that the guardian has power to consent to medical and surgical treatment. Now that the Family and Probate Codes are more specific, do they imply that no court order is necessary, that a parent or guardian can consent for any medical or surgical procedure no matter how invasive or medically necessary? The answer remains unclear because the statute has not specifically addressed the topic of sterilization. In Texas then, how should the physician act? Must the physician request a court order, obtain approval from hospital ethics committees, or perform the procedure interpreting the law as it is written? For this reason, ethical medical guidelines are important to address what the law does not.

Ethics

A review of the current professional guidelines offers an outline to physicians who are approached with a request for sterilization. The ethical issues include determination of the patient’s ability to give consent and who should make decisions for her, alternatives to

sterilization, and how to determine the best interests of the patient.⁴⁸

Decision Maker

A patient's "mental capacity" to determine the medical risks and benefits of a procedure and its alternatives and to express her personal choice is a functional determination made by appropriate medical professionals, while her "mental competency" to give informed consent is a determination made by a court of law.⁴⁴ As women with varying degrees of mental retardation have different capacities, professionals trained in communicating with those who are mentally handicapped, such as special educators, psychologists, physicians, and attorneys familiar with this patient population, should help determine what each patient understands. In some jurisdictions the above group of consultants can determine the capacity of the patient while in others the court must first rule about the patient's competency.⁴⁹ The guidelines of the American College of Obstetricians and Gynecologists recommend that efforts should be made to conform to the patient's expressed values and beliefs regarding reproduction.⁴⁹ This discussion, however, will consider those patients who are determined to be incapacitated by professionals or incompetent by the court, that is, those women who cannot decide for themselves.

In most medical settings, parents, immediate family members, and legal guardians are given legal power to make decisions for persons who are incapacitated or incompetent. Bioethicists generally approve of surrogates making decisions for incompetent patients.³¹ However, due to the injustices of the past, physicians should be aware of undue pressure from family members whose interests are self-directed. Primary or contributing indications for sterilization based on presumed or anticipated hardships to others must be viewed with great reservation.³¹ In fact, current law in many states assigns a guardian ad litem, assuming that the parents' best interests are in conflict with their daughter's. This might be overly protective, as parents usually have their child's interest at heart. The parents may not understand the scope of the problem or nonsurgical alternatives and they may be looking for a quick solution. For this reason, physicians must work closely with parents to help them determine the needs of their daughter. Consultation with experts such as pediatricians, neurologists, psychiatrists, social workers, and clergy and input from institutional ethics committees may be desirable.

Alternatives to Sterilization

Noninvasive modalities such as family counseling, menstrual hygiene training, sexual abuse avoidance training, and sex education should be considered in

place of sterilization and in combination with any procedure done. Recent guidelines read that the physician should advocate the least permanent and intrusive method consistent with the lowest risk for the patient.³¹ While medical treatment is usually preferred to surgery because it is less restrictive as it is impermanent, the risks of long term hormonal treatment must be considered.⁴⁴ Many model clinics across the United States have created programs for evaluation and treatment to ensure that patients are seen by an array of professionals to ensure that all appropriate impermanent alternatives are considered.⁴⁴ When considering the best treatment options, physicians, parents, and decision makers must weigh the interests of the patient when deciding between medical and surgical management.

Best Interest of Patient

Ultimately all decision makers must determine what type of treatment is in the best interest of the patient. As previous professional guidelines outline some of the issues to be weighed and courts use a myriad of considerations, the criteria must be organized into a logical framework to be used by all decision makers.

First, however, and this point is what has been confused by the abuses of the past, the decision maker must determine the interests of the patient before weighing any criteria because all patients do not share the same inherent interests. Most importantly, the assumption often made for all people is that they have an interest in procreating. Some women are so mentally disabled that they do not have this interest. This discussion will propose that some women are so disabled that they simply do not think about reproduction and thus do not have an interest in procreation that needs to be protected.

Many experts in mental retardation will argue that women with all levels of mental retardation have sexual interests. Those with mild and moderate retardation even can participate in consensual intercourse. There are women, however, whose cognitive functioning is so poor that they cannot possibly consent to sexual intercourse. 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. While it seems harsh to say that some women have no interest to procreate, logically one would need to have sex in order to procreate and some of these women will never have consensual sex. Therefore the decision maker should not stress the person's interest in procreation. In these cases, avoiding pregnancy would be more important than the interest in reproduction. Moreover, courts do not challenge the ability of parents to request and consent for continuous life-long medically reversible contraception or abortion, which are both restrictions

in the ability to procreate. It is inconsistent, to say the least, to allow a parent to provide a lifetime of DMPA or consent to an abortion without any court approval, and yet deny the right to an effective surgical equivalent of permanent contraception.

The next logical question involves the procreative interests of women who are so disabled that they cannot care for the child who will be born. The goal of procreation is to raise children. Any woman would be incapable of parenting if she could not understand the nutritional requirements of her child, protect her from physical harm, discern illness and get help, express affection, and supervise the daily routine of her child. If a woman did not have the cognitive ability to do the above, a court would deem her incapable of parenting and remove the child from her care. Therefore, there is a set of women who might be able to consent to intercourse but be sufficiently disabled that their children would be taken from them by any reasonable court. These women do not effectively have an interest in parenting because they will never be able to do so. The difference between these women's interest in parenting as compared to another woman whose child might be taken away, for example a drug addicted mother, is that the assumption is that certain women will have the disability forever and their interest in parenting will not change, unlike a mother who might overcome her drug addiction.

Another subset of women would be those who in the future will be able to care for a child with the help of parents and/or guardians. These women might very well have an interest in parenting and that interest should be weighed when determining the interests of the patient. Parents who favor sterilization said it should only be performed³⁰ if the retarded person could

not understand the results or consequences of intercourse or did not have the capability to care for the child—the same criteria as discussed above.

Human rights activists opposed to sterilization argue that the right to bear a child is inviolable. They argue that because the patient cannot consent, society should err on protecting the right to procreate unless it is medically necessary to sterilize. While protecting from repeating the wrongs of the past, they must not deny procedures that may benefit women who have no interest in procreating. One must remember that the "right to procreate" was created by law. In *Skinner v. Oklahoma* 1942, the Supreme Court denied Oklahoma the ability to punish criminals by sterilization because sterilization was considered cruel and unusual punishment and would not be justly applied to all criminals. Justice Douglas describes that procreation is "one of the basic civil rights of man. The power to sterilize, if exercised, may have subtle, far-reaching and devastating effects. In evil or reckless hands it can cause races or types which are inimical to the dominant group to wither and disappear."⁵⁰ Interestingly, the case cites *Buck v. Bell* multiple times as a case in which sterilization is deemed appropriate because the eugenic rationale of not having further generations of imbeciles was supported.

The other side of the argument suggests that women have the right not to bear children and the right to privacy; laws preventing sterilization deprive the right to equal access. Mentally competent individuals who choose sterilization want to express sexual freedom, avoid the physical and psychological burden of pregnancy, discomfort of childbirth, and the emotional burden of an unwanted child. Women with more severe mental retardation might not be taken care of by family

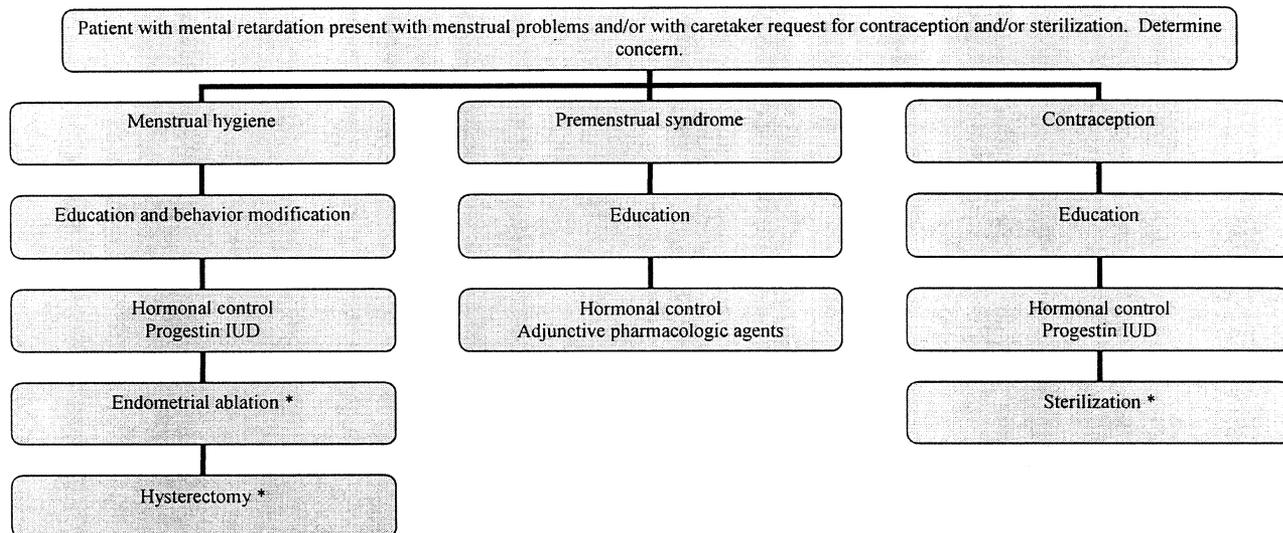


Fig. 1. Management Algorithm

their entire lives and as described above are potential victims for sexual abuse and sometimes physical and mental harm from pregnancy. Whereas they do not possess the same level of intellectual function as mentally competent individuals, they should have access to the same options with regard to contraception. Especially when a surgical procedure such as endometrial ablation is indicated, the concomitant performance of a sterilization procedure should not be categorically denied or made difficult to obtain.

New Algorithmic Approach with Criteria to Determine Best Interest of Patient

Pharmacologic and surgical advances have provided new minimally invasive alternatives for the woman with mental retardation. Thus, doctors, parents, judges, and ethicists should first determine the specific concerns of the patient and her ability to participate in the decision making process. When the following algorithmic approach (Fig. 1) indicates need for a sterilization procedure, the following criteria (Table 4), which are a combination of those currently used by some state courts guided by the ethical guidelines of the medical profession, can guide those making decisions to determine the best interests of the patient.

Endometrial ablation for menstrual hygiene, although not a sterilization procedure, carries potential risks for a subsequent pregnancy. In the general population, patients undergoing ablation are advised to seek permanent birth control, and this caveat holds true for the mentally retarded.

Summary

Most physicians are very rarely exposed to the severely mentally challenged woman who experiences menstrual hygiene problems or who is at risk of pregnancy.

Table 4.

Proposed Guidelines for Sterilization
The individual is unable to participate in consensual intercourse
Intellectual, psychological and physical ability to raise children is irreversibly impaired
The individual is fertile and postmenarchal
Pregnancy or preserving reproductive potential will significantly increase the difficulty or caring for the patient
Pregnancy represents a serious, objective physical and/or psychological risk
Method of medical treatment is consistent with standard medical practice, including the notion that appropriate reversible alternatives have proven unworkable or inapplicable
Proponents of sterilization are seeking sterilization in good faith and primary concern is for best interest of the respondent rather than their own convenience or the convenience of the public

In our institution, however, we see these patients almost every day. We have spent countless hours with families who are truly torn by the thought of sterilization but also concerned about the possibility that their child may become pregnant when not supervised.

When discussing these problems with professionals not directly involved in the care of these individuals, a common reaction is revulsion at the thought that anyone would propose sterilization of a retarded person. Alternatively, recommendations for surgical solutions for these problems are met with charges of sexism, although it should be obvious that mentally retarded males neither menstruate nor face the risk of pregnancy. Finally, critics occasionally cite the Nuremberg Laws and evince the slippery-slope argument that once we start sterilizing the retarded, then we open the floodgates for minorities and political prisoners.

At the beginning of the 20th century, involuntary sterilization of the institutionalized retarded was frequently performed using the rationale that society should not be burdened by future generations of handicapped citizens. Decades later, as a result of widespread abuse of sterilization, the eugenics rationale fell out of favor and access to sterilization procedures was restricted by various laws. While eliminating the ethical problems and surgical risks of forced sterilization, this attitude substituted a series of other risks for both the patient and the caretakers. The therapeutic options for contraception and menstrual hygiene were often suboptimal. In recent years, advances in pharmacologic therapy and minimally invasive surgical procedures for both menstrual hygiene and sterilization have greatly expanded the choices for these individuals.

We propose that all involved must rethink the ethical justification for allowing a sterilization procedure on a patient who cannot consent. Some women, namely those so profoundly disabled that they will never have consensual intercourse and others, who will never be able to parent, do not have an interest in procreation. They should not be denied the right to medical procedures that may benefit them, not only to safeguard them against unwanted pregnancy but also to improve their quality of life during menses.

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