

Sterilisation or hysterectomy for mentally retarded patients

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Mental retardation is characterized by significantly sub-average intellectual functioning (IQ of approximately 70 or below), with onset before age 18 years and concurrent deficits of impairment in adoptive functioning in at least two of the following skills areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety. Young women with mental retardation present a unique set of reproductive health concerns to both the physician and caregiver. They have varying levels of understanding of reproduction, contraception and sexuality and varying levels of ability to care for themselves and to make informed decisions.

Reproductive physiology of the mentally retarded

There are few series in the literature that report data concerning the physiologic differences in menstruation in mentally retarded patients compared with women with normal intellectual functioning, with regard to time of menarche and flow. Goldstein et al⁴ in a survey with Down syndrome and female controls, reported no statistically significant differences in menarche, duration of bleeding and cycle length between the groups. However, Salena et al⁵ in a study comparing females with mental retardation caused by multiple aetiologies with a control group, showed that menarche presented with a delay of two to three years in brain damaged and undifferentiated retardation groups and a delay of three to four years in patient with Down syndrome. Of the menstruating women 65% had irregular periods and 62% of the women ovulated, indicating potential fertility.

Specific menstrual concerns of the mentally retarded patient

Three major concerns exist: 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 or activity.

The management of menstrual hygiene in this population is challenging patients due to reduced ability to take care of her bleeding and extra demands on her caretaker. Associated problems such as relative immobility, existing contractures, or behavioural difficulties could prevent normal participation in personal hygiene. Bladder or bowel incontinence further complicates the self-care required during menses, which could be particularly problematic in girls with severe cognitive impairment. Behaviour modification programs have been successful in women with mild, moderate and even severe retardation, but they are rarely successful in the profoundly retarded.⁸ A striking finding among severely retarded is that many parents seek sterilization in the form of hysterectomy for elimination of menses.¹⁰ For this reason parents and physicians alike must work together to determine an appropriate management strategy while protecting the integrity of the patient. Effective algorithmic approach may help with the problem of mental hygiene, starting with behavioural education, secondly hormonal control and finally consideration of endometrial ablation or hysterectomy for those women who continue to suffer.

Premenstrual syndrome is another primary concern as seen in about 32% of patients. Symptoms include an increase in behaviour problems, seizures, aggression, tantrums, crying spells and self-abusive behaviour 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. Behavioural changes are associated with cycling; the algorithmic approach may include reducing cycling with hormonal agents. Selective serotonin re-uptake inhibitors have been shown to be highly effective in this disorder, especially in combination with hormonal regulation.

Of particular concern for parents is the potential for sexual abuse. A young woman with apparent mild cognitive impairment could still lack the capacity to give informed consent for sexual interaction. Patients with more severe cognitive

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disabilities might not be able to voice concern at all and might not protest or report that inappropriate sexual activity is occurring. Mildly retarded people show as much interest in marriage and sexual interaction as most other people, while severely retarded people show little interest in the opposite sex. Openness to the discussion of these issues by all healthcare providers is critical to ensure prevention of abuse and to provide timely contraception.

Non-surgical treatment options

Table I reviews the benefits and risks of medical and surgical treatment options. It is important that each treatment option must address the concerns of the parents with regards to compliance and side effect profile.

Hysterectomy

Hysterectomy solely for the purpose of sterilisation is inappropriate. The risk and cost of the procedure is disproportionate to the benefits, given the available alternatives.³¹ In the past century, hysterectomy has been used in the mentally retarded patient for control of menstruation and also serves as a contraceptive. Wheelless et al performed a small trial to review the success of different types of hysterectomies and reported that the majority of patients and guardians were pleased with the results.³² None of the patients was evaluated as having intellectual function consistent with the responsibility for sexual consent or menstrual hygiene.

The advantages of vaginal hysterectomy is that it offers a shorter hospital stay easier post-operative recovery, no abdominal wound and dressings, and fewer complications. Physicians may consider doing laparoscopic hysterectomies in this population when needed. A Cochrane review demonstrated that women preferred hysterectomy for improvement of heavy menstrual bleeding when compared with endometrial ablation. Thirteen percent of patients undergoing endometrial ablation did not have reduced bleeding at one year follow-up.³⁵

Tubal ligation

Tubal ligation or occlusion can be considered for two different groups of young women. The first group is those women who concomitantly opt for endometrial ablation for unmanageable bleeding. Secondly, as sterilization procedure for any woman who do not want to have any more children. Parents may consider sterilization, when menstrual hygiene is not a problem, especially because it is far less invasive than hysterectomy.

Parent's attitudes towards sterilization are shown in the following data. In Passer study, 65% of parents of severely retarded in women had thought of sterilization as had 63% of parents of moderately

retarded women.¹⁵ Two thirds of the parents had difficulty dealing with menstrual hygiene.¹⁰ Parents of mildly retarded women were three times more likely to consider tubal ligation rather than hysterectomy. Severely retarded patient parents were three times more likely to choose hysterectomy. The most common primary reason given for sterilization was protection from pregnancy, but 60% of parents seeking hysterectomy gave elimination of menses and related problems as the primary reason.

Ethical issues

The ethical issues include determination of the patient's ability to give consent and deciding who should take decisions on her behalf; alternatives to sterilization and how to determine the best interest of the patient.

A patient's "mental capacity" to understand 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.

This discussion, will consider those patients who are assessed as incapable by medical professionals or incompetent by court that is women who cannot decide for themselves. Parents, immediate family members and legal guardians in most medical settings are given legal power to make decisions for these patients. 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 hardship to others must be viewed with great reservation.

Summary of the Sterilisation Act, no. 44 of 1998 (With Amendments)

The Sterilisation Act sets out the circumstances under which sterilisation, and in particular sterilisation of persons incapable of consenting because of mental disability, may be performed. It changes the laws related to sterilisation as set out in the old Act of 1975.

The Act recognises the rights of all persons to be informed of and to have access to safe, effective, affordable and acceptable methods of sterilisation. Together with the Termination of Pregnancy Act, it also recognises everyone's right to bodily and psychological integrity, including the right to make decisions concerning reproduction and the right to security in and control over their bodies

How does the Act define consent?

Consent is defined as an agreement "given freely and voluntarily without any inducement", and on condition that the person has been given a clear explanation and adequate description of the proposed

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, contraception	Decrease in dysmenorrhea and mittelschmerz, 60% or more, reduced cycle length, can schedule fewer periods per year if taken three months continuously without inactive pills	Reduce risk 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 ² (and among healthy non-smoking women who use OCs with less than 50 mcg oestrogen, no increased risk of MI or stroke).	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	Gall bladder disease Same as OCs. May have reduced efficacy in women with body weight > 198 lb.	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	Studies suggest reduce bone mineral density 14 Adverse lipid changes	No			
IUD-nonhormonal	Contraception	Most increase menstrual bleeding ³	Passive - no hormonal side-effects	Might need to use general anesthesia to check string regularly, more difficult insertion in nulliparous women	Risk of infection	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, hypomenorrhoea, 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	Suggested			
Tubal ligation	Contraception	No change	Relatively low surgical risk outpatient procedure, no incision required	Requires general anaesthesia	Surgical and anaesthetic risks	Yes			
Hysteroscopic tubal occlusion	Contraception	None		General anaesthesia 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 anaesthetic risks	Yes			

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procedure, the consequences and risks; that the person has an understanding that he or she may withdraw the consent at any time before the treatment, and has signed the prescribed consent form.

Who is capable of consenting?

No person may be prohibited from having sterilisation performed, provided he or she is 18 years or older, is capable of consenting, and has provided such consent. No person capable of consenting may be sterilised without his or her consent.

In the case of persons under the age of 18 years, sterilisation may only be performed if failure to do so would jeopardise the person's life or seriously harm his or her physical health. In such instances, the parent, spouse or guardian must give consent and they have to forward the request for sterilisation to the person in charge of the hospital or health facility.

The hospital will then have to convene a panel (consisting of a psychiatrist or medical practitioner, a psychologist or social worker, and a nurse) to evaluate the request and concur that sterilisation is in the person's best interest.

What if a person is incapable of consenting?

A person can only be sterilised without giving consent if they suffer from "severe mental disability". This means that they are incapable of:

- Making their own decision about contraception or sterilisation;
- Developing mentally to a sufficient degree to make an informed judgement about contraception or sterilisation; or fulfilling the parental responsibility associated with giving birth.

In such instances, sterilisation may be performed with the consent of a parent; a spouse; a guardian; or curator, provided the request to do so is made to the person in charge of a hospital.

As in the case of persons under 18 years, the person in charge of the hospital will have to convene a panel consisting of a psychiatrist or medical practitioner; a psychologist or social worker; and a nurse to consider all the relevant information and concur that sterilisation is the preferred option. The panel must, among others, determine that the person is 18 years or older, unless the physical health of the person is threatened; and that there is no other safe and effective method of contraception except sterilisation. The person performing the sterilisation must ensure that the method of sterilisation has the least health risk to the person concerned.

The Act also stipulates that if the sterilisation is to be performed in a private health care facility, members of the panel may not be employees of, or have a financial interest in, that facility.

Who is allowed to conduct sterilisation on persons who cannot consent?

Sterilisation on persons incapable of consenting because of severe mental illness may only be performed at a facility designated in writing for that purpose by the State. The State may also determine the conditions and requirements with which a facility has to comply. If such conditions and requirements are not met, the State may withdraw the facility's permission to perform sterilisations giving reasonable notice to the person in charge of the facility in question.

The person in charge of a facility designated to perform sterilisation must be notified of every sterilisation performed in that facility and must keep a record of every such sterilisation.

Alternatives to sterilization

Non-invasive modalities such as menstrual hygiene training, family counselling, sexual abuse avoidances training and sex education should be considered in place of sterilization. Physicians should advocate the least permanent and intrusive method consistent with the lowest risk for the patient. Physicians, parents and discussion makers must consider the interest of the patient when deciding between medical and surgical management.

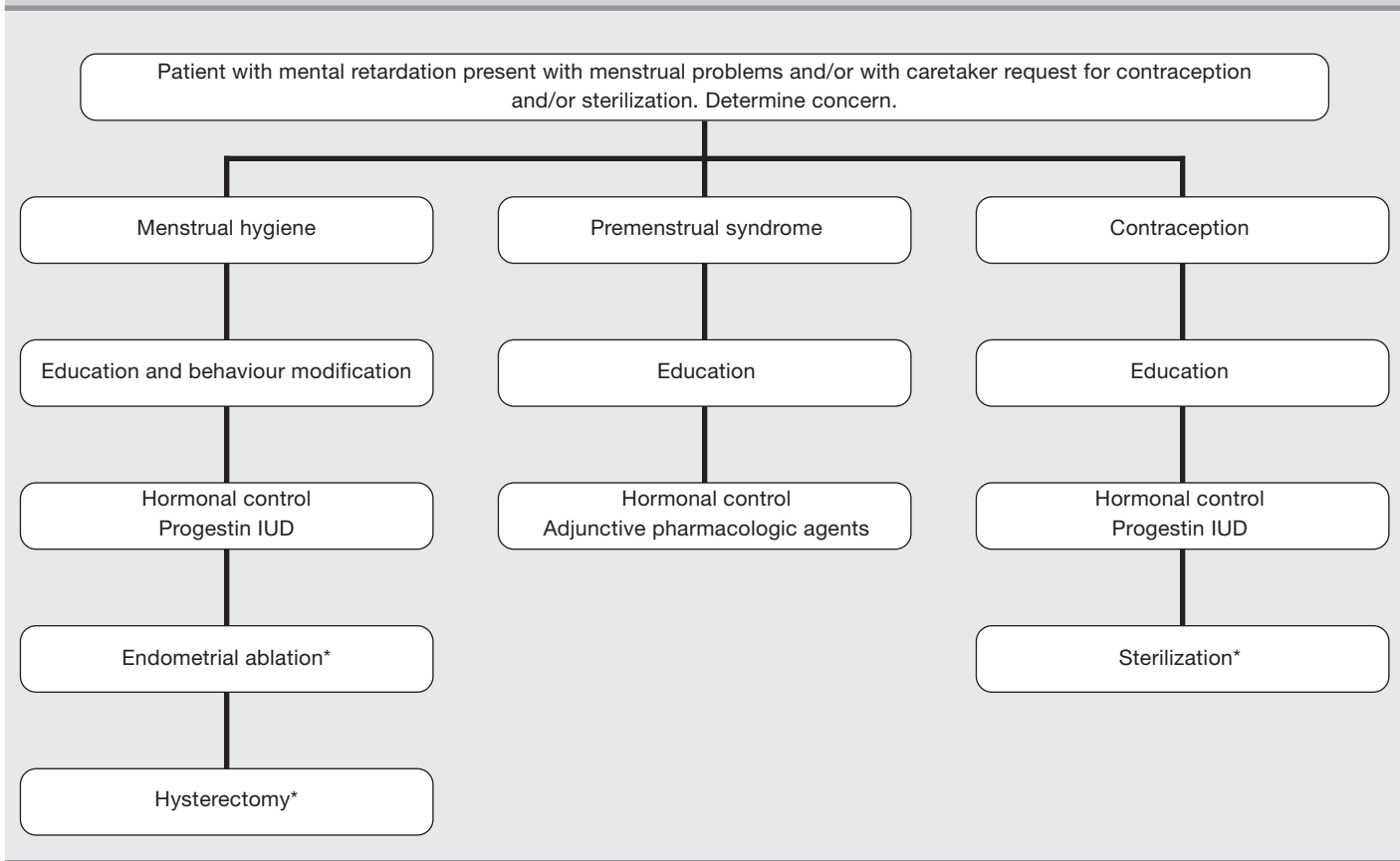
Algorithmic approach with criteria to determine best interest of patient

Pharmacologic and surgical advances have provided new minimally invasive alternatives for woman with mental impairment. Doctors, parents, judges and ethicist's should first determine the specific concerns of the patient and her ability to participate in the decision making process, Managing patients according to the algorithm below (Figure 1) will determine the need for surgery. The proposed guidelines for sterilization (Table 2) can be used to make decisions that are in the best interest of the patient.

Table 2: 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 post menarche.
- Pregnancy or preserving reproductive potential will significantly increase difficulty for the patient.
- Pregnancy represents a serious, objective physical and/or psychological risk.
- Methods of medical treatment are consistent with standard medical practice. Appropriate reversible alternatives have proven unworkable or inapplicable.
- Proponents are seeking sterilization in good faith and the primary concern is for is the best interest of the individual rather than their own convenience or the convenience of the public.

Figure1: Management Algorithm



Summary

Most physicians are very rarely exposed to the severely mentally challenged women who experiences menstrual hygiene problems or who is at risk of pregnancy. The therapeutic options for contraception and menstrual hygiene were often suboptimal in the past. In recent years, the advances in pharmacological therapy and minimally invasive surgical procedures for both menstrual hygiene and sterilization have greatly expanded the choices for these individuals.

All involved must rethink the ethical justification for allowing a sterilization procedure on a patient who cannot consent. Profoundly disabled patients will never have consensual intercourse and others, who will never be able to parent, do not have an interest in procreation. These patients should not be denied the rights to medical procedures that may benefit them, nor to medical procedures that may benefit them, not only to safeguard them against unwanted pregnancy but also to improve their quality of life during reproductive years.

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