MANAGEMENT OF MENSTRUAL PROBLEMS AND CONTRACEPTION IN ADOLESCENT WITH MENTAL RETARDATION

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INTRODUCTION:

- DSM V – mental retardation characterised by sub average intellectual functions (IQ < 70)
- Onset before 18 years
- Concurrent deficits in adaptive functioning at least two of following 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 have varying levels of understanding of reproduction, contraception and sexuality
- Varying levels of ability to care for themselves and to make informed decisions

REPRODUCTIVE PHYSIOLOGY OF THE MENTALLY RETARDED:

- Few series in literature report data concerning physiologic difference in menstruation with regard to the time of menarche and flow
- Gold study et al: Reported no statistically significant differences in menarche, duration of bleeding and cycle length between Down's syndrome and control group
- Salermo et al: Menarche presented with delay of 2-3 years in brain damaged and undifferentiated retardation group
- Delay of 3-4 years in patients with Down syndrome
- 65% had irregular periods
- 62% of patients ovulated

- These women also suffer from other processes that affect menstrual life:
  - Thyroid dysfunction
  - Obesity

SPECIFIC MENSTRUAL CONCERNS OF ADOLOSCENT WITH MENTAL RETARDATION:

- Categorize the nature of her and her family concern
- 3 Major concerns:
  - Menstrual hygiene
  - Premenstrual disorders
    - Premenstrual syndrome
    - Premenstrual dysphoric disorders
  - Contraception

Menstrual hygiene

- Elkins et al: Two most common causes are menstrual hygiene and pre menstrual-like symptoms
- Managing of menstrual hygiene is challenging because of balancing the patient ability to take care after bleeding with the demands of her caretaker
- Many women with menstrual retardation suffer from thyroid disease and obesity can effect the amount and frequency of bleeding
- Behaviour modification programs have been successful in women with mild and moderate retardation

Menstrual hygiene

- Chambers et al: Patient with varying degrees of retardation, showed 15/17 mothers of severely retarded women had difficulty training daughters
- A striking finding is that many patients preferred hysterectomy for elimination of menses

Premenstrual syndrome

- Premenstrual syndrome is another primary concern (32%)
- Symptoms include:
  - increase in behaviour problems
  - seizures
  - aggression
  - tantrums
  - crying spells
  - self abusive behaviour in the week before and first few days of menses
- Patients with severe and profound retardation often unable to express there discomfort verbally
- Management included reducing cycling with hormonal agents
- Selective serotonin uptake inhibitors have been shown to be highly effective

Contraception

- Parents concern about pregnancy:
  - Mildly retarded patient – normal interest in sexual interaction and marriage
  - Severely retarded patient – Show little sexual interest in opposite sex
- Concern about sexual abuse in institutional environment
- Reported data 25-40% have been sexual abused or assaulted
- 10% had been victims of incest

TREATMENT OPTIONS:

- Review benefits and risks of medical and surgical options
- Each treatment option must address concerns of patients with regards to
  - Complications
  - Side effect profile
- Most important task in initial visit with patient and family is to address their concerns
- This may include speaking with caretakers, school teachers and family members

TREATMENT OPTIONS:

- Oral contraceptives
- Contraceptive patches
- Injectable contraceptives
- IUCD
- Levonorgestel intra-uterine system
- Endometrial ablation
- Tubal ligation
- Hysteroscopic tubal occlusion
- Hysterectomy

Type of contraception	Indications	Menstrual hygiene benefits	Other benefits	Difficulties	Risks	Steri
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 (and among healthy non-smoking women who use OCs with less than 50 mcg estrogen, no increased risk of MI or stroke).	No

Type of contraception	Indications	Menstrual hygiene benefits	Other benefits	Difficulties	Risks	Steri
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

Type of contraception	Indications	Menstrual hygiene benefits	Other benefits	Difficulties	Risks	Steri
Depot Medroxy-progeste rone acetate (DMPA)	Menstrual hygiene, premenstrual syndrome, contraception	Amenorrhea in 50% of women within first year of use	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 Adverse lipid changes	No

Type of contraception	Indications	Menstrual hygiene benefits	Other benefits	Difficulties	Risks	Steri
IUD-nonhormonal	Contraception	Most increase menstrual bleeding	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	Risk of infection with sexual activity	No

Type of contraception	Indications	Menstrual hygiene benefits	Other benefits	Difficulties	Risks	Steri
Levonorgestrel intrauterine system	Menstrual hygiene, contraception	Progressive reduction of menstrual duration and menstrual blood loss, relief of menstrual pain	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

Type of contraception	Indications	Menstrual hygiene benefits	Other benefits	Difficulties	Risks	Steri
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	Pregnancy complications if contraception not used, surgical risks of perforation	Suggested

Type of contraception	Indications	Menstrual hygiene benefits	Other benefits	Difficulties	Risks	Steri
Tubal ligation	Contraception	No change	Relatively low surgical risk outpatient procedure, no incision required	Requires general anesthesia	Surgical and anesthetic risks	Yes

Type of contraception	Indications	Menstrual hygiene benefits	Other benefits	Difficulties	Risks	Steri
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 hystero-salpingogram	Yes

Type of contraception	Indications	Menstrual hygiene benefits	Other benefits	Difficulties	Risks	Steri
Hysterectomy	Menstrual hygiene, contraception	Absolute amenorrhea	Cessation of bleeding and sterilization	May not affect premenstrual symptoms	Invasive surgery, operative and anesthetic risks	Yes

HYSTERECTOMY:

- Hysterectomy solely for the purpose of sterilization is "inappropriate" (American College of O&G)
- Past century, hysterectomy used both to control menstruation and serve as contraception
- Wheeless et al: Advantages of doing vaginal hysterectomy
  - Short hospital stay
  - Easier post operative recovery
  - No abdominal wound
- Physicians may consider supra-cervical laparoscopic hysterectomy.

STERILISATION:

1. Parental attitudes towards sterilization
2. Ethics
3. Alternatives to sterilization
4. Algorithmic approach
5. Summary of the Sterilisation Act

Parental attitudes

- 63% of parents thought of sterilization
- 2/3 of the patients (mental retardation) had difficulty dealing with menstrual hygiene
- Parents of mildly retarded women are 3 times more likely to consider tubal ligation
- Parents of severely retarded women are 3 times more likely to choose hysterectomy
- Most common primary reason for sterilization is protection from pregnancy
- 60% of parents feeling hysterectomy is for elimination of menses and related problems

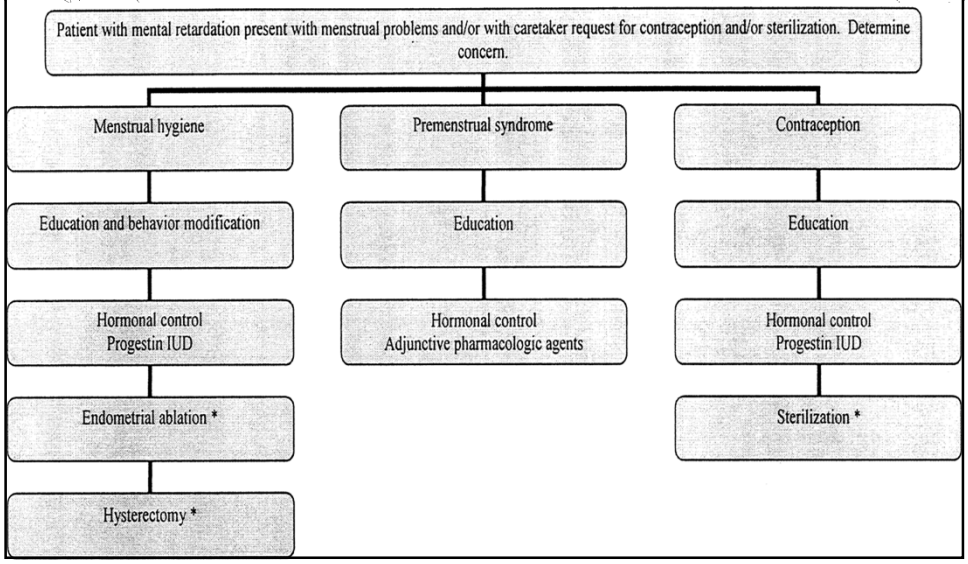
Ethics

- Ethical issues include determination of:
  - Patient ability to give consent
  - Who should make decisions for her
  - Alternatives to sterilisation
  - Best interest of the patient
- "Mental capacity":
  - to determine medical risk and benefits, alternatives and to express her personal choice
  - Functional determination made by appropriate medical professionals
- "Mental competency":
  - to give informed consent is determination made by court of law

Alternatives to sterilization

- Recent guidelines
  - Physicians should advocate the least permanent and invasive method
  - Consistent with the lowest risk for the patient
- When considering the best treatment options physicians, parent and decision makers – must weigh the interest of the patient (Medical vs. Surgical management)

Algorrithmic approach



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 post-menarchal
- 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

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

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.

How Does the Act Define Consent?

Consent is defined as a 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 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 Allowed to Be Sterilised?

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.

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

CONCLUSION:

- Most Physicians very rarely exposed to severely mentally challenged women who experiences menstrual hygiene problems
- Therapeutic options for contraception and menstrual hygiene were often sub optional
- Advances in pharmacologic therapy and minimally invasive surgical procedure greatly expanded
- Propose that all involved rethink the ethical justification for allowing a sterilization procedure on patient who cannot consent
- Should not be denied the right to medical procedures that may benefit them
- Not only for safety against unexpected pregnancy but also to improve their quality of life during menses