AMERICAN ACADEMY OF PEDIATRICS

Committee on Bioethics

Sterilization of Women Who Are Mentally Handicapped

The recent statement of the American College of Obstetricians and Gynecologists on the sterilization of mentally handicapped women (REF) is comprehensive and is endorsed in principle and substance by this Committee. As pediatricians, we reinforce and reiterate the following:

1. With rare exception, there is no indication for sterilization of a child before menarche. An example is when sterilization is not intended, but is an unavoidable consequence of other surgery, such as surgery for a malignancy.

2. The primary or contributing indications for sterilization (particularly surgical sterilization) based on presumed or anticipated hardships to others must be viewed with great reservation and in light of acceptable alternate care arrangements which might be made for the mentally retarded individual. The judgment of "hardship" is extremely subjective and must not be simply a matter of inconvenience or a preference for the easier of two alternatives.

3. When sterilization or pharmacological control of menses is chosen after the appropriate informed deliberations and attempts at obtaining consent, the pediatrician should always advocate the least permanent and intrusive methodology consistent with lowest risk for the patient. Present and future research and clinical trials may very well make newer forms of chemical contraception or pharmacologic amenorrhea preferable to surgical sterilization.

4. Even if satisfactory informed consent cannot be provided by the patient, all efforts must be made to communicate the procedure and intent of the planned intervention to the patient; estimations of the patient's ability to comprehend and participate in the decision-making process should be done by personnel who are familiar with the individual patient and who are experienced in communication with persons with diminished mental capacity. The individual's capacity to participate in decision-making concerning sterilization is determined both by the degree of overall mental impairment and by the individual's profile of specific capabilities. Persons with serious impairment in some areas of mental function may still be able to participate in decisions affecting their reproduction.

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The recommendations in this statement do not indicate an exclusive course of treatment or procedure to be followed. Variations, taking into account individual circumstances, may be appropriate.
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ACOG COMMITTEE OPINION: STERILIZATION OF WOMEN WHO ARE MENTALLY HANDICAPPED

The Committee on Ethics recognizes the need to preserve the principle of free and informed consent before performing a sterilization procedure. This statement is designed to provide background information and guidance to the Fellows of the American College of Obstetricians and Gynecologists when sterilization is being considered for persons whose ability to provide informed consent is questionable or absent. Although sterilization for males who are mentally handicapped may be analogous in many ways, other issues exist that are best addressed by other professional groups. This statement therefore pertains only to issues involved in sterilization of females who are mentally handicapped. Furthermore, the presence of a mental handicap alone does not, in itself, justify either sterilization or its denial.

Historical Background

In the United States, public policy regarding the sterilization of persons who are mentally handicapped has passed through three historical phases. The first was evident early in this century, when state laws encouraged compulsory sterilization of persons who were mentally handicapped, and judicial decisions gave approval to such actions based on eugenic principles and societal interests.[1]

The second phase was marked by growing social disapproval of mandatory sterilization. This became manifest in 1942, when the US Supreme Court proclaimed reproduction to be a fundamental human right.[2] In many jurisdictions this decision initiated legislative and judicial actions that prohibited sterilization of persons with mental disabilities.[3] In 1979 federal regulations denied the use of federal funds for the sterilization of any mentally incompetent person.[4]

As the third phase of public policy now emerges, widely differing viewpoints are expressed in state laws, which permit sterilization in some cases, prohibit it in others, or most commonly, offer no legal guidance. In each of these phases serious abuses and injustices have been committed: either persons who were objectively capable of parenting but who were incorrectly considered incapacitated were deprived of their procreative rights, or persons for whom pregnancy was a serious burden or harm were denied opportunity for a full range of contraceptive options.

Clarification of Terms

For the sake of brevity, persons with mentally handicapping disabilities are described within this document as persons who are mentally handicapped. The term "mentally handicapped" may be similar in some ways to other phrases, such as "mentally retarded," "mentally impaired," "mentally disabled," or "mentally deficient" that are not used in this document because of their unclear connotations. None of these terms, however, including the one we have chosen to use, describes the person's ability to give informed consent.

It is important to distinguish between the terms "mental capacity" and "mental competency." Within this document, a person's "mental capacity" (to give informed consent) is a functional determination made by appropriate professionals after evaluation of a particular patient. A person's "mental competency" to give informed consent is a determination made by a court of law.

Ethical Considerations

It is important that obstetrician-gynecologists be aware of the ethical issues inherent in sterilization procedures involving persons who are mentally handicapped, and of the need to give each sterilization request careful, individual consideration. A systematic approach is necessary in the consideration of sterilization of patients who are mentally handicapped.

Evaluation of Capacity to Provide Informed Consent

Individuals who are mentally handicapped are not necessarily incapable of providing informed consent for sterilization or other medical procedures. A person's capacity to provide informed consent for any medical procedure is often difficult to determine. The determination of the capacity to provide informed consent involves the patient's understanding of reasonable alternatives, risks and benefits of the procedures, and the ability to express her personal choice. These elements of informed consent are the same for persons who are handicapped and those who are not. In individuals who are mentally handicapped, however, impairments of communication skills and mental abilities exist, and vary from person to person and in the same person over time. For this reason, certain precautions must be undertaken to ensure that informed consent is achieved. Ensuring that decisions to request sterilization are not coerced and not transient may require multiple interviews with the patient alone over an appropriate time period. Obtaining the assistance of professionals trained in communicating with persons who are mentally handicapped is essential in seeking to assess capacity. These professionals may include special educators, psychologists, attorneys familiar with disa-

bility law, and physicians accustomed to working with persons who are mentally handicapped. In most jurisdictions, court action is not usually required to proceed with a sterilization procedure, even when a patient is mentally handicapped, if there is agreement among these consultants that an individual is capable of consenting.

Practices to determine a patient's mental capacity to make decisions differ among various legal jurisdictions. If the capacity to provide informed consent remains uncertain despite the aforementioned assessment attempts, a court determination of mental competency may be required by law before a sterilization procedure is performed.

For sterilization, the consent of minors, or of parents on their behalf, may not be recognized in certain jurisdictions under any circumstances. Because state laws vary widely, physicians need to know the laws in their jurisdictions.

Physician Response When a Patient Cannot Give Informed Consent

If a patient is mentally incapacitated or is adjudicated mentally incompetent, serious consideration should be given to a variety of issues before a sterilization procedure is performed. The initial premise should be that nonvoluntary sterilization is generally not ethically acceptable in our society because of the violation of privacy, bodily integrity, and reproductive rights that it may represent. In some unusual situations, however, sterilization may be considered a reasonable part of the overall health care of a person who is mentally incapacitated or incompetent.

Four categories of concern should be considered in any decision to sterilize a person who is mentally incapacitated or incompetent: (1) identification of an appropriate decision-maker, (2) alternatives to sterilization, (3) best interests of the person who is mentally incapacitated or incompetent, and (4) current understanding of applicable laws.

Decision-Makers. In most medical settings, parents, immediate family members, or legal guardians are given the power to provide proxy consent for medical treatment for persons who are mentally incompetent or incapacitated.[5] The best interests of the patient are generally served by immediate family members who have maintained a close, long-term, positive relationship with the person who is mentally incapacitated or incompetent. Reliance upon proxy consent (by family or guardians) alone, however, increases the risk of sterilization abuse because a conflict of interest may exist. Some states do not even allow family members or guardians to authorize a sterilization procedure. Therefore, in cases involving proxy consent, the physician should evaluate whether the best interests of the patient will be served. Consultation with other professionals should be considered. These may include pediatricians, neurologists, psychiatrists, psychologists, social workers, attorneys, special educators, or clergy. Input from institutional ethics committees may be desirable, and court opinion may be required except in those states where specific guidelines have already been developed.

Alternatives to Sterilization. In responding to requests for sterilization of patients who cannot consent because of mental incapacity or incompetence, due consideration should be given to alternative methods of management before any invasive procedure such as surgical sterilization is selected as the most appropriate alternative:

- Noninvasive modalities, such as socialization training, sexual abuse avoidance training, menstrual hygiene training, family counseling, and sexuality education should be considered in lieu of, or concomitant with, requests for sterilization.
- Although medical treatment is usually preferable to surgery, the risks associated with long-term medical contraception or hormonal treatment may be as great or greater than those of a single definitive surgical procedure.

Best Interests of the Patient. With all requests for sterilization of a person who is mentally incapacitated or incompetent the primary consideration is the best interests of the patient.

Certain facts should be ascertained in order to protect these interests:

- The mental incapacity or incompetency should be a permanent condition, and not one in which the functional capacity to choose or the capacity to be a parent would change.
- There should also be a reasonable likelihood that the patient is fertile and may experience sexual intercourse unless her social freedom is restricted.
- It should be determined whether pregnancy represents a serious, objective physical risk (e.g., severe heart disease) to the patient.
- Even if no health risks would be incurred through pregnancy, the burdens to the patient of childbearing, parenting or menstrual hygiene problems should be considered. When the harms to the patient are less direct or less immediately apparent, more careful appraisal of benefits versus burdens is warranted to be certain of the best ethical choice.

There may be cases in which other factors override sole consideration of the best interests of the patient. This can occur either when there is difficulty in determining the patient's best interests or

when other concerns are so serious as to merit consideration in themselves. Examples of such concerns may include the following:

- In some cases pregnancy would represent a significant risk that the infant would be born with a serious genetic or congenital problem.
- Pregnancy or preserving reproductive function may significantly increase the difficulty of caring for the patient; an infant would make further demands on the same caretaker or necessitate the shift of that responsibility to other individuals or institutions.

In some situations, particularly when requests for surgical sterilization are based on concerns about burdens to others, the apprehensions about these burdens may or may not be realistic, particularly in the case of the very young patient.

When factors such as these appear to override the best interests of the patient, additional review is indicated, such as by an institutional ethics committee.

Finally, if a surgical method is employed, the selection of the sterilization procedure should represent the most appropriate method of care that will achieve the intended benefits.

Legal Considerations. It is essential to recognize municipal, county, state, and federal statutes, regulations, or legal decisions that control the practice of sterilization of persons who are mentally incapacitated or incompetent.

REFERENCES

1. *Buck v Bell*, 274 US 200 (1927)
2. *Skinner v Oklahoma*, 316 US 535 (1942)
3. *Relf v Weinberger*, 372 F Supp 1196 (DDC 1974)
4. 42 CFR § 50.201–210 (1979)
5. Substantive and procedural principles of decision-making for incapacitated patients. In: President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: Making Health Care Decisions, Volume One: Report. Washington DC: US Government Printing Office; 1982:177–188

SUGGESTED READING

Haavik SF, Menninger KA II. *Sexuality, Law, and the Developmentally Disabled Person: Legal and Clinical Aspects of Marriage, Parenthood, and Sterilization.* Baltimore: Paul H. Brookes Publishing Co., 1981:105–150

Macklin R, Gaylin W, eds. *Mental Retardation and Sterilization: A Problem of Competency and Paternalism.* Hastings-on-Hudson, NY: The Hastings Center; 1981

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