MEDICAL ETHICS

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Suggested guidelines for hysterectomy in mentally handicapped women

Introduction

Forum for Medical Ethics sought and obtained opinion and advice from a variety of esperts. It also studied some of the publications on the subject in medical and other journals. The following draft guidelines were then drawn up and are presented here. They could form the basis for the preparation of a definitive directive on this subject.

Governing ethical principles

1. Society and the law protect the well-being and welfare of incapacitated individuals.

2. When a measure is undertaken on behalf of a person incapable of making a decision on its acceptance or rejection, it can only be implemented if it is directly beneficial to that person.

3. Where such a measure carries risk to life or body, the benefits must be clearly seen to outweigh the risks.

4. When several options are available that may confer a similar benefit to such a person, the least injurious must be selected.

5. The benefits that may accrue to guardians, attendants and other well-wishers of such a person should not play any role in making the decision to implement a measure that could, in any way, prove harmful to the person.

Some practical points

1. Conclusions based on the principles enunciated above must be applicable in real-life situations in this country.

2. Given the limitations in our country in terms of poverty, illiteracy, financial resources. lack of social security, inability on the part of the governments to attend to several pressing problems affecting the very poor and a judicial system that is already so overburdened that most cases drag on fbr years and decades, we have to modify our guidelines so that they can be put to immediate use without entailing expense or harassment to mentally handicapped women or their families.

3. Such pragmatic alternatives can only be temporary compromises whilst sincere and whole-hearted steps are taken towards the ideal situation.

4. The authorities in charge of institutions looking after these women must make public:
(a) the prevailing state in terms of(i) resources available (ii) efforts made to meet the objectives of the institution (iii) fraction of total resources used specifically towards maintenance of hygiene of these women

(b) time-bound programme for overcoming the deficiencies in providing humane care and security for them

(c) procedure for periodic objective review of progress, the findings to be made public through the media.

5. There is a very real danger that medical and surgical procedures carrying inherent hazards can and will be used unscrupulously on hapless individuals who already find it difficult to grasp the implications of what is suggested for them or their relatives. It is all-too-easy to extend the performance of an operation such as hysterectomy or castration to groups ill-favoured bv society or its dominant groups. The experiences in Nazi German; and Colombia are fresh in our minds. Even in our own country those in power have been shown to treat social outcasts as 'the disposable& fair game not only for castration and mutilation but also for murder.

5. To avoid such catastrophe, periodic objective review of all invasive medical and surgical procedures on these women must be carried out and the findings made public, ensuring the privacy of these women. Such reviews must announce whether the procedures achieved their purpose and the costs in terms of bodily harm done to the women and deaths from such procedures.

GUIDELINES ON HYSTERECTOMY IN MENTALLY HANDICAPPED WOMEN

I Diagnosis of type and extent of mental handicap

1. The woman concerned must be examined on more than one occasion by a panel of at least one qualified psychiatrist, one clinical psychologist and a social worker with experience in the problems faced by the mentally handicapped. If the woman is in an institution, members of the panel should include only those not on its payroll. Their findings, results of tests carried out and considered opinions on type, cause and extent of mental handicap must be recorded on the woman's case sheets.

2. A particular reference should be made to this panel when hysterectomy or any other medical or surgical procedure carrying inherent risks is being considered. The opinion of the panel on whether such a procedure is justified should be recorded on the case sheets.

3. Hysterectomy can only be considered in a woman with irreversible brain damage that has left her with no understanding of her bodily functions and incapable of looking after her own needs despite conscientious efforts at training her to do so. Such persons fall under the category of profound mental retardation (KS- 10 classification F73).

II *Rationale for hysterectomy*

1. Inability to maintain personal hygiene during menstruation

a) This must be documented on the case sheets. The effects of such documented lack of hygiene on the men tally handicapped woman must be clearly stated. Reference must be made in writing to the state of personal hygiene on other days when she is not menstruating, especially with regard to excretion of urine and feces. It must be evident to an objective observer scrutinising the case sheets and inspecting the woman's surroundings that despite all available care and assistance, there is breach of hygiene from menstruation hazardous to the woman's health and well-being.

b) Where available care and assistance are less than what can be reasonably expected, the shortcomings must be corrected before a decision is made on hazard to the woman from breach of hygiene.

c) Hysterectomy in the absence of a conscientious effort at helping the woman to maintain personal hygiene cannot be justified.

Note: Whilst improvement in facilities for maintenance of personal hygiene to the state where it would be unnecessary to consider such options as hysterectomy would be ideal, given the circumstances in most institutions for the mentally handicapped in India, this is likely to remain infeasible for quite some time. Whilst every effort should be made to reach this ideal, in the interim the above guidelines appear practical.

It must be emphasised that all concerned, especially members of the panel referred to above, should ensure that recourse to hysterectomy does not become the refuge of the inefficient, corrupt or unconcerned. Public institutions, running on subsidies from society, cannot evade their responsibilities towards these women or consider the promotion of personal hygiene amongst them as 'extraordinary care'.

2. To prevent unwanted pregnancy

Hysterectomy is not justified solely to prevent unwanted pregnancy. Laparoscopic tubal ligation is the procedure of choice for this purpose.

3. For medical indications such as menorrhagia (profuse bleeding resulting in severe anaemia), uterine tumours and endometriosis

The decision by a qualified gynaecologist to perform hysterectomy as therapy for such indications documented on the patient's case sheets cannot be challenged.

4. To avoid the consequences of rape

This is an untenable reason for hysterectomy. Prevention of rape is the responsibility of the legal guardian of the mentally handicapped woman. When such a woman is in a state institution, the onus for preventing such assault lies squarely on the administrators of the institution. The very nature of the handicap necessitates special protection.

III *Competent authority to permit this operation*

1. The principle of informed consent by the person to be subjected to surgery cannot be enforced here on account of the mental handicap faced by the woman.

2. Where the parents or other relatives who are the legal guardians are alive and able to decide on behalf of the woman, the informed consent of such guardians must be obtained in writing after explaining, in the language used by them, the need for the operation and the likely complications that could follow it. The consent must be witnessed by an unrelated individual who does not stand to benefit in any way from the operation.

It must be ensured that there has been no coercion by the administrators of the institution. The relatives of such women are especially vulnerable to threats and subtler forms of 'persuasion'.

3. Where the woman is an orphan, the officer in charge of the institution in which she is housed should permit the operation after getting the need for it endorsed by the panel recommended above (see I, 2 above).

Note: The greater legitimacy for such surgery afforded by judicial sanction obtained by making these women 'wards of court' cannot be insisted upon in our country as our courts of law are already hopelessly over-burdened.

IV The operation

1. Hysterectomy on a defenseless woman entails a responsibility greater than that on one in full possession of her senses and able to exercise her choice of operation and surgeon.

2. Such an operation must be carried out by a senior and experienced gynaecologist with several such operations to her or his credit.

3. The operation must be performed in an institution possessing all the staff and equipment necessary for the purpose and for immediate identification and management of any ensuing complication.

4. The choice of the nature of operation (vaginal or abdominal hysterectomy) is best decided by the surgeon concerned.

5. As such women are unlikely to be able to identify and voice symptoms heralding a complication, the post-operative care afforded to them must be far more intensive than that provided to other patients.

6. For the reason noted above, the patient should not be sent away from the hospital till full recovery has occurred.

7.. All such operations must be fully documented. The documents must be open to scrutiny by reputed agencies working for the welfare of women to ensure that no untoward event is swept under the carpet.

8. Provision must be made in advance for adequate compensation in the event of an error in the evaluation of mental handicap or complication after the intervention.

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Why are study circles necessary?

Fundamental issues are often lost sight of in the hurly-burly of practice. Issues relevant to ethics, social justice in medicare, audit of medical practice, peer review of humaneness and the use of appropriate care are ignored.

We shall focus on these in our study circle meetings. Thus far we have considered drugs and the medical profession (with special emphasis on the Indian scene), whether doctors have a role in the program to control population, the privatisation of medical education and the World Development Report 1993 (published by the World Bank) advocating disinvestment in health. Background papers prepared for these meetings are available with Dr. Pilgaokar at cost (address on page 12 of this issue). Ethics in medical research is the topic for the next meeting (June 1994). Dr. Eustace de Souza will provide the background paper and start the ball rolling.