**UNESCO Chair in Bioethics** 

# **REPRODUCTIVE HEALTH** Case Studies with Ethical Commentary

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<u>The International Center for Health, Law and Ethics</u> Faculty of Law, University of Haifa

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Chairholder: Prof. Amnon Carmi

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# **<u>REPRODUCTIVE HEALTH</u>** <u>Case Studies with Ethical Commentary</u>

# Introduction

The concept of Reproductive Health has been afforded international prominence by its strong endorsement at two United Nations' conferences in the mid-1990s, namely the International Conference on Population and Development, held in Cairo, Egypt in 1994, and the International Conference on Women, held in Beijing, China in 1995. The full definition is that:

Reproductive health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are the right of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant.

Many countries have committed themselves, by both international undertakings and their national laws, to give effect to this concept, as an ethical duty reinforced by law.

In order to equip health care professionals, health care students and others to consider the ethical requirements of respect for reproductive health, and to recognize the duties on which individuals' enjoyment of their reproductive rights depend, two authors of this publication have participated with a colleague in preparing a text that offers guidance on means to integrate medical, ethical and legal elements of reproductive health. Published in different languages, this is:

Rebecca J. Cook, Bernard M. Dickens, Mahmoud F. Fathalla

English:	Reproductive Health and Human Rights:
	Integrating Medicine, Ethics and Law.
	Oxford: Oxford University Press, 2003.
	<u> http://www.oup.co.uk/isbn/0-19-924133-3</u>
	Updates will be available at:
	http://www.law.utoronto.ca/faculty/cook/
	ReproductiveHealth.html

- French: Santé de la Reproduction et Droits Humains: Intégrer la Médecine, l'Éthique et le Droit. Paris: Masson, 2005.<<u>http://www.masson.fr</u>>
- Spanish : Salud Reproductiva y Derechos Humanos : Integración de la Medicina, la Etica y el Derecho. Bogotá, Colombia: Profamilia, 2004. Contact: juridico@profamilia.org.co
- Portuguese: Saùde Reprodutiva e Direitos Humanos: Integrando Medicina, Ética e Direito. Rio de Janeiro, Brazil: CEPIA, 2005. Contact: sandra@cepia.org.br
- Chinese: [Reproductive Health and Human Rights: Integrating Medicine, Ethics and Law].Beijing: China Population Publishing House, 2005. Contact: chinapphouse@163.net

Further translation is forthcoming in Arabic from the Egyptian Fertility Care Foundation (efcf@link.net).

The purpose of that text, and also of this publication, is not to

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direct readers to particular conclusions. It is to assist in identification of key ethical considerations of which account must be taken for an adequate ethical assessment of resolutions of conflicting values in reproductive health care. Ethical judgments are not either black or white, ethical or unethical. There can be more than a single way to behave ethically, depending on the ethical principle to which priority is given. Ethical decision-making requires that central elements underlying a decision be identified, and ethical reasons be provided for favouring one approach over another.

The following 31 case studies, drawn from real-life experiences, are based on simple fact situations, so that readers can address their ethical elements, rather than evade ethical engagements by resort to technical means or development of additional facts. Readers are invited to develop their own ethical explanations for the resolutions of these case studies that they favour.

# **CASE STUDIES**

# <u>Case study 1</u>: Contraception counseling of adolescents

(contraception counseling; adolescent; confidentiality; parental consent)

BT, aged 15, visits Dr. HK, who serves under her parents' family health insurance plan, and introduces VG, aged 19, as her fiancé, explaining that they intend to marry when BT is 18 and no longer requires parental consent. She further explains that, because sexual abstinence is straining their relationship, she and VG will soon become sexually intimate, but do not want to risk her pregnancy before they marry. BT therefore asks Dr. HK to advise her and VG on preferable contraceptive choices. She also asks Dr. HK not to inform her parents, since they do not approve of her relationship with VG. Local law makes it an offence for a male to have sexual intercourse with a female aged under 17, unless he is no more than 3 years older than she is. Advise Dr. HK.

### Questions

- What advice should Dr. HK give to BT?
- Can Dr. HK counsel VG on protected intercourse with BT?
- What is Dr. HK's ethical responsibility to preserve BT's confidentiality?
- How should Dr. HK handle the conflict of interest with regard to preserving BT's autonomy and providing information to BT's parents?

### Responses

While aged under 17 and unmarried to him, BT cannot give VG legally effective consent to sexual intercourse because he is more than three years older than she is. The law is designed for BT's protection, however, so that, if she was to consent, she would not become an offender, even though VG would.

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Accordingly, Dr. HK can advise her about contraceptive protection, but cannot counsel VG on protected intercourse with BT at the present time, since this would appear to be facilitating an offence. Nevertheless, in BT's absence, Dr. HK can inform VG in general terms how to acquire reliable medical information he may want. It is commonly accepted in economically developed countries that, by age 19, young men should be informed about contraception.

Maintaining BT's confidentiality presents practical and ethical concerns. The practical concern is that Dr. HK is entitled to bill services to the parents' family health insurance plan, and they may be entitled or required to verify receipt of services billed under the plan. If there are no means to mask contraceptive services to BT, confidentiality may be compromised, unless Dr. HK's services are unpaid or covered in another way. However, payment by VG should be precluded. The ethical issue concerns BT's right to be treated as an autonomous adult. Local law may recognize the concept of the "mature minor." If so, and Dr. HK is satisfied that BT has the capacity to understand the information and to act accordingly, she may be granted some autonomy to decide her medical care and who may share her medical information. However, since BT is a minor, her parents may have some responsibility for her health care, and may need information of any medical products prescribed for her for proper discharge of their responsibility. An argument to support confidentiality is that, unless adolescents feel secure in their confidences, they may be deterred from seeking medical care they need.

Counseling BT alone, Dr. HK may accordingly advise her to consider the chances of her parents learning of any contraceptive prescription, the possibility of finding an alternative method of payment, her reliance on a partner's use of a condom or other male contraceptive method, or remaining abstinent. Should she opt for contraception, Dr. HK could ethically provide a prescription, but with no assurance of full confidentiality if the services will be paid for through the parents' health insurance plan. Dr. HK may bear heavy ethical responsibility for relying on any personal moral condemnation of adolescent and premarital sex to deny BT contraceptive means, if she becomes sexually active unprotected.

# <u>Case study 2</u>: Request for sterilization without telling spouse (access to sterilization: confidentiality; husband's authorization)

Mrs. TW, aged 37, is the mother of four daughters, the youngest aged three years old. She is rather anemic, says she is often fatigued, and lives with her husband in a modest rural home, supporting her family by growing crops, feeding a few domestic animals, gathering firewood and taking some products to the local market while her husband looks for work in the nearest town. She comes to the local family planning clinic and asks Dr. JB to sterilize her, because she feels that, on grounds of her health and the family's few means, she cannot cope with another pregnancy and rearing another child. She says she can pay for the procedure from her savings but that Dr. JB must promise that the clinic staff will not inform her husband because he can be violent and has always wanted to father a son. In the local culture, husbands expect to be consulted on their wives' medical care, but this is not legally required.

# Questions

- What are the ethical implications of this case?
- Does Dr. JB have an ethical obligation to disclose Mrs. TW's request to her husband?
- Does Dr. JB have an obligation to request Mr. TW's authorization to fulfil Mrs. TW's request?
- Should Dr. JB perform a sterilization procedure on Mrs. TW?

### Responses

The medical evidence may be that a further pregnancy is contraindicated for Mrs. TW, but the ethical challenges arise from the local culture of male entitlement to influence and even control wives' medical care, and her husband's disposition to violence. Dr. JB may feel bound to respect the local culture, and decline to treat Mrs. TW without her husband's knowledge, on the ethical grounds of not becoming party to his deception, and of aggravating his frustration in failing to father a son.

The ethical case for treating Mrs. TW according to her request that her husband not be informed rests on medical indications that sterilization is appropriate, and that she may suffer violence if her husband knows that she has frustrated, or proposes to frustrate, his hope to father a son. The significance of having a son to the family's economic prospects may weigh in the ethical balance, but any advantage may be offset by the cost to Mrs. TW's health, the reduction of her energy affecting her central contribution to the family's resources, and her means to attend to the needs of the existing family members. In any future pregnancy, she might, of course, have another daughter.

Practical challenges with ethical implications are whether a sterilization procedure would leave physical evidence such as a scar of which the husband might become aware, and whether all staff members of the clinic can be expected and relied upon to preserve the confidentiality of the procedure.

The husband's ignorance of Mrs. TW's being sterilized carries ethical weight, but any concern about him being deceived may be resolved by the consideration that Mrs. TW is free to become a patient according to her own right to reproductive self determination, with an accompanying right to confidentiality. The clinic has no ethical duty to enforce any moral obligation of disclosure Mrs. TW may owe her husband, and the clinic should not make Mrs. TW's access to medically indicated care dependent on her surrender of her ethical right to confidentiality.

# <u>**Case study 3</u> Maternal refusal of indicated care** (emergency obstetric services; maternal-fetal conflict)</u>

A 24-year old woman with three children following four pregnancies is seen in the emergency room with heavy vaginal bleeding that is only partially slowed by vaginal packing. She is found to have a Stage IIB cervical cancer and is eight weeks pregnant. The recommended next steps are either to embolize the uterine artery or try high dose fractions of radiation to stop the bleeding – both of which will cause termination of the pregnancy. The patient speaks only a foreign language, but both the interpreter and her husband confirm that she refuses treatment because she will lose the pregnancy. She continues to hemorrhage, loses consciousness, and her health and perhaps her life may be endangered if she continues to bleed. The husband asks that the health team please move forward with any procedure needed to save his wife.

### Questions

- What ethical dilemmas is the health care team facing in this case?
- What questions might the health care team consider to validate whether the patient's refusal of treatment is reasonable?
- What should the health providers do?

#### Responses

It is not usually considered unethical for health care providers to act to preserve their patients' lives. When a pregnant woman will risk her life to save the life of her viable fetus that cannot otherwise be saved, however, it may be ethically justified to comply with her choice of self-sacrifice out of respect for her ethical right of autonomy. Nevertheless, in this case, survival of the eight-week old pregnancy is not certain, particularly when the pregnant woman suffers heavy untreated bleeding and

#### has cervical cancer.

The woman's inability to express herself in the local language is of no ethical consequence, since the interpreter and her husband confirm her refusal of treatment. The husband's evidence is particularly credible because the preferences he attributes to her differ from his own. The decision on her treatment has to be made when she is unconscious, but ethically there is no more latitude to treat an unconscious than a conscious patient contrary to the patient's reliably known preference.

The ethical challenge in this woman's case is that her intention to preserve the unborn life, though competently made and communicated with adequate reliability, may be unrealistic. In over-estimating the prospect of fetal viability and also her own prospects of survival if her heavy bleeding remains untreated, and not sufficiently considering the well-being of her three young children, her choice may appear insufficiently informed, or naïve. The husband's request, made particularly on behalf of the dependent children, warrants ethical respect, and may set an ethical limit to his wife's autonomy that a court of law would recognize. The wife's preference to favour the embryo or fetus she carries may be ethically of less weight than the interests of her three dependent young children. Accordingly, while the health care provider has ethical grounds to comply with the woman's refusal of care, as in the case of refusal of life-preserving blood transfusion by Jehovah's Witnesses, equally arguable ethical grounds also exist, by a utilitarian benefit-to-risk assessment, to give priority to her own survival.

The medical team should consider the fact that although she may lose the fetus through the medical intervention, her successful recovery might provide an opportunity for another pregnancy. <u>Case study 4</u> Young bride requests secret access to contraception (access to contraception; confidentiality; husband's authorization)

EF, aged 16, was married six months ago to a man aged 27 she knew only very little, by an arrangement made between her parents and his family. Her husband has brought her to Dr. GH, a family physician, for a routine health examination. Dr. GH finds EF quite petite, malnourished and with an underdeveloped pelvis. EF informs Dr. GH that she wants to delay childbearing until she is aged 20, although her husband and his family are anxious that she should bear a child as soon as possible. She asks Dr. GH for a contraceptive method.

### Questions

- What is Dr. GH's primary ethical responsibility in this case?
- What social and medical conditions should Dr. GH discuss with EF during the consultation?
- Should Dr. GH inform EF's husband about EF's request without her approval?

### Responses

Dr. GH should explain to EF that, as a physician, Dr. GH should undertake to advise her husband that it is not in the health interests of his future child or of EF that she should conceive before she is adequately developed for child bearing, and that waiting for a few more years will promote the health of the family for which he is responsible. The doctor should also advise EF, however, of her likely position in her husband's family should she appear to be infertile, and that it would be preferable that her husband knows if she uses contraception. Ethical concerns arise if it seems likely that her husband would prohibit EF from using contraceptive means, and of not disclosing such use to him if means were available to apply without his knowledge.

The doctor's primary ethical responsibility to EF is protection of

her health. She is at risk of premature pregnancy, with complications of obstructed labour, and perhaps prolonged labour liable to result in fistula damage. Dr. GH must take account of all of EF's surrounding circumstances to assess how well obstructed or prolonged labour would be managed in the event of early pregnancy. If the indications are that early pregnancy would be prejudicial to her health, supply of contraceptive means may be ethically appropriate. The doctor should not plan to deceive EF's husband, but should observe the standard practice of patient confidentiality, including not being specific if the husband is charged medical fees for EF's treatment. However, disclosure may arise if EF has to take a prescription for a contraceptive product to a pharmacist.

If Dr. GH reports to EF's husband on the general state of EF's health, the doctor might observe that the arrangement by which EF became his wife did not adequately consider her stage of physical development for motherhood and that, through no fault or incapacity of EF's, her pregnancy is contraindicated on medical grounds for the next three years or so. However, Dr. GH should consult with EF and have her approval before so reporting to her husband.

# <u>Case study 5</u>: Adolescent sex education (adolescent sex education)

Dr. JK is employed by a governmental school board to provide health services to students aged 11 to 16 who attend a mixed-sex non-denominational secondary school. Dr. JK has found, over five years of experience, that there has been an increase in pregnancies and sexually transmitted infections (STIs) among students aged over 14, and proposes to provide general instruction to them on sexual health , the benefits of sexual abstinence, and the options for practice of contraception as well as the importance of protection against STIs . Some parents object to their children receiving instruction about contraception because this offends the parents' religious beliefs, and others object for fear that such instruction will promote sexual experimentation.

# Questions

- Should Dr. JK offer sexual health information to the students?
- What is Dr. JK's ethical duty towards the students and the parents in this situation?

# Responses

Since Dr. JK is responsible for health care services, which include direct care and health care instruction and advice to the secondary school students of whose formal education the school board is in charge, reproductive health and sex education ethically fall within Dr. JK's mandate. Discharge of that mandate should take account of students' prevailing health status and circumstances, which include rising rates of pregnancy and sexually transmitted infection (STI) among the upper age group. Accordingly, Dr. JK must provide for students' most effective health protection in these regards. The ethical challenge does not arise primarily from meeting students' needs of appropriate education and instruction, but from parental opposition. Part of the duty of the school board, discharged through its officers and employees, is parent communication and counseling. Dr. JK should accordingly inform the parents of what the school board can undertake, and the part of their children's education and socialization for which parents are responsible. Since the school board is non-denominational, it does not instruct students in adherence to particular religiously-inspired values, although it may instruct students in the values of different religious faiths. Parents therefore cannot expect the schools to cater to the moral teachings of their own faiths. School instruction advises abstinence, but also on preventive protection when sexual activity occurs. Instruction should include guidance on minimization of vulnerability to nonconsensual and involuntary sexual intercourse. Dr. JK should emphasize during the discussion with the parents that the provision of information on sexual health can prevent serious consequences of unprotected sex, such as unwanted pregnancy, unsafe abortion and STIs including HIV.

Dr. JK must consider compliance with parents' requests that their children be excused attendance at reproductive health or contraceptive instruction. Compliance may be an option to which Dr. JK succumbs under pressure. However, students' nonparticipation may stigmatize them among their peers, and deny them guidance necessary for their protection and reproductive health and well-being. Accordingly, Dr. JK should advise parents of the hazards of ignorance of sexuality to students' longer-term and more immediate welfare, that denial of appropriate instruction is contrary to educational goals, and that instruction does not exclude or contradict instruction in religious and social values parents teach at home. <u>Case study &</u> Emergency contraception for rape victim and conscientious objection (access to emergency contraception; conscientious objection)

Dr. RM is the only physician serving a remote village. Late on Saturday, the village police officer has brought to Dr. RM's office a young girl aged 13 who the day before had suffered a traumatic, violent assault and been left in a ditch. She is now conscious, and from her missing and torn clothing, bruising and lacerations appears to have been raped. The police officer asks Dr. RM to treat her injuries, and obtain any tissue samples from the assailant, such as semen, for forensic purposes. However, when Dr. RM attempts to retrieve samples the girl resists and cries that she does not want any instruments to be put inside her. She also says that she does not want to become pregnant. Dr. RM has access to emergency (post-coital) contraceptive means, but objects on conscientious grounds to emergency contraception. The girl cannot be referred to reach another practitioner until about noon on Monday, but at considerable cost to the clinic's modest funds she can be transported tomorrow to reach an urban hospital emergency department by Sunday evening.

# Questions

- What ethical dilemmas is Dr. RM facing in this case? How can Dr. RM treat the young victim appropriately?
- What ethical and legal responsibility has Dr. RM towards providing emergency contraception to the young girl?
- What boundaries may Dr. RM have in refusing treatment on the ground of conscientious objection?
- What should Dr. RM do about obtaining forensic evidence from the young victim?

# Responses

The medically indicated treatment for the young girl, who appears, on reasonable grounds, to have been raped, is

emergency contraception. This is available to Dr. RM, but the doctor faces an ethical challenge because of holding a conscientious objection to using it. This may be based on a conviction that emergency contraception is a form of abortion, or that artificial contraception itself is wrong. The former view requires Dr. RM to provide an ethical reason to reject the overwhelming consensus of the gynecological profession that emergency contraception, employed within 72 hours of unprotected intercourse, has its effect before a pregnancy can begin. The latter view, like the former often resting on religious conviction, is not open to biological disproof. Religious conviction warrants respect, but the ethical and legal responsibility of conscientious objectors is to refer patients to care by those not conscientiously opposed to provide it. Dr. RM must therefore resolve the ethical issue of compelling expenditure of the costs of transferring the girl to the urban hospital, and of exposing her to the psychological effects of transportation and prolonged separation from her family. If Dr. RM finds these costs unconscionable to impose, the doctor has an ethical obligation to subordinate personal conscience and treat the girl immediately, by the available means.

The ethical duty of Dr. RM to do no harm, and the ethical right to autonomy that the young girl enjoys, require the doctor to act promptly in order to prevent pregnancy, especially in the case of rape and considering the age of the girl. Dr. RM's conscientious objection creates a conflict of interest in that the doctor's protection of personal conscience may leave the patient at risk of pregnancy, or scarce funds of the clinic may be spent to get her to the urban hospital for treatment Dr. RM's clinic is equipped to provide.

The police demand for forensic evidence may be met by medical collection of tissue from the outer surface of the victim's body, such as skin and hair, but there is usually no power of bodily invasion without the victim's consent or a court order. The young girl in this case may have undetermined capacity to accept medical treatment, but appears capable to refuse unwanted non-therapeutic bodily intrusions, especially into her

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vagina. Accordingly, Dr. RM may lack ethical means fully to comply with the police request. It may appear ethically inappropriate and legally ineffective to threaten the girl with an offence such as obstructing the police in the execution of their duty by withholding consent. If intrusion is essential for the girl's proper care, however, any acquired tissue samples may be preserved for forensic examination.

# <u>Case study 7</u>: Contraceptive Sterilization: counseling and consent (contraceptive sterilization counseling, consent)

JS, who is aged 23 and enjoys normal physical health, has severe expressive aphasia. She cannot communicate her wishes verbally, although she can maintain affectionate personal relationships. She lives with her 58-year old widowed mother, who is fearful that because JS is attractive and attracted to men, she may become pregnant if allowed a social life that includes time alone with men friends. The mother asks Dr. RE to undertake a sterilization procedure on JS, in order to permit her to enjoy a less chaperoned, more normal social life, and suggests hysterectomy to spare JS the inconvenience of menstrual periods. Local law allows contraceptive sterilization "when indicated on health grounds."

### Questions

- How should Dr. RE respond to the mother's request?
- Does the sterilization exceed the guardian's power of authorization in this case?
- Should Dr. RE seek legal help in order to make the ethically and legally acceptable decision? Or with whom should Dr. RE consult in this case?

### Responses

In the Constitution of the World Health Organization, "health" is described as a state of "physical, mental and social well-being." Contraceptive sterilization is not clearly of physical advantage to JS, although she might find pregnancy uncomfortable and temporarily physically constraining. Pregnancy might prejudice her mental well-being, in that she might find the physical effects incomprehensible and stressful. Sterilization might serve her social well-being, however, in that she would be more liberated to spend private time with a man friend of her choice. On these grounds, Dr. RE may consider it ethical to be sympathetic to JS being sterilized. Dr. RE must be cautious, however, because JS's mother, who has requested the procedure and would presumably provide consent for legal purposes, is not necessarily disinterested or concerned only for JS's benefit. Were JS to bear a child, responsibility for its care and rearing might fall on the mother. Her request for hysterectomy may suggest willingness to expose JS to a considerably more invasive procedure than is required for contraception, which intellectually competent women do not seek or agree to undertake for the sake simply of convenience.

In some countries in which women able to express their own wishes have lawful access to sterilization procedures, leading courts of law have considered contraceptive sterilization impermissible to be undertaken on intellectually compromised people on their parents', or other third parties' authorization. As non-therapeutic, usually irreversible and possibly major surgery, it may be found to exceed guardians' powers of authorization. On this basis, Dr. RE may decline to accede to JS's mother's request. If Dr. RE is willing to consider sterilization, it might be on condition that the mother receive judicial agreement, and that the least invasive means be employed. The mother's request for hysterectomy seems to exceed any intervention that is ethically acceptable for sterilization alone.

# <u>**Case study 8: Sexually transmitted infection and confidentiality** *(sexually transmitted infection; confidentiality)*</u>

Dr. DL is the only doctor serving a small suburban community. Dr. DL is treating JT, the 22-year old son of the T. family, for active venereal infection, which JT says he probably contracted in his relationship with an exotic dancer who works in a nightclub in the nearby town. On testing JT, Dr. DL has found no evidence that he has contracted HIV infection. When Dr. DL's patient Mr. MA is in the doctor's office for treatment, he informs Dr. DL that his daughter, aged 17, is to marry JT in two months' time, and asks Dr. DL whether there is any health information about JT, who MA knows is a patient of Dr. DL's, of which his daughter should know.

## Questions

- What is the ethical dilemma in this case?
- What may Dr. DL reply?
- With whom may Dr. DL consult in this case?

### Responses

It may be ethically difficult for Dr. DL to do other than remind Mr. MA that a physician must preserve patient's confidential information, in the same way that Dr. DL cannot discuss Mr. MA's health status with neighbours. It would be problematic for Dr. DL even to say that JT does not carry HIV, the AIDS virus, since this may be taken to mean that he has no transmissible infection. Further, Mr. MA may know that, despite other means of transmission, HIV is a sexually transmitted infection (STI), and realize that, if Dr. DL was testing JT for STI, and stating only one that he does not have, he probably has another. Accordingly, Dr. DL may have to advise Mr. MA that his daughter, like any prospective bride, should ask JT that they exchange health information about themselves.

In exceptional circumstances, however, Dr. DL may be ethically

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justified or excused in breaking JT's confidentiality, but not necessarily to Mr. MA. If his daughter were to ask Dr. DL for a contraceptive prescription, explaining that she and JT are, or are about to become, sexually active with each other, Dr. DL might act defensibly in asking her whether JT has discussed his medical status. Whether or not this degree of disclosure by Dr. DL satisfies ethical standards, courts of law have held that a physician's protection of a vulnerable person at the cost of a patient's confidentiality can be legally excusable, and not cause legal liability.

Accordingly, while Dr. DL may be better advised to reply by maintaining JT's medical confidentiality, especially for fear that people will avoid seeking medical care if confidentiality is violated, there may be exceptional circumstances of significant hazard to a vulnerable person not preventable in any other way that would ethically justify or excuse disclosure, provided that the scope of disclosure was the least that would serve the preventative purpose. Dr. DL may contact JT to remind him of his responsibilities to sexual partners, and to enquire whether he has informed Mr. MA's daughter of his treatment.

# <u>**Case study 9</u>**: **Domestic violence and confidentiality** (domestic violence; confidentiality)</u>

When Dr. CI examined a patient, Mrs. MV, the 27-year old mother of three young children, who had come for gynecological care, Dr. CI found evidence of severe bruising and laceration around her genital area, and observed bruising on other parts of her body. Dr. CI asked if she had suffered violence. Mrs. MV replied that her husband was often forceful, in sexual and other ways, and sometimes punished her for household errors, although he did not beat the children. However, Mrs. MV asked Dr. CI not to inform police or other authorities, because this would make her husband angry. She explained that she and the children depend on her husband for support and shelter, and could not afford for him to be imprisoned or dismissed from his employment as a school teacher.

## Questions

- What ethical dilemmas might Dr. CI face in this case?
- What may Dr. Cl do?
- What advice and information should Dr. CI give to Mrs. MV?

### Responses

Dr. CI must respect Mrs. MV as a mature person and guardian of her children's interests, who can make a better assessment of her own and her family's priorities than Dr. CI can, and accordingly abide by her wishes as fully as possible. Few countries have laws of mandatory reporting of spousal abuse comparable to child abuse reporting laws. Nevertheless, Dr. CI can advise Mrs. MV whether she has access to any domestic abuse counseling services, and, if Dr. CI acquires evidence of escalating violence and fears for Mrs. MV's life, the physician's discretion may arise to notify police authorities for preventative intervention. However, Dr. CI has to consider whether notifying the police might arouse further violence in the future.

Dr. CI may also suggest to Mrs. MV that she and her husband should attend together, or that her husband should visit alone, whether or not he is also Dr. Cl's patient, to discuss anger control and marital violence in their family, or visit a specialist in reduction of domestic violence. The physician's approach would be neither judgmental nor accusatory, but directed to how the husband's conduct endangers the health of Mrs. MV and of the family. Dr. Cl would address the husband as a person in need of care, and of education about alternatives to use of force and violence in his sexual and domestic interactions with his wife. Dr. CI would base the discussion on observations of Mrs. MV's condition, and emphasize the truth that Mrs. MV herself did not complain of abuse, nor raise the issue of her husband's mode of correction or of communication with her. If Dr. Cl is not the husband's physician, Mrs. MV and Dr. Cl together may consider the option to talk to the husband's physician about the circumstances of his violence towards his wife.

Should the husband respond negatively to this approach, denying violence or displaying anger, Dr. CI may inform him of the possibility of police involvement, at the doctor's initiative or otherwise, and of the harm this might do to the husband's career and family. Dr. CI may explain the respect owed Mrs. MV's preference of non-reporting, but that a physician need not remain inactive in the face of a patient's continuing submission to violent assault.

# <u>Case study 10</u>: Maternal refusal of indicated care of fetus on religious grounds (caesarian delivery; maternal-fetal conflict)

Treating Mrs. TP for complications late in her pregnancy, Dr. RR diagnoses placenta previa and concludes that, by following Mrs. TP's intention of natural delivery, the fetus would not be born alive and the life of Mrs. TP herself would be in serious peril. Mrs. TP rejects the advice of Dr. RR that she delivers by caesarean section, however, stating her religious conviction that, if the diagnosis is correct, the condition will be resolved by divine intervention, and she will safely deliver a healthy baby.

### Questions:

- Can Dr. RR impose caesarean delivery over Mrs. TPs objection?
- Can Dr. RR request a court to authorize caesarean delivery?

#### Responses

Physicians have no authority in ethics or law unilaterally to impose their sense of patient's best interests on their patients. Accordingly, Dr. RR is bound in principle to proceed consistently with Mrs. TP's intentions of natural delivery. Both Mrs. TP and her husband must be advised, as they apparently have been, of the disastrous medical prognosis, emphasizing risks to the survival of the fetus and of Mrs. TP herself, but if, when adequately informed, Mrs. TP rejects that advice, Dr. RR is ethically and legally entitled not to schedule caesarean delivery, but to have preparations ready for a perilous natural delivery.

Despite Mrs. TP's confidence that all will be well, Dr. RR may seek the couple's guidance on resolution of a dilemma that may arise in delivery when the life of the fetus or of Mrs. TP can be saved, but not both. If the couple remain in denial and refuse decision, Dr. RR may inform them of what the priority of rescue would be, and invite their response. Dr. RR might also inform the couple that, under ethical and legal principles applicable to emergencies, if natural delivery proved impossible, the fetus was destined to be stillborn, and the life of Mrs. TP was at grave risk, an unscheduled emergency caesarean section would be undertaken if it appeared the only means to save her.

Dr. RR might be cautious in prognosis, because instances exist in which the prognoses of disaster proved incorrect, and despite courts appointing legal guardians of unborn children, the women have naturally delivered healthy babies. Nevertheless, Dr. RR might review the option, if it is feasible in the circumstances, to go to court for authorization of a scheduled caesarean delivery. International experience of court-ordered caesarean deliveries is mixed at best, and a tragic outcome for child and mother in a notorious leading case in which the court order was identified as a cause of death in the mother's death certificate, should have a chilling effect on court initiatives. However, if Dr. RR pursues this option, action should be in sufficient time to allow both sides to gather relevant evidence, including expert opinions.

# <u>Case study 11</u>: Contraception and STI counseling of abused adolescent (contraception counseling, sexual assault; confidentiality; STI counseling)

YL, aged 18, has come to Dr. NG for contraceptive care and testing of her status for sexually transmitted infections, explaining that her father's friend has been sexually abusing her, including by non-consensual intercourse. She further explains that, when she complained to her parents, they angrily denied the possibility, and accused YL of flirting and being sexually provocative. The family lives in a small community and has few means, so she is not able to leave home and be self-supporting. The community is also religiously devout, so any sexual scandal involving police or other authorities would be very stigmatizing. YL asks that her parents not be informed that she is receiving contraceptive care, because this would confirm their suspicions of her immorality.

### Questions

- What should Dr. NG do? How can Dr. NG assist YL?
- With whom may Dr. NG additionally consult in this case?

### Responses

The confidentiality YL requires is not about abuse by her father's friend, which she has already disclosed to her parents, but about Dr. NG's prescription of contraceptive means. Dr. NG may therefore ask YL if her parents would find her victimization more credible if they learned from the doctor that she was suffering it, and that it was affecting her physical and psychological health. No mention need be made of the prescription, since YL is entitled to confidentiality, but should the parents enquire, Dr. NG would reply that YL had been placed on appropriate medication.

Dr. NG may also have means, in this small community, of speaking to the father's friend, if YL agrees. Without disclosing

the prescription to YL, Dr. NG could approach the friend as him being equivalent to a patient, if not an actual patient of Dr. NG's, with an assurance of his confidentiality. Dr. NG could relate YL's complaint, and ask the friend whether it has any substance, because verification or non-verification of the complaint is required for YL's care. Even if the friend denies the accusation, realization that YL is seeking assistance may deter future occurrences.

A further option, in this religiously devout community, may be for Dr. NG, again with YL's consent, to speak to a minister of the father's friend's religious community. The minister, like a doctor, will be aware of duties of confidentiality. Further, Dr. NG may attribute the complaint about the identified friend to a patient of the doctor's, but not name her. The minister's discussion with the friend might result in him denying the accusation, but also in him being on notice that his abuse has come to significant attention. Further, if Dr. NG or the religious minister left the friend with the belief that YL might become pregnant and that his identification would result from inescapable police-initiated paternity testing, he might become motivated to cease abuse of YL. At a wider level, the doctor may also consider the option to raise awareness, for instance by consulting with other physicians, ministers and other community leaders, about such cases that may occur in their community, without disclosing any particular victim.

## <u>Case study 12</u>: Married woman requests abortion without husband's knowledge (abortion; confidentiality, husband's authorization)

FT, aged 33, married, mother of four healthy children, the youngest ten months old, is again involuntarily pregnant. She thought she was protected against pregnancy by breast feeding. Gestational age is 12 weeks. She requests an abortion clinic to terminate the pregnancy, although because of his religious beliefs, her husband opposes abortion. She asks whether her husband's agreement is necessary in order for her to get an abortion, and is correctly told that his agreement is not required by local law. She is anxious not to stay away from home without informing her husband. Because of a recent history of domestic violence, she fears that he could reach her by force in the clinic and hinder the procedure. Further, she is uncomfortable about abortion since she fears that her husband could divorce her if he becomes aware of the procedure. She is unemployed and hesitates to put at stake the future of her four children.

## Questions

- How should the abortion clinic respond to FT's request?
- What ethical issues does this situation raise?

#### Responses

This situation raises ethical issues of patient autonomy and confidentiality, of husband's rights and duties, and of protection of dependent children. Within any limits of local law, the clinic is ethically entitled to accept this woman as a patient for abortion, on the basis of her own informed consent and the well-being of her dependent children. The ethical challenge concerns her confidentiality and her husband's claim to be consulted, and not to be deceived. It is unclear whether he is aware of his wife's pregnancy.

If the clinic were to uphold the husband's interest in being

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consulted, on the basis of his fatherhood, it might inform Mrs. FT so that she will be aware that the clinic will comply with his veto of the procedure. She can then withdraw from this clinic's care and ethically require that her husband not be informed of her abortion request, because of his record of violence and the threat of divorce.

If the clinic decides to accept Mrs. FT's request to terminate her pregnancy, the issue arises of disclosure to the husband. The clinic has no ethical duty to enforce or monitor ethical duties that patients may owe their partners, but Mrs. FT will probably be unable to have the procedure without her husband becoming aware of her attendance at the clinic. An option is to inform Mr. FB that his wife requires gynecological care, without disclosure of abortion. If he is unaware of the pregnancy, he need not be informed of it. Incomplete disclosure may satisfy ethical duties of truth-telling, and does not necessarily violate ethical principles against deception. If he knows of the pregnancy, however, the clinic staff must address whether non-disclosure of its deliberate termination and his supposition of spontaneous miscarriage is ethically justifiable. Beneficence would justify non-disclosure if it would cause him distress on religious or familial grounds. Non-maleficence would also justify non-disclosure if he would be aggressive to intervene in a surgical procedure, violent towards Mrs. FT, or harmful to his children by initiating divorce.

Accordingly, the husband may be appropriately informed of the miscarriage, but not that it was induced. If he enquires whether induced abortion has been requested or performed, the ethical benefit-to-risk assessment, particularly directed to his disposition to react with force or violence, may justify a nonexplicit reply.

The response assumes that Mrs. FT will probably be unable to have the procedure without her husband becoming aware.

## <u>**Case study 13</u>**: **Maternal-fetal conflict and caesarean delivery** (emergency obstetric services: caesarean delivery; maternal-fetal conflict)</u>

KB is in labour in the delivery room, with a cervical dilatation of 3-cm. The fetal membranes are ruptured and amniotic fluid appears to be tinged with thick meconium. Fetal heart rate monitoring displays recurrent, deep decelerations suggesting umbilical cord compression and fetal asphyxia. A caesarean delivery is decided upon. However, KB herself and KB's husband who is present in the labour room, refuse caesarean section. They argue that culturally a woman has to deliver naturally, from below, and that any caesarean scar on the abdomen would endanger KB's safety if she returns to her country of origin, where access to caesarean section is scarce. The attorney has been called by phone. The local legislation does not usually allow a woman to be forced by law to have surgery. The attorney confirms that any medical decision, emergency caesarean section or not, will be legally approved, because local law does not govern emergency cases. Technically, it is possible to inject an anesthetic to KB and then proceed to caesarean section.

## Questions

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- What should the physician responsible for KB's care do?
- What ethical issues arise in this case?

### Responses

In ethics as in law in this case, it must be remembered that KB is the patient, not her husband. His role, if needed, is only to provide information of what she wishes or, if her wishes are not known, to assist in, but not necessarily decide, in determination of her best interests. It must also be remembered that the fetus, though of great concern, does not have a moral status, even if it is viable, that supersedes the patient's right to be treated according to her wishes or interests. The fetus is not a true patient in ethics or usually in law, but a "patient" only by analogy. In this case, it appears that the circumstances of time do not allow resort to a court of law to decide on a court-ordered caesarean delivery.

KB is in labour, but capable of forming and expressing her wish, which is not to be delivered by caesarean section. This decision may not be fully informed of its impact on fetal viability or health, but ethically, this is an insufficient basis to require that it be disregarded. If time allows, KB may be again informed that her fetus is in peril, and may be saved death or serious injury only by caesarean delivery. However, if she still refuses consent, the peril to the fetus may have to remain. Injection of anesthetic and undertaking surgery without consent would be a grave assault on KB. Accordingly, accepting her refusal of this intervention is ethically justifiable, and consistent with local legislation.

The attorney has advised, however, that an anesthetic-assisted caesarean procedure will be approved, presumably on the reasonable speculation that a court would find it an excusable emergency intervention. The legal defence of a charge of surgical assault rests on necessity. This is usually necessity to save the life or health of the patient, but a claim to avoid preventable loss of viable fetal life may be judicially allowed, according to the ethics of professional obstetric practice. Further, although ethics usually requires compliance with the law, liability for breach of the law may be minimal, unless the court decides severely to condemn an apparently paternalistic medical intervention, since parents are not usually significantly compensated for assaults intended to save the lives of their viable fetuses. The likelihood of the couple to return to their country of origin, and for KB to be endangered there, will weigh in the balance, but as an *ex post facto* consideration of an ethically-inspired choice.

<u>Case study 14</u>: Maternal refusal of indicated care of fetus on personal health grounds (HIV positivity: mother-to-child transmission: maternal fetal conflict)

SM is HIV positive. She is four months pregnant. Her immunity status is satisfactory, with a viral load of 2000 copies/ml. She does not need anti-HIV treatment for her own condition. She is informed that, in order to prevent mother-to-child transmission (MTCT) of the virus, antiretroviral treatment is advised during the third trimester of pregnancy. She refuses any treatment, on the grounds that she does not like to take medications, and that she might later develop resistance to drugs that will eventually be of vital need for herself in the future.

### Questions

- What should SM's physician say to her?
- Is SM's self-interest of greater concern than the risks for her child?
- Is it possible for SM's physician to compel her to comply with treatment, and if so, how?

#### Responses

Patients' ethical rights to self-determination over their own bodies, including when they are pregnant, usually prevail over their ethical duties to protect others, including unborn children. Accordingly, SM's health service providers have no ethical claims by themselves to compel her to take medications she does not want to take. They might make her future care dependent on her taking antiretroviral medication, but cannot withdraw from her care without due notice and arranging transfer of her care to other competent practitioners to whom she has reasonable access. SM has been counseled about implications of refusal of medication for the health and longer survival of her fetus, but her fear of developing resistance to drugs that become vital to her own care is ethically relevant. The ethical principle of respect for persons requires that she not be treated as selfish or indifferent to welfare of her fetus or born child.

The only means to force SM to be medicated is by judicial order. Courts have legal power, including by punitive means such as involuntary detention, to compel people to act against their will, and even against their best health interests, but it is not always ethical to ask courts to do so, or for courts to apply the full legal power they possess. If a clinic or health service provider wants to impose its will by obtaining the reinforcement of court order, the ethical principle of respect requires that prospective patients should be informed in advance, so that they can seek care by alternative facilities or providers. It is an ethical challenge of clinical practice that patients may make decisions of which their service providers disapprove. Courts of law have observed that providers unwilling to allow this should transfer patient care, or not undertake clinical practice. <u>Case study 15</u>: Sepsis and incomplete abortion in adolescent, where parental consent required for abortion (emergency obstetric services: post-abortion care; adolescent: parental authorization)

A 17-year old young woman is brought to the emergency room with a septic abortion. She is living separately from her parents, from whom she is estranged and who live in a distant town. Local law requires parental consent if there is an abortion in a minor. The patient is septic, blood pressure is stable, and antibiotics are started. The patient does not want her parents informed, but the practitioner is concerned about legal consequences if the patient is treated without parental consent.

#### Questions

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- What should this practitioner do?
- How should the principle of double effect be considered in this case?
- How should parental rights and the evolving capacity of the child be balanced?

## Responses

The practitioner's concern with legal liability is understandable, but ethically, first priority must be given to appropriate care of patients. If completion of termination is a medically indicated treatment for the emergency of septic abortion, it will be ethically appropriate to characterize the minor patient as having emergency care rather than scheduled abortion. Under the philosophical principle of Double Effect, the patient is treated for sepsis rather than for abortion. Although local law requires parental consent to treatment, this law will govern only elective treatment. Parents have legal power over their minor children for the purpose of discharge of their duties. Parents have no legal power or ethical entitlement to deny or obstruct emergency care for their minor children, but are under ethical and legal duties to provide, or to consent to, their children's medically-indicated care, particularly if they know of its emergency nature.

In this case, the parents do not know, and do not have to be informed for provision of emergency treatment. That is, the law does not require the minor to forgo medically-indicated emergency care until her parents consent.

The local law is also subject to international human rights law by which the country binds itself. The International Covenant on the Rights of the Child, now accepted by all countries of the world, except the USA and Somalia, governs care of all human beings under 18 years of age. This respects parental rights, but subject to the evolving capacities of the child. The 17-year old in this case is living independently in a different town from her parents, and apparently has capacity to make her own medical care decisions. There is a low threshold of capacity to consent to medically appropriate emergency care. Accordingly, it is ethical for the practitioner to treat her as able to exercise autonomy over both her care, and her confidentiality. The greater ethical challenge the practitioner faces would be establishing grounds for refusing care, or to violate her confidentiality, since exposing the patient to medical neglect or to intrusion by her estranged parents would not seem to serve her interests. If there is evidence of the patient being sexually abused, this may ethically justify informing local police or welfare agencies rather than her distant parents.

# <u>**Case study 16</u>**: **Abortion in case of alleged rape** (sexual violence (violence, sexual assault); abortion)</u>

Dr. AB is on call in the hospital gynecology department and is required to examine Ms S who complains that four days ago she was sexually assaulted. She says that a boyfriend raped her and that she wants to avoid pregnancy because she is not ready to bear its consequences. The local law permits abortion in the case of rape, when a complaint is filed with the police, and they conclude their inquiries into the circumstances. Ms S says the boyfriend has falsely denied having sexual intercourse with her, and Dr. AB knows police and forensic inquiries are often prolonged.

#### Questions

- What are Dr. AB's ethical obligations to Ms S in light of knowledge that abortion is better undertaken earlier rather than later in gestation, and that means of pregnancy prevention by emergency contraception are not available?
- What should Dr. AB do?

#### Responses

Dr. AB faces a conflict of commitment, being bound by ethical duties to Ms S and to the local law. Physicians' first duties, however, are to patients' maximum health protection, and laws are not intended, and ethically should not be applied, to obstruct emergency medical care. Emergency contraception is not available in this case, but if intercourse was recent, Dr. AB may provide dilation and curettage (D&C) to empty the uterus in order to reduce risk of venereal infection and to prevent commencement of pregnancy.

Local law may regard the emergency care indicated for Ms S as abortion, and permit this procedure only on complaint to the police and their satisfaction that rape occurred. However, Dr. AB may ethically treat the patient as appropriate, and inform the police later. The law permits abortion only on police satisfaction of rape in order to guard against access to abortion based on false accusations, but is dysfunctional in delaying and perhaps frustrating recourse to the procedure, and is demeaning to women in treating them as likely to be deceptive. If women should actually make false accusations, they are liable to other legal sanctions, such as for filing false police reports and perjury.

Dr. AB, with the patient's consent, may conduct an invasive forensic procedure on her to acquire and preserve tissue samples liable to show the boyfriend's sexual involvement. This in itself does not prove rape, of course, but may compromise his denial of intercourse, placing the burden of exoneration on him and supporting the patient's lawful entitlement to abortion. Dr. AB's refusal to provide Ms S with prompt and appropriate care would be ethical if the local law has been judicially ruled not to expose her to cruel and inhuman treatment.

# <u>Case study 17</u>: Emergency care of woman with apparent illegal abortion (emergency obstetric services; post-abortion care)

Mrs. A, a 25-year old mother of two children, is brought into the hospital emergency room suffering from bleeding from the vagina. On examination, she is diagnosed as having incomplete abortion. On questioning, Mrs. A stated that the pregnancy was not wanted, but she did not admit that abortion was induced. Abortion is legally restricted in the country to conditions in which the life of the woman is endangered. Dr. XY is brought in to care for Mrs. A. Two months earlier, another doctor was suspended from practice at that hospital and threatened with prosecution for performing elective abortions.

## Questions

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- How may Dr. XY ethically provide care for Mrs. A.?
- Can Dr. XY deny the provision of medical care in this situation?
- Why may Mrs. A's case be considered differently from the provision of elective abortion in the other doctor's case?

## Responses

The central ethical responsibility that Dr. XY bears to Mrs. A is to treat her presenting condition by medically appropriate means in a professionally non-judgmental manner. Mrs. A's symptoms should be recorded, without speculation as to their cause being induced or spontaneous, and if the appropriate treatment is completion of uterine evacuation, this should be undertaken. Since the medical record will show that on emergency admission Mrs. A had already begun to miscarry, Dr. XY has no reason to fear legal liability for violation of the restrictive law on abortion. However, if the atmosphere in the hospital is oppressive or sensitive regarding abortion-related procedures, Dr. XY may ask another physician bound by the principle of confidentiality to confirm Dr. XY's diagnosis of incomplete abortion. Since Mrs. A has disclosed that her pregnancy was unwanted, Dr. XY should also enquire about her contraceptive practice, and advise appropriate contraceptive or other means to reduce risks of repetition. If Mrs. A is not in a stable relationship and has several sexual partners, Dr. XY may also address reduction of risk of contracting sexually transmitted infections.

An ethical concern arises if local law requires reporting to police or comparable authorities of illegal or suspected illegal abortion. Some physicians consider that such laws displace their ethical judgment and their duty of confidentiality, and that they must comply with the law. Others find that suspicion of illegality falls outside their role as physicians, and they cannot make determinations of illegality, since any abortion may have been life-saving, such as from the risk of suicide. Yet others find it ethically appropriate to invoke rights of conscientious objection to compliance with a law that compels violation of physicians' ethical duties of confidentiality. However Dr. XY would respond to a mandatory reporting law, the doctor's first ethical duty is to treat Mrs. A appropriately according to her presenting symptoms.

# <u>**Case study 18</u>**: **Request for female genital cutting** (female genital cutting - medicalization)</u>

Mrs. BE brings her six-year old daughter to Dr. GH asking that she be safely "circumcised." Mrs. BE explains that she wants the procedure done for fear that the daughter will not be eligible for marriage in the rather isolated community where the family lives if it is not done, and for fear that her daughter will be considered negatively by members of her wider family and by her young peers. The mother further explains that she wants Dr. GH to undertake the procedure because such procedures performed on her two older daughters by a traditional birth attendant resulted in their severe bleeding and infection. Mrs. BE adds that, unless Dr. GH performs the procedure, her mother-in-law, who lives with the family, will insist on undertaking the procedure herself by customary means, or on taking the daughter to a traditional birth attendant. There are no legal prohibitions in the jurisdiction that ban the practice.

## Questions

- What should Dr. GH do?
- What ethical issues should Dr. GH consider?
- What additional ethical responsibilities may Dr. GH have towards the community that performs such procedures on young girls?

## Responses

Dr. GH has the ethical choice to decline to undertake female genital cutting (FGC) on the ground that it is not a medicallyindicated procedure and does not relieve or prevent a pathological condition, or to undertake it to a minimal degree, such as by a minor token genital cut. Dr. GH should refuse major removal of genitalia for infibulation, and anything more than a minor cut, on the ground that it is harmful. Dr. GH should also advise Mrs. BE that the procedure is opposed and prohibited by medical professional associations and the World Health Organization, and is a declining cultural custom which is liable to be unrequired by the time of the daughter's marriage, although, depending on local practice, this may be no more than ten years ahead.

Beyond the physician's ethical response to Mrs. BE's request are wider ethical powers and responsibilities. One is to educate local communities on dangers of this practice and that, while perhaps deeply ingrained in some cultures, FGC responds to no religious mandate or sacred text. (In this regard as well as the medical, it differs from male circumcision). Dr. GH may also consult with local traditional birth attendants on the hazards of FGC, and on their general duties and means, in all that they undertake, to maintain sterile practice.

Both in countries where FGC has been traditional, and in other countries that have immigrant families or communities from the former, medical associations and/or medical licensing authorities have condemned performance of FGC as professional misconduct. If Dr. GH is subject to such a ruling, it will be unethical to undertake the procedure, even though there may be no legal prohibition. Professional bodies may characterize FGC as physically harmful and socially demeaning to women, designed to control or contain their sexuality. Moreover, several medical associations have directed that it should not be medicalized, since it associates the medical profession with harmful, cruel and oppressive practices. Dr. GH, however, if not legally bound by a professional prohibition, will have to consider whether professional conduct of a minimal procedure may ethically be the lesser of two evils, knowing that it is a non-therapeutic procedure widely condemned as a human rights offence.

## <u>Case study 19</u>: Reproductive health services in affluent and impoverished settings: Cross-subsidization (abortion; obstetric fistula; caesarian section)

Dr. LM operates gynecology and obstetric clinics in a large city divided between wealthy and impoverished communities in a country where the government provides no financial support for private health services, but runs an overcrowded public general hospital. Women in the poor community tend to be married at a young age and lack general obstetric care. They suffer a high rate of obstetric fistula, which has a devastating effect on their lives if not treated promptly. Dr. LM provides prompt fistula repair in a clinic in a poor district at low or no charge, by providing services to paying patients in a clinic in an affluent part of the city. These services are primarily purely elective caesarean deliveries and gynecological examinations that cause miscarriages, although local law prohibits abortion that is not necessary to preserve a woman's life or physical health. Community leaders including physicians have recently protested that elective caesarean deliveries are bad medicine, as unnatural, and that legally disguised abortions offend religious and medical professional values.

## Questions

- Should Dr. LM continue to cross-subsidize fistula repair services by these elective procedures?
- What ethical principles should be considered in this case?

## Responses

The ethical claim in favor of continuation of Dr. LM's two practices is that they do not simply provide services to the affluent in order to cross-subsidize services to the poor, but that they provide essential services to patients whose family and social lives would otherwise be devastated, by providing services to patients who would otherwise purchase them elsewhere. This is a pragmatic or utilitarian claim, that discontinuation of the two clinics would at most slightly inconvenience affluent women's resort to cosmetic or lifestyleenhancing caesarean procedures or to abortions, while leaving poor women to be cast out by their husbands' families and communities to the despair of isolation, infection and hopelessness.

High rates of obstetric fistula affect primarily women who suffer the multiple disadvantages of being young, poor, often malnourished, pregnant while underdeveloped for childbirth, and at risk of prolonged obstructed labour because they lack medical assistance. Dr. LM may claim that provision of otherwise unavailable care to these women is ethically defensible by cross-subsidization of services.

The ethical claim that Dr. I M should close the clinic in the affluent area does not deny the virtue of treating the poor, but rests on the principled belief some hold that good cannot properly come from wrongdoing, and that the services of the affluent clinic are inherently or functionally wrong. Elective caesarean deliveries are sometimes condemned as a misuse or abuse of medicine, and conducting medically contrived abortions that are unnecessary to preserve women's lives or health is a violation of human dignity and an abuse of unborn human life. Dr. LM should pursue virtuous means to achieve fistula repair services, such as by campaigning for pubic funding of services and seeking support from benevolent and charitable agencies. Dr. LM may also call upon the altruism of physicians anxious to maintain the good name and virtue of the profession, to mobilize fistula repair services for the poor and exhibit the self-sacrifice that in classical culture has distinguished the learned professions from self-serving trades and commerce.

# <u>**Case study 20</u></u>: <b>Sex Selection and pre-natal diagnosis** (sex selection; pre natal diagnosis)</u>

Mrs. SA, a 36-year old mother of three healthy boys, comes to Dr. CL explaining that, following a torn condom, she thinks she is now about 10 weeks pregnant. Local law allows abortion on request up to 12 weeks' gestation, and up to 20 weeks' on medical grounds, which Mrs. SA's medical history shows she satisfies. Local law prohibits pre-natal sex determination except for a sex-linked genetic disorder. Mrs. SA says that she wants her pregnancy terminated unless the embryo/fetus is shown to be female.

#### Questions

- What should Dr. CL advise?
- What ethical issues should be considered?

#### Responses

Laws have been enacted to prohibit pre-natal sex determination due to the offensiveness of sex-based abortion, and the belief that sex selection would be employed primarily against female fetuses. This would constitute and perpetuate discrimination against girl children and the cultural devaluation of women. There are cultures and countries in which this belief appears well founded. The ethical challenge Dr. CL faces is the paradox that, in several legal systems, early abortion is lawful on request without providing reasons, but obstructed when the reason concerns embryonic or fetal sex. Accordingly, Dr. CL may inform Mrs. SA that she may terminate her pregnancy, providing no reason if it is of up to 12 weeks of gestation, and up to 20 weeks on medical grounds, but that sex determination cannot be undertaken to afford her the option of continuing the pregnancy.

Dr. CL might have no honest reason, based for instance on family history, to claim fear of a sex-linked genetic disorder.

Further, if such a reason appeared credible, Dr. CL would not necessarily be able to disclose the fetal sex to Mrs. SA. The doctor would report that the genetic condition that justified the test had or had not been found. If the condition was sex-linked and had been found, that would disclose the sex, but if it had not been found, either because the fetus was not of the relevant sex or because it was of that sex but unaffected or only a carrier of the gene, only the negative test result would be properly provided.

Alternatively, Dr. CL could undertake pre-natal sex determination for Mrs. SA's information, claiming that the law is directed against preparation for sex-based abortion, not for sexbased continuation of otherwise lawfully terminable pregnancy. Dr. CL might be advised to consult with legal and police authorities, or at least a medical association or licensing authority, before undertaking pre-natal testing under this claim.

# <u>Case study 21</u>: IVF (*in vitro* fertilization) in a polygamous cultural setting (*IVF*; polygamous cultural setting)

A couple was seen in the infertility clinic, and the diagnosis was of severe incapacity of sperm (oligozoospermia). The couple was referred for intracytoplasmic sperm injection (ICSI) treatment. The man was recognized by the nursing staff as having recently had treatment with another woman, which had been successful. It was clear that he had two wives. The situation was discussed with the man alone, and then with the woman who was now requesting treatment.

The man readily admitted that he had two wives, and that polygamy was allowed by local law and within his culture and religion. The previously treated wife was his "love" relationship, and the present woman was his wife in an earlier arranged marriage. He spent most of his time in the "love" relationship, but cared for his first wife, and supported her financially. Because of the importance to the first wife of having children, he wanted to give her a child. The wife has an extended family and support locally. The second, love wife, who lives in another city, has no family living in the country. The first wife says that she is aware of the man's "love" relationship in his second marriage. Local law permits IVF for married and cohabiting couples.

## Questions

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- Should the clinic treat this couple?
- Should the clinic bring all the parties together to find out how they all feel?
- Does the clinic have the right to impose its own cultural views on others?

## Responses

The ethical principle of respect for persons requires that the preference of this man, who the clinic has already accepted

as a patient, be regarded with respect. Similarly, his first wife, who knows of his "love" relationship, should be regarded in the same way. The clinic might be concerned about whether his second wife knows of his first wife, and his intention to have a child with her, since the love partner has also been the clinic's patient.

The ethical duties to protect the vulnerable and to do no harm concern the existing and prospective children. The clinic has no ethical claim to interfere with the first wife's right, protected under international human rights law, to marry and found a family, although the husband has no such right to found two families at the same time. The first wife's child would fit within an extended family, but the clinic may be concerned that a second child may be preferred to the first, especially if local culture and inheritance law favour sons over daughters and the love partner's child is a daughter. That is, for the clinic to aid birth of the second child may not be in the best interests of the first child the clinic assisted to be born.

The clinic may not be entitled to act paternalistically by insisting that all parties be brought together, since, were the man and his first wife able to conceive a child naturally, the clinic would have no power of intervention, and should not impose its preference because of the couple's reproductive disability, and related dependency. However, if the clinic accepts this wife as a patient and she delivers a child of the other sex than the love partner's child, the clinic might advise that the children be informed, at an appropriate age, of their kinship, in case they should meet later in life and consider marriage. Since the two women live in different cities, the clinic may judge such counseling unnecessary.

If the clinic is publicly funded and has assisted the man to have a child, the justice principle may require that other childless couples be accepted as a priority. The first wife's claim to assistance should not be prejudiced, however, by aid afforded the love partner, since she is equally entitled to pubic resources where local culture allows polygamy. Accordingly, the clinic would be ethically entitled to treat the man and his first wife. The clinic might also be entitled, however, to advise due counseling of the love partner and of resulting children if they are of opposite sexes.

# <u>**Case study 22</u>: IVF and possible risk of genetic disease** (*IVF; refusal of diagnostic testing*)</u>

A couple attended a fertility clinic wishing to conceive a child, and needed IVF treatment. In the female history, the woman reported that her father had Huntington's chorea, an autosomal dominant condition which presents in the fourth decade of life, and leads to dementia and an early death. The woman was in her early 30's. She had chosen not to be tested for the condition (she has a 50% risk of having it), as to find out that she has the condition would be psychologically too much to bear, and has implications for insurance purposes.

## Questions

- Should the clinic treat this couple?
- How should the ethical principles of parental autonomy be considered in the context of beneficence and nonmaleficence?

#### Responses

The ethical issues concern the autonomy of the couple and the balance between the duties to do good (beneficence) and to do no harm (non-maleficence). The couple's autonomy is served by counseling them on the implications they must consider of the wife's unfortunate but real (50%) chance of disability and premature death, leaving the husband to bring up a child, and the chance of the child's inheritance of the mother's condition if it is present. If means of local genetic diagnosis exist, the woman may be able to produce several ova for IVF and creation of early embryos that can be screened by preimplantation genetic diagnosis (PGD). Then, only unaffected embryos would be transferred for gestation *in utero*. The use of this means to produce a healthy child or children might make clear, however, contrary to the woman's choice, whether or not she has inherited Huntingdon's chorea.

Accordingly, the clinic has the ethical choice to treat this

couple, and might act unethically in rejecting them by discriminating against them on grounds of the mother's possible disability, and by acting paternalistically by considering it preferable that they not have a child. However, acceptance of the couple for treatment would require that they be genetically counseled, and that the mother's status would probably become known by PGD of her embryos. The chance of an unscreened embryo resulting in birth of an affected child is not an ethical barrier to care, since young children are not usually to be genetically tested for risk of late-onset disorders.

# <u>**Case study 23**</u>: Wrong embryos transferred in IVF (*IVF*; access to care; embryo transfer)

A couple was being treated in the fertility clinic and underwent IVF treatment. As soon as the embryos had been transferred, the embryologist realized that the embryos belonged to another couple. The embryologists informed the clinical director, who immediately consulted both couples. One couple (the genetic parents of the embryos which were transferred) wanted the embryos to be allowed the opportunity to implant, and if the pregnancy was successful, for the baby or babies to be passed back to them. The woman who had the embryos replaced inside her was adamant that she wanted the treatment cycle aborted immediately.

## Questions

- Whose wishes are paramount?
- How should the principles of autonomy, non-maleficence and beneficence be balanced in this case?
- How might the local law that allows therapeutic abortion be relevant in this case?
- What should the clinic do by way of remedy?

## Responses

Although the ethical duties to do no harm (non-maleficence) and to do good (beneficence) are involved, the key ethical issue is the clash of autonomy between the couple whose embryos were incorrectly transferred and the woman in whom they were placed. The embryos might be removed by a procedure such as uterine lavage, but this would result in their loss, since they could not be transferred to the woman for whom they were intended due to risks of viral transmission. Even if she was willing to accept this risk, the clinic should refuse under the principle to risk no harm.

It is understandable that the genetic parents do not want their

embryos lost, but they have no ethical claim to insist that the recipient woman serve their interests by continuing the pregnancy as a surrogate mother for them. She should be counseled about the advantages both to the other couple and to herself of continuation of pregnancy, and the implications of surrendering the child(ren) at birth and of retention, in the latter case with the chance of the genetic parents taking legal proceedings for custody of their genetic child(ren).

A concern for the clinic is whether local law would allow preimplantation removal of the embryos, such as by lavage. Medically, pregnancy commences at completion of implantation, so that preimplantation removal is not abortion, but local abortion law might regard removal as termination of pregnancy. If removal were legally considered nontherapeutic, since the recipient woman faced no unusual medical risks, and pregnancy became established and resulted in childbirth, the gestating couple might have the legal option of surrender of the child(ren) to the genetic parents, or of retention but subject to the outcome of the genetic parents' legal challenge for custody. A conservative law that severely limited rights of termination of pregnancy might also regard a gestating woman as the mother, so that, if she refused surrender of the child(ren) for adoption by the genetic parents, she could retain custody. The clinic will have to decide whether these considerations are part of its ethical responsibility, or its concern.

## Case study 24: IVF and pregnancy risks (IVF; denial of treatment)

A woman with a previous renal transplant and hypertension was trying for a baby. She had been told that getting pregnant would put her health at risk, (including risking the transplanted kidney – a 25% risk) and that she was at risk for severe pregnancy complications such as preeclampsia at an early stage of the pregnancy, even before fetal viability (40% risk). Nevertheless, the couple was keen to try for a baby, and had been trying naturally for three years. She now applied to a fertility clinic, and was told that she would need IVF. However, the clinic was not keen to support her decision, because of the significant risks to the patient's health. Surrogacy was discussed, but was not acceptable to the couple. In addition, finding a surrogate host was thought to be too difficult.

If the couple had succeeded in having a baby spontaneously, then the obstetric services would have managed as best they could.

## Questions

- Now that the couple needs assisted conception, should this option be denied them, especially as they are fully aware of the risks?
- How shall patient autonomy be considered in the context of the ethical principle of 'Do No Harm'?

## Responses

Patients' willingness to consent to accept risks is a necessary but not alone a sufficient ethical condition to creating them. The clinic may invoke the Do No Harm principle to justify not participating further in this couple's try to achieve pregnancy by IVF. A high-risk pregnancy would be liable to impose burdens on other agencies, including possibly those with many public responsibilities and scarce resources. Imposition of this burden might violate the ethical principle of justice, since those subjected to the burden would not be party to the decision from which it resulted. Further, the clinic itself might be under such pressure of high demand for its limited services that their expenditure to create a high-risk pregnancy would be disproportionate.

The clinic management must be forthcoming and transparent in decision-making, in order to show that there is no discrimination against this couple on grounds of the woman's physical disability. The clinic might also be faced with ethical accountability for taking fees from this desperate, vulnerable couple to undertake procedures that expose the woman to serious health risks, and embryo loss or damage, as well as exposing a new-born to compromised health. Nevertheless, on grounds of social justice, a clinic should not be condemned for undertaking to assist hard-to-treat patients.

Clinics may legally and ethically decline to initiate procedures that they consider would unduly jeopardize the health of even consenting patients, and clinics undertaking reproductive techniques are also entitled, if not positively required, to consider the reasonably foreseeable health risks to prospective children. This clinic is entitled, but not required, to consider the risks of pregnancy in this case to be disproportionate.

# <u>Case study 25</u>: Surrogate Motherhood Counseling (surrogate motherhood counseling)

Mrs. NP, aged 39, her husband of two years Mr. OP, and RS, aged 21, Mrs. NP's unmarried daughter by her first marriage, came to the Citycentre IVF clinic. Mrs. NP explained that she and Mr. OP propose to provide ova and sperm for IVF and, because Mrs. NP cannot carry a pregnancy for medical reasons, RS will be a surrogate mother for them to gestate the embryo(s). Local law allows surrogate motherhood provided that surrogates are at least 20 years old, act voluntarily, and are unpaid except for reimbursement of expenses actually incurred. When interviewed privately, RS explained that she wants her mother and Mr. OP to have a child to ensure that they stay together, and that her pregnancy will be inexpensive because she is living with Mrs. NP and Mr. OP while completing the final year of her college program.

## Questions

- Should the Citycentre IVF clinic implement this proposal?
- Can the decision of RS be seen as a free choice based on adequate information? What should the clinic do in this regard?

## Responses

Ethical challenges concern whether RS is exercising adequately informed and free choice, and whether her living arrangements at home conform to the legal prohibition of reward payment. RS appears reasonably motivated to assist her mother and stepfather, but may have no experience in being pregnant and of the natural hazards of this condition, particularly if she lives in a region favoured by low rates of maternal mortality and morbidity. RS's free consent raises the concern that she may be motivated less by an altruistic commitment to her mother's and step-father's happiness than by her own and her mother's desperate fear that the mother's marriage is unstable. A child may be seen as a bargaining or ransom object to deter the new husband's departure.

Although RS may receive no more than her usual allowance for college expenses, or earn her own income by vacation, weekend or evening employment, the shelter and maintenance she receives at home may be seen as payment in kind. Since she receives no more than she otherwise would, however, subject to any costs she incurs for maternity clothing and nutritional supplements, fear of the arrangement violating legal provisions, which prohibit financial and similar rewards being offered as inducements to gestational mothers, may appear minimal.

The clinic should pay attention ethically to whether RS is genuinely volunteering, or whether she is being pressured or conditioned at home to agree to the proposal to a degree that violates genuine consent. Further, all three parties should be counseled regarding how family dynamics can deteriorate, and on the implications for a child. RS may be willing to gestate her half-brother or sister, but the child may be confused whether RS is its half-sister or mother, and whether Mrs. NP is its mother or grandmother. If counseling indicates that these relational concerns can be managed, such as RS not becoming possessive of the child or unduly intrusive in NP and OP rearing the child, the clinic may proceed. Empirical data increasingly suggest that such arrangements can prove satisfactory, and the children unexceptional.

# <u>Case study 26</u>: Request to implant multiple embryos (embryo transfer)

The IVF clinic of the hospital treating Mr. and Mrs. W produced nine embryos fit to transfer to Mrs. W. Two were transferred in each of two cycles of treatment, without success. The couple now says that they can afford only one more treatment cycle, and propose that the remaining five embryos all be transferred at that time. They say that if multiple pregnancy results, they will have fetal reduction to a singleton pregnancy. Local law allows a doctor to "procure a miscarriage" (meaning to terminate a pregnancy) only on therapeutic grounds.

## Questions

- Should the clinic agree to implement this proposal?
- Does the clinic have an ethically compelling ground to justify compliance with Mr. and Mrs. W's proposal?

## Responses

Multiple pregnancy resulting from medically assisted reproduction (MAR) is increasingly considered a failure or dysfunction of MAR rather than a success. Transferring more than two or exceptionally three IVF embryos to a woman in the same cycle is considered clinically inappropriate. Accordingly, the clinic will need ethically compelling grounds to justify compliance with Mr. and Mrs. W's proposal. The clinic may refuse the proposal on the ground that transferring more than two or three embryos is bad medicine, and perhaps professional misconduct. Reliance on fetal reduction to ensure no more than a singleton or at most a twin birth may resolve the numerical concern, but the sacrifice of embryonic or fetal life that is considered "surplus" may be considered disrespectful of human life and ethically offensive, even if lawful according to some approaches.

Compliance with the couple's request may be ethically proposed on the grounds of their autonomy, and the good of maximizing their last opportunity to have a child. The clinic's production of nine embryos indicates that the couple and the clinic are tolerant of embryonic wastage, since, had Mrs. W. conceived in the first or second cycle of treatment, surplus embryos would have remained for potential wastage. Significant rates of embryonic and fetal loss occur in nature, and the couple's proposal is to do on purpose and under control what nature does by chance.

Whether fetal reduction complies with the law on abortion is legally and ethically problematic. The law probably has historical roots established before a fetus could be deliberately "reduced" without ending the pregnancy. A fetus may now be induced to miscarry, but because multiple pregnancy may be harmful to the health of the pregnant woman and perhaps of the fetus that will be born alive, if fetal reduction is recognized as abortion it may fall within the therapeutic exception to the general prohibition. If the clinic considers complying with the couple's proposal, it might seek legal advice on the permissibility of fetal reduction. <u>Case study 27</u>: Conscientious objection of pharmacist and access to emergency contraception (access to emergency contraception; conscientious objection of pharmacist)

Dr. GV is medical director of a small hospital whose rape crisis unit is busy. Local law prohibits abortion unless a woman's life is in danger from continuation of pregnancy. However, the national Ministry of Health drug agency has just allowed the use of drugs for emergency contraception (EC). Dr. GV and the unit's medical staff consider themselves professionally bound to offer these, in order to reduce the risk of victims becoming pregnant. The hospital's chief executive officer agrees that the hospital pharmacy should stock the approved drugs. However, the three pharmacists who work at the pharmacy in rotation, providing 24-hour service every day, all claim rights of conscientious objection to supply these drugs, on the ground that they are abortifacient.

## Questions

- Can EC services be denied in a public hospital on the basis of the conscientious objection of pharmacists when the drugs should be lawfully available?
- What can Dr. GV do?

## Responses

Dr. GV has the choice not to address this situation through ethical reasoning and assessments, but to hand it to the hospital's lawyers to pursue in accordance with employment laws and the terms of the pharmacists' contracts of engagement with the hospital. If Dr. GV wants to seek resolution in accordance with ethical reasoning instead of, or before, resort to legal process, however, several approaches are available.

The pharmacists do not hold their positions at the hospital as individuals who know about pharmaceutical products, but as qualified and licensed members of the pharmacists' profession. They would be entitled to invoke their professional code of ethics to decline to follow any of the hospital's instructions that would cause them to violate that code. Accordingly, their professional ethics code or determination process might be consulted on the professional approach to dispensing emergency contraception. If this assesses that the drugs are not abortifacient, or requires that, if patients for whom they are indicated would otherwise be denied timely access, they be dispensed, pharmacists who refuse to dispense them might face unpaid suspension for failing to discharge their professional duties, and be replaced.

The ethical and legal requirement is that health care practitioners who invoke conscientious objection refer patients to nonobjecting colleagues, and alternative pharmacists should be sought. However, if no other pharmacist appears reasonably accessible, a legally available non-pharmacist may be considered. Physicians can lawfully supply patients with products for which prescriptions are required. Although emergency contraception drugs are all of the same dosage, so that a physician's assessment of each patient is not medically required, they remain on prescription to provide counseling before use. In several countries, counseling is provided by pharmacists, but it can be given by physicians. Accordingly, Dr. GV can respect the pharmacists' conscience by locating the stock of emergency contraception drugs not in the hospital pharmacy but in the rape crisis unit, and ensuring their availability there within a physician's clinical judgment of each patient admitted there. Similarly, non-emergency patients may be referred there for EC, and receive EC drugs without being admitted.

## <u>**Case study 28</u>**: **HIV positivity, confidentiality and duties to warn** (*HIV positivity; confidentiality*)</u>

BG, aged 16, has been found HIV-positive at Dr. KD's charitymaintained clinic. She explains that she is the third wife of a husband entitled in their culture to have several wives, and has had sexual intercourse only with him. Dr. KD is aware of the husband's polygamous marriages, and has treated his other two wives, but does not know their HIV status. BG says that her husband is unaware that she has come to Dr. KD's clinic, and would angrily disapprove because she did not seek his prior consent. She therefore asks Dr. KD not to let him know.

## Questions

- Has Dr. KD any ethical duty to notify the husband or his other wives of the presence of HIV infection among them?
- What presumptions may Dr. KD ethically make about the origin of BG's infection?
- What ethical dilemmas may Dr. KD face in this situation?

#### Responses

HIV infection is sexually transmissible but it can also be spread by other means, including accidental or incidental means. Dr. KD therefore has no grounds to believe that BG's husband spread the infection to her. However, in light of BG's diagnosed positive status, she could spread it to him if she did not acquire the infection through him, and perhaps spread it to other household members. If Dr. KD has no means to place BG's husband and household on notice of their exposure to the risk of HIV infection other than by directly or indirectly exposing BG's status and her resort to the clinic, Dr. KD may feel ethically constrained by principles of confidentiality, and not warn them. Dr. KD should inform BG of the risks and implications for others of her status, as the means of alerting the family that are least invasive of her confidentiality. In countries with developed public health infrastructures, public health officers may receive legally mandatory or voluntary reports of HIV positive diagnoses, and notify those found to have been exposed to infection, without disclosing identities of the persons responsible for that exposure. If Dr. KD's clinic is in an area where involvement of such officers is required or possible, notification to them of BG's status seems to discharge the physician's ethical duties to those the patient endangers.

Ethics often requires observance of the law, and leading courts have ruled, for instance in North America, that persons aware of their HIV-positivity have a duty to inform their sexual partners if intercourse could spread infection. They have also ruled that physicians must notify reasonably foreseeable victims of the hazards their patients present, on the ground that patients' confidentiality ends where peril to the public begins. On this ground, Dr. KD may feel ethically if not legally obliged to warn BG's husband and household members that they are at risk of HIV-infection. If Dr. KD is prepared to breach BG's confidentiality in this way, BG should be warned in advance, so that she can consider ending her professional relationship with Dr. KD. As against this, Dr. KD may prefer not to risk BG becoming the victim of her husband's anger and violence towards her. Dr. KD's duty might be complicated if those to whom a warning is owed are also Dr. KD's patients. However, if BG is new to Dr. KD's clinic and has a separate physician, Dr. KD is obliged to inform that physician of BG's diagnosis, and may satisfy responsibilities to members of her household by that means.

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# <u>**Case study 29</u>**: **Sex selection IVF** (*IVF; sex selection; pre-natal diagnosis*)</u>

An infertility clinic is considering whether or not it wants to include sex selection in its offerings. A long debate has been going on between the faculty on the issues of selection of embryos based on genetic characteristics that do not influence the health of the child. One side maintains that all such selection is discrimination and usually against females. The other side maintains that there should be no discrimination if selection is offered only for a second or later child when couples are seeking the sex different from that of the first child or previous children. The other fertility center in town has been offering sex selection without regard to whether there is a first child or "family balancing".

### Questions

- What should this facility do regarding sex selection?
- Are there any other ethical issues the clinic may consider in setting its policy, such as its own commercial viability?

### Responses

A significant volume of ethical literature and discussion characterizes sex selection as invariably unethical, addressing not only abortion of healthy fetuses of the disfavoured sex, but also embryo preimplantation sex diagnosis and wastage of disfavoured embryos, and sperm washing or screening to identify, X- or Y-bearing sperm for creation of sex-predetermined children. Sex selection to detect sex-linked genetic disorders is much less ethically contentious. These tend to affect male embryos and fetuses, but the presumption has been that sex selection is most commonly applied to disfavour female embryos and fetuses, reflecting and perpetuating unethical discrimination against girl children and women.

Where preference for sons is prevalent, such as in China and

India, legislation may prohibit some or all sex selection methods, but without law, ethical perception may justify a clinic's refusal of sex selection because, except for sex-linked genetic disorders, sex selection does not address a pathological or medical condition. A less absolutist approach is exclusion of selection for first children but allowance for second or subsequent children of the other sex than a family has; that is, for "family balancing." Programmes must address their policies regarding collaboration to produce first children for couples whose partners had children in earlier relationships.

Refusal of otherwise lawful sex based abortion, on the ground that sex selection devalues women and girl children, may appear paradoxical in that it compels women to continue pregnancies against their will. This refusal itself may seem to devalue women as decision-makers in their own families. The claim that women are not free decision-makers when they are subject to family oppression not to deliver girl children may be true, but does nothing to relieve that oppression. Further, where women can have resort to abortion regardless of fetal sex, whether safely or unsafely, their willingness to continue pregnancy if fetuses are of a favoured sex shows sex selection as a means to preserve rather than terminate fetal life. These are factors the facility should ethically consider in determining its sex selection policy.

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<u>Case study 30</u>: Intellectually impaired adolescents: Research and contraceptive services (reproductive health research: contraceptive services for intellectually impaired adolescents)

Dr. AF is medical director of a residential home for intellectually impaired adolescent and young women, aged 15 to 25, associated with a small community hospital. Residents have frequent home visits, and Dr. AF is concerned at residents' high pregnancy rates and the resulting medical and social complications. The home has no budget for contraceptive services, and residents usually lack the understanding properly to take contraceptive pills that families sometimes provide. Dr. AF has been approached by a pharmaceutical manufacturer that wants to test an experimental long-acting contraceptive implant against an already marketed implant, and will supply both the experimental and marketed products free of charge for a three-year period.

## Questions

- Should Dr. AF agree to conduct the study at the home?
- How can the best interest of the inmates be ethically balanced in this case?
- Who should be involved in the decision-making procedure?

## Responses

A key ethical principle of research with human subjects is that studies should not be conducted with intellectually impaired persons that could be undertaken with scientific validity on persons who can provide their own competent informed and free consent. If competent persons informed of studies decline to participate, perhaps because of the risks, inconvenience or irrelevance of the proposals, such studies should not be proposed instead for those incapable of making competent decisions for themselves. Since the proposal made to Dr. AF could be undertaken with intellectually competent persons, Dr. AF would be ethically required to reject it.

There may be features in this proposal, however, that are distinctive and ethically significant. Residents of the home tend to be sexually active when away, and have no effective contraception. If the pharmaceutical product has satisfied Phase I (toxicity) tests and Phase II (small scale) tests, so that larger scale Phase III (prospective marketing) testing with sexually active young women is appropriate, it may be ethical to conduct the study at the residential home. Implanted contraceptives are accepted by intellectually competent women, although some lack access to convenient means of removal. Recruited residents will receive either the approved and already marketed implant, or the test implant. Recipients of the test product will not be denied protection they would otherwise have, and recipients of the marketed product will enjoy care indicated for them but which the home cannot afford to provide. That is, some recruits to the study will benefit, and the others will not be prejudiced, and may benefit if the test product exceeds, equals or approaches effectiveness of the marketed product.

Dr. AF may set a condition relevant to resource-poor study populations, that if a product becomes approved for marketing as a result of the residential home hosting a study, the study sponsor will provide the product to the home for a given period at no or affordable cost. This might result in residents of the home enjoying significant contraceptive care.

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## Case study 31: Surplus embryos (embryo research)

Mr. & Mrs. BA were successful in their first cycle of IVF treatment, and have a healthy child. They have now returned to Dr. CD's IVF clinic in a university-affiliated hospital, seeking a second child. In their first treatment, Mr. and Mrs. BA declined the freezing of any surplus embryos, but, with some anxious discussion between themselves under the pressure of having to make a decision quickly, allowed the two fresh surplus embryos resulting from their treatment to be available for embryo research. Dr. CD knows that researchers at the university want fresh healthy embryos for stem cell research and development of cell lines, that the time for couples to decide whether to donate any surplus fresh embryos is short, and that the decision can be emotionally stressful. Dr. CD therefore wants to ask Mr. and Mrs. BA, in advance of initiating any treatment, whether they would agree that, if there are any surplus fresh embryos, they be donated to research. However, the university prohibits the creation of embryos for research purposes.

## Questions

- What should Dr. CD do?
- How can the best interest of Mr. and Mrs. BA be considered in the context of the institution's needs?

## Responses

Dr. CD may appear to be in a conflict of interest, or at least a conflict of commitment, in that the clinic has commitments to patients, such as Mr. and Mrs. BA, but also to supply the university scientific investigators with tissues on which their research depends. The option for resolution of such a conflict is through avoidance or due disclosure. However, avoidance of the appearance of conflict is not possible since, as in the couple's first cycle of treatment, surplus fresh healthy embryos may remain from clinic care that are suitable for research.

Dr. CD does not want to confront the couple again with a sudden stressful choice on donation, but does not want any fresh embryos that opportunistically become surplus to be wasted through natural disintegration when they might represent a valuable resource for research and therapy. However, Dr. CD's first ethical priority is to the well-being of Mr. and Mrs. BA, whose prospects of having a healthy child may be furthered by deliberate creation of more embryos than they will probably require. If their decision on research use of any surplus embryos creates harmful stress for them, they should not be asked to make it, and the research opportunity should be sacrificed. If the surplus embryos are unfit for donation to other couples, or Mr. and Mrs. BA decline consent to donation, the embryos will be left to natural disintegration.

However, Dr. CD might consider the ethics of informing, or reminding, Mr. and Mrs. BA that their future routine IVF treatment might leave surplus fresh embryos, and that, although they will not again be asked the stressful question about donation, they might want to discuss with each other whether, should a surplus remain, they would want voluntarily to offer it for research use. Further, Dr. CD might approach the university administration to present the mode of operation of the IVF clinic, including treatments liable to leave surplus fresh embryos. Dr. CD might seek to establish the university's agreement that, since the surplus is incidental to *bona fide* treatment, it does not constitute the deliberate creation of embryos for research, and so does not violate the university policy.

In support of such a ruling, Dr. CD might open the IVF clinic to independent audit, to show that its record on creating surplus ova is comparable to that of clinics not associated with research units, and that its clinical procedures are not extravagant in IVF embryo creation, resulting in any excessive surplus.

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