

CASEBOOK ON

HUMAN DIGNITY AND HUMAN RIGHTS

1

Casebook Series

**BIOETHICS
CORE
CURRICULUM**



United Nations
Educational, Scientific and
Cultural Organization

Social and Human Sciences Sector
Ethics Education Programme

BIOETHICS
CASEBOOK ON
CORE
HUMAN DIGNITY
CURRICULUM
AND HUMAN RIGHTS



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FOREWORD

The *Framework for Action* of the 1999 *World Conference on Science* in Budapest, under the aegis of UNESCO and the International Council for Science (ICSU), states that ethics and the responsibility of science should be an integral part of the education and training of all scientists, and that they should be encouraged to respect and adhere to basic ethical principles and responsibilities of science. During the 32nd UNESCO General Conference (2003), Member States expressed the need to initiate and support teaching programmes in ethics, not only in bioethics but in all scientific and professional education. In response to these statements, and to *The Teaching of Ethics* (2003) report by UNESCO's *World Commission on the Ethics of Scientific Knowledge and Technology* (COMEST), the Organization launched its Ethics Education Programme (EEP) in 2004 to reinforce and increase the capacities of Member States in the area of ethics education.

A dimension of the EEP is the establishment of the *Advisory Expert Committee on the Teaching of Ethics*, composed of members of COMEST and UNESCO's International Bioethics Committee (IBC), as well as representatives of the UNESCO Chairs in Bioethics, the Academy of Sciences for the Developing World (TWAS) and the World Medical Association (WMA). The first task of this ad-hoc committee was to develop the *UNESCO Bioethics Core Curriculum*, launched in 2008, which sets out to introduce the bioethical principles of the 2005 *Universal Declaration on Bioethics and Human Rights* (hereafter referred to as the Declaration) to university students.

The Declaration embodies a set of bioethical principles that has been agreed upon by the Member States of UNESCO after an intense elaboration and consultation process involving independent and governmental experts from all regions of the world. This set of bioethical principles provides a common global platform by which bioethics can be introduced and strengthened within each Member State, and UNESCO is mandated to promote, disseminate and elaborate these principles for practical purposes.

Since bioethics teaching has not been introduced in many universities in many countries, the UNESCO Bioethics Core Curriculum can provide an incentive to start introducing such teaching. Furthermore, its content does not impose a particular model or specific view of bioethics, but articulates ethical principles that are shared by scientific experts, policy-makers and health professionals from various countries with different cultural, historical and religious backgrounds.

The casebook you have before you is part of the *UNESCO Bioethics Core Curriculum Casebook Series*, launched by UNESCO in 2011, and designed to be used with the core curriculum, or as stand-alone study material for one of the bioethical principles in the Declaration. The casebook series is intended to reinforce the introduction of ethics teaching, especially in developing countries. In order to encourage wide dissemination and usage of this series, the casebooks are freely available in hardcopy as well as for electronic download through the UNESCO website (www.unesco.org).

On behalf of UNESCO, I would like to express our gratitude to the *Advisory Expert Committee on the Teaching of Ethics*, especially to Professor Amnon Carmi, the Coordinator of the working group, as well as to the other members of the working group responsible for this casebook, for their commitment and voluntary assistance to the work of UNESCO in the strengthening of ethics education around the world.

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INTRODUCTION

The Constitution of UNESCO, adopted on the 16 November 1945, states that the wide diffusion of culture, and the education of humanity for justice and liberty and peace are indispensable to the dignity of man and constitute a sacred duty which all the nations must fulfill in a spirit of mutual assistance and concern.

On 19 October 2005, the 33rd Session of the General Conference of UNESCO adopted the *Universal Declaration on Bioethics and Human Rights* (hereafter referred to as the Declaration). Article 3 of the Declaration reads as follows:

1. *Human dignity, human rights and fundamental freedoms are to be fully respected.*
2. *The interests and welfare of the individual should have priority over the sole interest of science or society.*

There are several concepts of dignity. One meaning or use of dignity refers to the presentation of honor and esteem for personal merit, inherited or achieved. Thus, it might be used to mark a ‘height’ of human excellence, and of those qualities that distinguish certain persons from others. On the other hand, in certain religions human dignity is considered to be predetermined by the creation of human beings in the image of God. The Biblical assertion that human beings have been created in God’s image has often been taken as the ground of equal worth.

Modern philosophies tend to associate the concept of dignity with the idea of human rights. An individual has inherent inviolable rights. The term signifies an innate right to respect. The use of the idea of dignity is to refer to a naturally human way of being in the world. Immanuel Kant’s principle of treating a person as an end, not as a means, has been accepted by moral and political philosophy as a basis for the concept of human rights. No man should be treated or regarded as a ‘subject’. He held that there were things that should not be discussed in terms

of value, and that these things could be said to have dignity; ‘morality, and humanity as capable of it, is that which alone has dignity.’

Dignity refers to the minimum dignity which belongs to every human being. The notion of dignity is used to mark a threshold, a kind of respect and care beneath which the treatment of any human being should never fall. Unlike merit as an embodiment of publicly recognized personal achievements, a person is dignified as a human being as such. Human dignity appears to perform a distinct role, as the source from which human rights are derived, or as a reason for promoting human rights. The rights are needed and expected to secure and uphold the dignity of the human person.

Human dignity appears in various contexts in international instruments, even though this term was rarely or accurately defined. In contemporary international law, national constitutions, and other normative documents, human dignity is connected with human rights. According to Article 1 of the *Universal Declaration of Human Rights* (1948), ‘all human beings are born free and equal in dignity and rights.’ This article established human rights on the inherent dignity of every human being. The Council of Europe expressed in the Oviedo Convention (1997) the need to respect the human being both as an individual and as a member of the human species, and to recognize the importance of ensuring the dignity of the human being. Human dignity is a foundational concept and it is theoretically and normatively inappropriate to reduce it to functional characteristics of person’s activity. And as it is indicated in Article 12 of the *Universal Declaration on Bioethics and Human Rights*, the regard to cultural diversity is not to be invoked to infringe upon human dignity.

All human beings are equal in dignity irrespective of gender, age, social status or ethnicity. Our society is committed to equal human dignity. This concept adopts ethics of equality, valuing all human beings in light of their common humanity, rather than ethics of quality, valuing life when it embodies certain humanly fitting characteristics. Of course, treating people equally need not and should not mean treating them identically.

The idea of dignity is being associated with both a concern for equality and for protection against the risk of harm. It does not admit to any degrees. It is equal to all humans. It cannot be gained or lost. Any living human being, even one severely disabled does not lose human dignity. Even where freedom is by law denied, dignity must still subsist.

Even the vilest criminal remains a human being possessed of common human dignity.

Justice William Brennan
Supreme Court of the United States of America
Furman v Georgia (1972)

Recognition of a person's dignity presupposes active respect for his human rights, self-esteem and self-determination. Human dignity should not be measured according to any individual worth. It is a synonym for human worth, the inherent excellence of the human person as it is. A society should respect each of its members as a person on the basis of the notion of human dignity. This notion also requires that the interests and welfare of the individual are considered as prior to the sole interest of society. The individual should never be sacrificed for the sake of society or science. However, there might be exceptional circumstances in which the interests of others or the community as a whole are so important that infringing upon the interests of individuals is unavoidable in order to save others or the community.

This casebook contains 30 case studies. Every case has been dealt with by a high judicial instance and offers a description of the type of ethical problems involved. Each case is followed by general guidelines for the edification of students who must themselves, under the guidance of their lecturer, study the case, discuss the possible solutions and reject what they consider unsuitable before reaching their own decision. The aim of the project is to produce a tool and a platform for active participation of the students in the decision-making process.

Combined efforts of teaching, educating and training by the use of such a methodology may plant and root in the hearts of the students ethical values that should guide any physician providing patient care.

At this point, I would like to thank my colleagues of the working group for this casebook for their perseverance and commitment to this project, as well as the editorial assistants from the International Center for Health, Law and Ethics at the University of Haifa and from the UNESCO Secretariat.

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CASE STUDY 1

Privacy

Dr. D was an obstetrics/gynecology resident pursuing a joint residency at the State University Medical Center and the regional Hospital. During an invasive surgical procedure, Dr. D was accidentally cut by the attending physician. The record does not indicate whether there was any actual blood contact between Dr. D and the patient. It appears there was no blood exposure, although no one can be certain.

The following day, Dr. D voluntarily submitted to blood testing for the HIV virus. The results confirmed that Dr. D was HIV-positive. After being informed of the test results, Dr. D willingly withdrew from participating in further surgical procedures, informed the appropriate officials of his condition, and requested a voluntary leave of absence.

Upon investigation, the Medical Center identified 279 patients who had been involved to some degree with Dr. D during the course of their medical treatment. Likewise, the Hospital identified 168 patients who had been in contact with Dr. D since the time of his joint residency. Unfortunately, hospital records do not necessarily indicate each time a physician is cut, nor do they specify the distinct role of each physician in a surgical procedure. Thus, every patient with a reasonable chance of exposure to Dr. D was included in the statistics outlined above.

Both the Medical Center and the Hospital filed petitions alleging a ‘compelling’ need to disclose information regarding Dr. D’s condition to those patients potentially affected by contact with him. In addition, the hospitals believed there was a compelling need to disclose Dr. D’s name to the other treating physicians in the department, so that those physicians could contact their patients in the event they had been assisted by Dr. D in any invasive procedures.

In response, Dr. D asserted his right to privacy, arguing that no compelling need was tantamount to a justification to disclose his HIV-related information.

→ Should the hospitals disclose Dr. D's disease?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

- YES** Medical institutes have a duty to insure the health of their patients to the best of their ability. Therefore, it is the hospital's responsibility to inform possibly affected individuals of their potential exposure to HIV and to offer them treatment, testing and counseling. In addition, disclosure of Dr. D's identity is necessary to prevent the spread of AIDS.
- NO** The hospitals have no right to disclose Dr. D's name to the other treating physicians in the department. Dr. D's right to privacy is not different from that of any other person. Therefore, disclosing Dr. D's name is a severe violation of his right to privacy.
- YES** Undoubtedly, an individual's health problems are a private matter to be dealt with subject to informed consent. However, Dr. D's medical problem is not his alone. It became a matter of public concern the moment he picked up a surgical instrument and joined a team involved in invasive procedures. Therefore, the hospitals must disclose Dr. D's disease.
- NO** Disclosing Dr. D's disease will send the public a message that they are at risk of contracting AIDS if treated by an HIV-infected physician. Hence, hospitals in the future will risk liability if they fail to follow through with similar unsubstantiated patient notification. Expensive medical care will become even more costly due to needless repeated HIV testing and the high cost of doctors indemnity insurance. Furthermore, physicians and other health care workers will be discouraged from treating those infected with HIV.
- NO** This extensive notification will discourage physicians and other health care workers from treating HIV infected patients.

Notes about the case study

Court decision

The case came before the Court of the country. The court weighed the competing needs of public disclosure and the doctor's right to privacy. The Court ruled that the hospitals had met the test and ordered that Dr. D's identity and his HIV-related information may be conditionally revealed.

The trial court's order:

...Petitioners are hereby authorized to disclose the identity of Dr. D, M.D. as follows and only as thus authorized:

- 1. By providing the name of Dr. D to the physicians in the Obstetrics and Gynecology Departments including the physicians in the residency program.*
- 2. By providing the name of Dr. D to a physician authorized in writing by a patient for whom Dr. D participated in a surgical procedure or obstetrical care.*
- 3. By describing Dr. D in letters to patients and in media releases as 'a physician in our joint Obstetrics and Gynecology residency program' and by setting forth the relevant period of such service.*

Each physician to whom the name of Dr. D is provided under 1. and 2. above shall be reminded that the Act prohibits further disclosure of such information.

The Superior Court affirmed the trial court's order allowing the hospitals to inform patients of Dr. D's HIV status, stating that the hospitals were allowed to release otherwise confidential information about the appellant due to the compelling need to inform and treat patients potentially exposed to HIV.

Discussion Privacy

Human dignity is probably one of the most important principles of bioethics. Although there is no clear definition for this principle, it is not just a saying, but rather reflective of the need to promote respect for the intrinsic value of every individual human being. To achieve this goal, international bio-law defines dignity as an overarching principle accompanied by other effective and practical rights, such as privacy.

The right to privacy is an integral part of the inherent right of every human being to dignity. It represents the right of every individual to determine when and how much personal information will be exposed to the public. Every human being has a right to privacy and thus, patients, as well as practitioners, are entitled to it.

This right actually enables individuals to maintain their autonomy and to live as they want. Some countries ground this right in their laws, as stated in Article 9 of the *Universal Declaration of Bioethics and Human Rights*:

The privacy of the persons concerned and the confidentiality of their personal information should be respected. To the greatest extent possible, such information should not be used or disclosed for purposes other than those for which it was collected or consented to, consistent with international law, in particular international human rights law.

Nevertheless, the right to privacy sometimes conflicts with other rights, such as the right of others to know the truth about their health. In such situations, we must find a balance between the different rights and interests.

The right to confidentiality is not an absolute right. Sometimes, third parties face risks that require the withdrawal of this right. We must consider the gravity and imminence of the threat. Where the threat is serious and imminent, then even coerced disclosure would be appropriate.

It should be emphasized that, in some countries, such disclosure is set out by the law.

In addition, the public's right to know about incidents that may affect them is also part of their right to dignity.

One of the most common practices for balancing the two rights is revealing only the relevant information while avoiding disclosure of names etc.

CASE STUDY 2

Physician's rights

Dr. M was an obstetrician and gynecologist. He performed an abdominal hysterectomy on Mrs. H, a 53-year-old patient.

Prior to the surgery, Dr. M informed Mrs. H of the risks and potential complications of the procedure. He discussed with her the general anesthetic she would be receiving and its possible complication. He told her about the potential of injuring other organs adjacent to the uterus, including the bowel, bladder, uterus, and rectum. The risk of bleeding during and following surgery was discussed with her, as well as the risk of post-surgical infection. After Dr. M had disclosed all material risks attendant to the surgery, Mrs. H consented to the operation.

Dr. M had been suffering from epilepsy since 1989, information he did not disclose to Mrs. H. Dr. M did not suffer an epileptic seizure in the operating theatre during Mrs. H's operation, nor was his ability to perform the surgery affected by the medication he was taking.

During the two days subsequent to the surgery, Mrs. H's bladder failed to function correctly because an incision had been made to the bladder (cystotomy) during the initial surgery. A urologist was called in to repair the damage to the bladder. Early the next morning, Mrs. H passed away due to a pulmonary embolism in her lungs.

→ **Should Dr. M have disclosed his epilepsy to Mrs. H prior to obtaining her consent to the surgery?**

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES When obtaining a patient's consent for a surgical procedure, an attending surgeon must disclose any personal medical history that might have a bearing on the patient's decision of whether to be operated on by the attending surgeon. Failure to disclose such information may be considered medical battery, which is defined as 'the intentional violation of a patient's rights to direct his or her medical treatment'. Dr. M's non-disclosure of his medical condition constituted misrepresentation or fraud toward Mrs. H when she signed her informed consent to the hysterectomy surgery.

NO The fact that Dr. M suffered from epilepsy should not be disclosed in obtaining Mrs. H's consent. A physician has the same right to confidentiality as any other person, so long as his medical condition does not harm his ability to perform surgery.

Notes about the case study

Court decision

The case came before the Court of the country. The court concluded that Dr. M's non-disclosure to Mrs. H of his personal medical condition was not part of the surgeon's duty to inform the patient of a material risk attendant to the recommended surgery.

Dr. M was not obligated to disclose his personal medical history to Mrs. H. According to Dr. M and his own doctors, as indicated in the letters put in evidence, the medication he was on kept his epilepsy under control. He did not have an epileptic seizure in the operating room at the time of performing surgery on Mrs. H.

Dr. M met the required standard of care in obtaining the patient's informed consent to the material risks of the surgery contemplated. Dr. M's non-disclosure of his medical condition did not constitute any misrepresentation or fraud committed against the patient.

Discussion Physician's rights

Individual privacy is one's ability to protect oneself, or information relating to oneself, and thus reveal oneself selectively. Doctors are entitled to privacy just as their patients are. Privacy, as a human right, is derived of the individual's will, so long as it doesn't hurt another person. Rights, such as privacy, are natural and everyone is entitled to them just by force of their being human. One of the most difficult issues pertaining to this subject matter is determining when keeping one's right hurts the right of another.

A doctor's right to privacy is derived from his right to dignity and the social concept of the autonomy, by which a physician may treat himself and continue working (insofar as he does not harm his patients). Moreover, where a doctor discloses an illness from which he suffers, patients may develop a sense of anxiety, avoid treatment from the physician, and thus cause harm to themselves.

On the other hand, it is the patient's prerogative to be sure of his physician—having no doubt that the physician has only his welfare at heart, confident that the physician will maintain his secrets and sure of the trust between them. Failure to reveal an illness, from which the physician suffers, could seriously harm this trust.

However, in cases where the physician suffers from a disease, he must consider his own rights and obligations as a doctor and as human being. This includes his right not to reveal his illness, and the obligation to care for his patients in the best possible manner, without causing them unnecessary harm or anxiety.

In such cases, an ethics committee or another external professional body may be consulted in order to examine the delicate balance and assist in reaching an informed decision.

CASE STUDY 3

A patient's right to personal medical information

During 1999, the welfare authorities received many inquiries about Ms. X's mental condition. One of these inquiries was addressed to Dr. R, director of the psychiatric clinic at the local Hospital.

Dr. R was afraid Ms. X might harm herself. He therefore transferred the inquiry to Dr. A, the district psychiatrist, who decided to call in Ms. X for a medical examination.

Ms. X came to Dr. A's clinic. After speaking with Ms. X, Dr. A concluded that although she is paranoid, there is no reason to force her to receive mental treatment. Nevertheless, Dr. A advised her to submit to voluntary mental treatment, but Ms. X rejected Dr. A's proposal.

Ms. X felt she was being tagged as 'mentally ill.' She wanted Dr. A to provide her with medical information about her case, including his medical opinion and his diagnosis.

Dr. A refused Ms. X's request.

► Was Dr. A entitled to refuse to provide Ms. X medical information about her mental state?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES Dr. A has the right to refuse to provide medical information to his patient if he believes the patient should not know this information.

NO The medical information belongs to the patient. The psychiatrist has no right to deprive the patient of this information unless there is clear evidence that the information might be harmful.

Notes about the case study

Court decision

This case came before the Supreme Court of the country. The court concluded that the point of departure is the patient's right to receive medical information. Information about the patient's state is not the private property of the physician or the medical institute. The information belongs to the patient, and the physician keeps this information in good faith. A patient's right to receive medical information derives from the patient's autonomy and dignity as a human being. If there is no major reason to deprive the patient of such information, the patient's right prevails, and the physician must provide the information to the patient.

However, the patient's right to receive medical information is not an absolute right. The physician must consider the impact on the patient's mental and physical state as a result of being exposed to the information.

Discussion A patient's right to personal medical information

The notion of 'respect for dignity' is not absolutely clear, and there is no specific definition for that phrase, although it is used in many legal and ethical instruments. One of the reasons for not defining it is that it is used in many contexts and has different meanings, which cannot be fully captured by a single definition. Nevertheless, in order to use 'dignity' in our lives, some practical principles were established.

While most of the world agrees on the need to respect the dignity of others (although there are different meanings to the term ‘dignity’ around the world), there are debates as to the practical principles. For example, we can accept the need to respect the dignity of a mentally ill person, but we can disagree with the need to provide him with all medical information (as part of this dignity).

Sometimes, the lack of knowledge increases the patient’s fear and the pressure that he feels, which could detract from the successful outcome of the treatment. Moreover, providing the information in the proper manner, contributes to the trust which the patient feels towards the physician.

On the other hand, there are cases when the patient is unable to internalize the extent of his illness, and revealing the information could expose him to injury. For example, a person could become despondent or depressed, or even harm himself.

Because the physician’s aim is to benefit the patient and not to harm him, he must take care, with regard to certain patients, which information should or should not be revealed to them.

It should be noted that the reason for not revealing the information should be to protect the patient; the decision may be made within the framework of an ethics committee or an external body, which would weigh the importance of giving the patient the information, as part of his basic rights to dignity and respect, on one hand, and the fear of harming him, on the other.

CASE STUDY 4

Objection to unapproved treatment

Mrs. CS is a 78-year-old widow afflicted with terminal cancer. She was admitted to a hospital, where she underwent extensive treatment for her cancer. Mrs. CS has undergone extensive chemotherapy and availed herself of all the technology which would offer her the best hope for recovery, but the treatment was ineffectual in arresting or curing her cancer. Her condition has steadily deteriorated and her prognosis is poor; death is imminent.

Due to the unsuccessful conventional treatment, Mrs. CS desires to receive an alternative drug in an effort to cure or arrest the course of her cancer. This drug is a chemical compound extracted from the kernels of apricots and has been, over the years, recommended for the treatment of cancer.

This drug is not generally recognized by qualified experts as a safe and effective cancer drug, but it has been claimed by its various proponents to cure or control the spread of cancer, or more moderately, to mitigate the symptoms of the disease without curing it.

This drug has not been approved by the Food and Drug Administration or the National Cancer Society of that country. It has not been proven to be an accepted method for the treatment of cancer. Because of this, the hospital, in the exercise of its best medical judgment, refuses Mrs. CS or any other hospitalized patient therein to be treated with this alternative drug.

→ Does the hospital have a right to refuse a treatment that the patient would like to receive?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

NO Mrs. CS has a fundamental right to determine the course of her treatment, even if the desirable treatment is not recognized by the hospital. The right is intensified according to the fact that Mrs. CS has tried all of the treatments that were offered her by the hospital.

YES It is well known that the patient has a fundamental right to determine the course of his treatment; likewise, the hospital has the right to refuse such treatment. If Mrs. CS wishes to pursue a course of treatment using this alternative drug, she is free to do so in another hospital that does not prohibit its use.

Notes about the case study

Court decision

The case was held at the Superior Court of the State. The court concluded that the right of the patient to choose or reject a cancer treatment on the advice of a licensed medical doctor, whether or not it is approved by the State or hospital, could not be of a more fundamental nature.

By refusing to grant the instant injunction, it would effectively undermine the very independent choice which is a fundamental basis of the right to privacy.

Doubtless, the hospital desires to protect the public and, in so doing, its own good name. However, the Constitutions of the nation and this State are irrevocably committed to the principle that individuals must be given the maximum latitude in determining their own destiny. In

addition, where a person is terminally ill with cancer and unresponsive to other treatments, the alleged public harm in the administration of alternative therapy is considerably reduced.

The hospital asserted that if Mrs. CS or her physician wishes to pursue a course of treatment using the alternative drug, they are free to do so in another hospital, which might not prohibit its use. The court held that, after giving due consideration to the age and weakened physical condition of Mrs. CS, it would be unconscionably burdensome to both Mrs. CS and her family to be forced to change hospitals at this time.

The court added that denying Mrs. CS her last opportunity to make a choice as to how to combat a disease which has ravaged her body would display a lack of understanding of the meaning of the individual's rights in a free society.

Discussion Objection to unapproved treatment

Terminal patients, whose conditions do not respond to conventional treatment, face a very difficult situation. Physicians, striving to do their best for their patients, seek new ways to relieve their problems and pain.

The use of unapproved technologies raises the question of progress versus morality. Scientific progress has affected our moral values, some argue that such progress, without well defined limits, is dangerous and we must set these limits before accepting the innovative solutions. Another perspective would argue that humanity or mankind is able to define ethical guidelines within the medical and scientific advancements.

One of the options, in cases like these, is to refer the patient for experimental treatment, which is not registered or defined as 'conventional treatment', but is at an advanced stage of research for medical treatment and marketing. Countries usually provide legal guidelines for the application of medical research to treatment. It must nevertheless be remembered that, whilst we are in need of research, the benefit to the patient must be increased and harm prevented, to the maximal possible extent.

When research is the issue, extra care must be taken with these principles, as research is not always predictable, and doctors and patients are not always able to know the impact that the research treatment will have on the patient's medical condition. We should apply new technologies only in a manner that promotes moral and human qualities. However, the difficult question in cases where there is no cure is whether the 'experimental technology' promotes these qualities – this is the challenge facing the physician.

Sometimes patients, being despaired of the existing treatments, are willing to take risks and participate in studies involving medication, substances, or treatments which have not been proven as safe and effective. In such cases, their participation in the study could cause them even more harm by not only giving them false hope, but also shortening their lives and causing damage, as they might discontinue conventional treatments if they only offer relief and not a cure. Therefore, it is the physician's obligation to ensure that patients are treated in a safe way.

When consenting to use treatments that are still in initial stages of experimentation (e.g. animal experimentation), patients and their families expose themselves to emotional stress. Being in an already delicate situation – willing to spend money on potentially unsafe and improperly tested procedures – they are vulnerable to harsh disappointment as well as deterioration in the patient's medical condition.

It must be stressed that consenting to experimental treatment in the early stages of research, with no guarantee of minimal efficacy and safety, could detract from public acceptance and convey a message by which the patient was ostensibly 'flung' into treatments that were not only non-beneficial, but even harmful. Article 4 of the *Universal Declaration on Bioethics and Human Rights* stresses the need to ensure benefits to the patient, as well as benefits for the whole of mankind.

However, notwithstanding the wish and right of the patient to receive non-conventional medical treatment, doctors are not obliged to satisfy patients' request for such treatment if they are not convinced of its efficacy and safety.

CASE STUDY 5

The right to life with dignity

X, a woman in her 26th week of pregnancy, consulted a physician at a private obstetrics and gynecology clinic and asked him to perform an abortion.

The physician's clinic lacked facilities and equipment available at a hospital to provide medical care for premature infants, for example incubators.

The physician performed the abortion in his own clinic. The fetus delivered as a result of the aforementioned abortion was alive. The estimated weight of the premature infant was less than 1,000 grams, but there was a possibility that the infant could continue to develop.

The physician had the ability to implement lifesaving measures swiftly and easily. Nevertheless, he left the infant unattended and provided no measures necessary for the infant to survive at the physician's own clinic. As a result, the infant died 54 hours after birth.

→ Should the physician have acted differently?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

NO X wanted to undergo an abortion and requested it of her own free will. It is her right to determine whether the fetus will live or die. The fetus lacks any rights. Therefore, the doctor did not breach his duties.

YES If the fetus has a possibility of surviving outside its mother's womb, it should be considered the same as any other human being. The infant could have survived if appropriate treatment had been administered. Not only did the doctor breach his duty to provide appropriate medical care, he also committed a crime by condemning and sentencing the infant to a cruel death. The doctor should have referred the pregnant woman to a hospital.

Notes about the case study

Court decision

This came before the Supreme Court of the country. The Supreme Court ruled as follows; this is a case of an expert physician in obstetrics and gynecology who was asked to perform an abortion on a woman in her twenty-sixth-week of pregnancy. Said physician was aware that the premature infant born as a result of said abortion had the possibility of continuing to develop if provided appropriate medical care.

Moreover, said physician was capable of implementing such measures swiftly and without difficulty. Nevertheless, the physician abandoned said infant in his own clinic, leading to said infant's death fifty-four-hours later. Under these conditions, the crimes of professional criminal abortion and abandonment by a guardian resulting in death are established.

Discussion The right to life with dignity

The individual's right to dignity, alongside the medical staff's obligation to act with respect towards the patients, might apply not only to a physician's direct patients, but also to others who become patients requiring medical assistance such as: infants born to a woman who is actually an obstetrics patient.

In situations like this, we must ask ourselves whether the life of the parent bears the same dignity and rights as the newborn child. Based

on the stance that any form of life is sacred, the fetus enjoys the same right to dignity as the mother, and abortion is forbidden. Some would say that the fetus should be considered a human being from the very beginning of the pregnancy or at least from an early stage of the pregnancy. In that case, we must consider its ‘best interest’ at any stage of pregnancy, and we should not prefer the mother’s interests over those of the fetus.

Another position will say that parental life is not equivalent to that of the newborn and, having said that, it is easier to grant the mother the option of undergoing an abortion. Countries usually pass laws on this issue, creating a balance between the different positions. However, some¹ state that the *Universal Declaration on Bioethics and Human Rights* argues that unborn infants have no right for dignity.

However, what happens when the ‘unborn infant’ is born? Is his dignity after birth equivalent to his mother’s? If so, he should be treated just like any other patient, although his mother wanted to abort him. In such cases, the physician has obligations towards the baby as well.

In addition, we must remember that newborns (especially premature babies) constitute an extremely vulnerable population that must be fully protected and sheltered.

In cases where the good of the mother, as she perceives it, clashes with the good of the fetus, her sole right as the one who decides what should be done with the fetus (who was already born and is alive) can be revoked, and the separate rights of the infant could be evaluated without considering the mother’s wishes.

However, when considering the good of the infant, treatment should be provided in such cases when it can be saved. Standing aside and avoiding treatment when medical intervention is called for, while objectively considering the good of the infant separately from the mother, could be considered a criminal act.

1 For more information see: Schmidt, H. 2007, Whose dignity? Resolving ambiguities in the scope of ‘human dignity’ in the Universal Declaration on Bioethics and Human Rights, *Journal of Medical Ethics*, 33: 578–584

CASE STUDY 6

Withdrawal of medical care from minors at the terminal stage of life

D is a 14-year-old boy who has Hunter syndrome, a serious genetic disorder for which there is no known cure. His life expectancy is less than two years.

D was admitted to the University Medical Center because he was experiencing difficulty breathing. Within a day of admission, he was placed on a ventilator to enable him to breathe. At the onset of aspiration, a tracheotomy procedure was performed, and a feeding tube (PEG tube) was inserted into his stomach.

D's condition is considered stable. He is alert, tracks people with his eyes, recognizes his mother, and seems to enjoy watching cartoons and videotapes. D is generally not in pain, though he makes it known he does not like to be suctioned. He experiences pain when he is moved because he is edematous. His connective tissue is filled with water, causing him pain and tightness. He is not on any pain medication due to the fleeting nature of the pain, which he experiences when he is moved, washed, or suctioned.

D's parents decided to remove D from the respirator. D's mother and father both testified they understood that removing the ventilator would hasten D's death, but felt removal was in his best interest and would put an end to his suffering. D's mother visits D every day in the hospital and was his primary caregiver until he was admitted. There is no question D's parents want what is best for him.

When D's parents requested that D be removed from the respirator and that other medical care be terminated, Dr. C and Nurse H were not in agreement with the parents' decision. Therefore, Dr. C brought the case before the hospital medical ethics committee for review.

→ Should the medical ethics committee decide to discontinue life support?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES The medical ethics committee must approve the parents' decision and consider their feelings. In this case D's parents are undoubtedly good parents, and their only wish is to put an end to their son's suffering. D lacks the capacity to give his consent to his medical treatment, and is suffering from a terminal disease. Since D's wishes cannot be known, his parents, in their capacity as D's natural guardian, are expressing D's wishes. Therefore, removing the ventilator is unavoidable.

NO The medical ethics committee must refuse D's parents' request. A physician's primary obligation is to the patient, and Dr. C is definitely acting in the interests of his patient. From the medical perspective, D is not at the point of being unresponsive. Therefore, it is not medically appropriate to remove the ventilator at this time because D is alert and aware of his surroundings.

Notes about the case study

Court decision

The members of the ethics committee independently concluded that the parents' decision was an ethical one, since it was based upon their feelings for their child and their concern for his well-being.

Based upon the decision of the ethics committee, this case came before the Supreme Court of the country.

The court appointed Mr. S as guardian *ad litem* to protect the rights and interests of D. Mr. S also supported the parents' decision to

remove D from the respirator in light of the hospital ethics committee's decision.

Although the medical ethics committee and the guardian *ad litem*, Mr. S, supported the parents' decision, the court reversed this decision:

This court appreciates that young D has lived a very difficult life, suffering from a progressive life-threatening and altering disease. It is, however, D's right to live and this court will not consider or determine whether it is a life worth living from anyone's perspective other than D's.

The court went on to say:

This decision is made with heartfelt appreciation for all that D and his parents have endured what they are now going through and with compassion for what lies ahead for this family. The parents are devoted, conscientious, sincere, loving and trying to do what is best for their child. They have prepared themselves to accept the inevitable and love D enough to let him go. Based upon the evidence adduced at the hearing, however, this court does not find that it has been proven by clear and convincing evidence that it is in D's best interest to withdraw the ventilator while he is alert, responsive, seemingly pain free and the burdens of prolonged life are not so great so as to outweigh any pleasure, emotional enjoyment or other satisfaction that D may yet be able to derive from life.

After due deliberation, the court finds that the patient lacks the capacity to make reasoned decisions concerning his treatment and that the request of his parents to discontinue his medical treatment is premature and not in his best interest at this time.

Discussion Withdrawal of medical care from minors at the terminal stage of life

This case introduces several issues, one of which is the need to respect one's choices. The attitude that emphasizes the sanctity of life will not condone any action whose goal is to shorten life. The viewpoint which respects the will as a reflection of dignity would consider this kind of request. However, even the strongest 'will as a right' believers do not confer the right to obtain help toward committing suicide because of a broken heart. Where is the limit? It is not obvious. One of the answers might be the principle of rationality. Hence, another question can be: who defines rationality?

Another issue can be considered as the ability of parents to make such decisions on behalf of their children. On the one hand, parents usually act in the best interest of their child, and as guardians, they have the right to make decisions like these. Moreover, they love their child and want to minimize his pain and suffering. On the other hand, we cannot be sure of how the situation affects them, the difficulties they live and cope with, and to what extent this situation influences their decision.

Another issue in this situation is that of 'informed consent.' Preventing or terminating medical treatment is part of the principle of informed consent to medical treatment. Indeed, a person's consent to medical treatment of his body also includes his right to refuse such treatment, even if the treatment could prolong his life.

When this relates to minors, who are genuinely (if the minor is too young) or legally unable (when the law does not authorize an older minor to such consent) to reach an informed decision regarding the possibility of avoiding specific medical treatment, then the parents, as the minor's natural guardians, may and should sign such informed consent forms on his behalf. This principle is usually secured in the legislation of every country, where the age of the minor and the extent of parental involvement is defined.

The most important consideration in this case is the best interest of the minor. Guardian decisions are not necessarily always in the best

interest of the minor, and we cannot always know whether or not the decision was in his best interest. The decision must be objective and it must consider only the minors good, best interest, beneficence and nothing else.

When the minor is an adolescent, in terms of age, with capacity to understand his situation and the ramifications of receiving or not receiving medical treatment, he should be given the possibility to express his opinion and will regarding the situation.

When referring to a minor who does not have the ability or authority to determine what should be done with his body, his best interest must first and foremost be considered, as determined in Article 7 of the *Universal Declaration on Bioethics and Human Rights*:

In accordance with Domestic Law, special protection is to be given to persons who do not have the capacity to consent:

(a) Authorization for research and medical practice should be obtained in accordance with the best interest of the person concerned and in accordance with domestic law, However, the person concerned should be involved , to the greatest extent possible in the decision making process of consent, as well as that of withdrawing consent.

CASE STUDY 7

Withholding life-saving treatment

Baby J was born very prematurely on 28 May 1990 after 27 weeks of gestation. He weighed only 1.1 kg at birth. During his short life, he has suffered almost every conceivable misfortune. He was not breathing at birth and almost immediately was placed on a ventilator. He was administered intravenous antibiotics to counteract infection. His pulse rate frequently dropped very low, and for the first ten days of his life, his survival was touch and go. By September 1990, when J was only three months old, he had already been ventilated on two occasions for a total of six weeks.

J's current status is that he is severely brain damaged due to oxygen deprivation and impaired blood supply around the time of his birth. This damage is permanent, and the brain tissue lost is irreplaceable. It is debatable whether he will ever be able to sit up or hold his head upright. J appears to be blind, although he may possibly regain some degree of sight. He is likely to be deaf as well. He may be able to make sounds that reflect his mood, but he is unlikely ever to be able to speak. It is highly unlikely that he will develop even limited intellectual abilities. Most unfortunate of all, he is likely to be able to feel the same extent of pain felt by a normal baby because pain is a very basic response. He may achieve the ability to smile and cry. Finally, as one might expect, his life expectancy has been considerably shortened; at most he will live into his late teens, but will probably die long before then.

J is not terminally ill, and he is not at the point of death or of dying.

At the moment, J appears to be stable and is breathing independently. In some ways his condition has slightly improved. Nevertheless, this improvement is fragile and a crisis could occur again at any time.

The doctors responsible for J's care have unanimously agreed that they do not wish to give J further prolonged ventilation and intensive care

if and when such need should arise. One doctor, however, thought that a situation might arise in which very short-term ventilation might be appropriate. The doctors stressed that such treatment is very unpleasant and distressing to J.

The position of J's parents is not consistent. At first, they accepted the doctors' recommendations, but now they want J to be given any chance possible.

► **Should the doctors put J on a mechanical ventilator and subject him to the intensive care associated with this treatment if in the future he suffers another collapse and cannot continue breathing unaided?**

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES Withholding lifesaving treatment based on the patient's quality of life can never be justified. No one but the patient can determine whether life is worth living. J is not terminally ill and is expected to live into his teens. Therefore, if possible, life should always be prolonged by treatment, regardless of the quality of life being preserved and regardless of any added suffering caused by the treatment itself.

NO Under these circumstances the nature of the treatment necessary to preserve J's life is distressing and painful. Life should not be preserved at all costs. The quality of the life to be preserved and the caused distress to the patient by the treatment necessary to preserve his life must be taken into consideration; said treatment may not be in the best interests of the patient.

Notes about the case study

Court decision

This case came before the Court of Appeal of the country. The trial court judge approved the recommendation of the consultant neonatologist that, in the event of further convulsions requiring resuscitation, J should not be revived by means of mechanical ventilation, unless so doing seemed appropriate to those involved in his care in that particular situation. By his order, the judge directed that the relevant health authority continue to treat J in accordance with that recommendation.

The Official Solicitor appealed. The Court of Appeal dismissed the appeal and held that although there was a strong presumption in favor of preservation of life, no principle of public policy regarding the sanctity of life displaced the paramount value of J's best interests. Accordingly, even though J is not terminally ill, the court withholds its consent to life-saving treatment.

Discussion Withholding life-saving treatment

It seems that the question of prolonging the life of an infant whose condition is terminal is one of the most difficult and painful issues with which we are forced to cope. Today, unlike in the past, we have the technology that enables premature infants to live; yet, often such life is involved with significant suffering to themselves and their families.

A very important question we must ask ourselves is whether someone with very poor quality of life can be considered a 'human being'. In other words, does quality of life influence the definition of someone as a human being? Those who argue that he is not a human being or that there are several degrees of definitions of being a human being might agree to withhold treatment, and perhaps even subject such people to research. The other approach would argue that he is a human being and his dignity should be preserved as any other person's dignity. The fact that his quality of life is negative does not influence his dignity as a fundamental right granted to any human being.

Another problem in these cases is that they involve a person who is incapable of informing us of his opinion or will. It is impossible for babies to understand, process the information, and make decisions. The best candidates to make the decision for them are the parents, on the assumption that, of all people, they will consider the best interest of their child. However, if the parents cannot make such a decision, it still must be made; if we take advantage of the technology, we are obliged to accept its consequences.

The primary consideration should be the welfare of the infant and not that of the parents or the healthcare system, as determined in Article 3(2) of the *Universal Declaration on Bioethics and Human Rights*:

The interests and welfare of the individual should have priority over the sole interest of science or society:

We are, therefore, obligated to safeguard the interests of the infant, a responsibility that is, undoubtedly, extremely difficult in situations such as this one.

A very important principle regarding this issue is the sanctity of life. One can argue that human life has value and, therefore, it is wrong to take steps to end a person's life, directly or indirectly, no matter what the quality of that life. On the other hand, others might say that there are circumstances in which a person's quality of life is so poor that it should not be maintained, even if technically it is possible. Only people who believe in the latter can accept the distinction between actively killing someone and refraining from action that may save or preserve that person's life. However, the most difficult question relating to quality of life is the question of how it is defined and by whom. Would the court decide the same if baby J was only blind?

There is no doubt that all of the infant's parameters must be considered, both the medical, what exactly is he suffering from and whether there are technologies capable of helping him or alleviating his suffering from such a deformity. One must also consider other parameters; will the infant receive love and warmth even in his current condition and is it possible to improve anything at all in his present difficult state?

It would be appropriate, even if it is decided not to prolong the infant's life, to do all that is possible to prevent him from suffering (for example, not to withhold sedatives, not to let him die of suffocation), and certainly not to carry out active euthanasia (such as a lethal injection etc.) even if it is done out of compassion.

CASE STUDY 8

End of life considerations

Mr. AB, a 21-year-old patient in the care of the General Hospital, has been in a persistent vegetative state (PVS) for three and a half years, subsequent to a severe crushed chest injury that caused catastrophic and irreversible damage to the higher functions of his brain. In this condition, the brain stem remains alive and functioning, while the brain cortex loses its ability to function. Although he continued to breathe unaided and his digestion continued to function, he could not see, hear, taste, smell, speak or communicate in any way, was incapable of involuntary movement, could not feel pain, and had no cognitive function.

He was being fed artificially and mechanically by a nasogastric tube that had been inserted through his nose into his stomach.

Dr. K examined Mr. AB and testified that this was the most severe case he had ever seen. He went on to say that Mr. AB was likely to survive for a few years, though no more than five, mainly due to his high risk of developing infections.

The unanimous opinion of all the doctors who had examined him was that there was no hope whatsoever of recovery or of any kind of improvement in his condition.

Mr. AB gave no clear indication of his views prior to his injury, and his family was unable to consent on his behalf. Based upon their knowledge of their son, his parents said he would not have wished to continue in his present condition.

Under these circumstances, the hospital's geriatric consultant reached the clear conclusion that further treatment should be withheld. This would involve discontinuing artificial feeding through the nasogastric tube and withholding antibiotic treatment if and when infection appeared. If this course were to be adopted, within 10 to 14 days the

physical functioning of Mr. AB's body would come to an end, and he would die of starvation. This process would be unpleasant for those observing, but Mr. AB himself would be totally unaware of what was taking place.

→ Is starvation the proper way to hasten Mr. AB's death?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES The most dignified way for Mr. AB to die is by withdrawing the artificial feeding system. If this course of action is not followed, he will die within five years from infection, a much more distressing death than through the withholding of nourishment. The manner of his death should not be distressing or humiliating. Therefore, withdrawing nourishment is the most considerate and controlled way for him to be allowed to die.

NO Denying Mr. AB nourishment can never be a respectful way to die. Food is a basic human requirement, and withholding nourishment is distressing to watch, even if the patient himself would not experience any sensation.

YES Continuing artificial sustenance and medical treatment will keep Mr. AB alive, but will not restore him to normal life in any sense of the word. If he were capable of making his desires known, he would likely choose to put an end to his humiliation and to his family's distress. Allowing him to die and be mourned by his family would show him greater respect than keeping him alive in this grotesque form.

Notes about the case study

Court decision

The aforementioned case was heard before the Court of Appeal of the country. The General Hospital responsible for Mr. AB's care asked the court to issue a declaratory judgment that would lawfully enable the hospital and the physicians in charge to discontinue all life-sustaining treatment and medical support measures designed to keep Mr. AB alive in his existing persistent vegetative state, including the termination of ventilation, nutrition and hydration by artificial means. They further asked the court to rule that they could lawfully discontinue medical treatment to Mr. AB and thereafter need not furnish medical treatment, except with the sole purpose of enabling him to end his life and die peacefully with the greatest dignity and the least pain, suffering, and distress.

The hospital's action was supported by Mr. AB's parents and family. The judge granted the requested declaratory judgment. The Official Solicitor appealed to the Court of Appeal, which affirmed the judge's decision. Consequently, the Official Solicitor appealed to the parliament, contending that the withdrawal of life support was both a breach of a doctor's duty to care for his patient, an indefinite duty, and a criminal act as well.

The parliament also dismissed the appeal, stating that under these circumstances, discontinuation of life support by withdrawing artificial feeding did not constitute a criminal act because if maintaining an intrusive life support system was not in the patient's best interests, the doctor was no longer under any obligation to maintain the patient's life.

It is true that, in this case of discontinuance of artificial feeding, it can be said that the patient will as a result starve to death; and this may bring before our eyes the vision of an ordinary person slowly dying of hunger, and suffering all the pain and distress associated with such a death. But here it is clear from the evidence that no such pain or distress will be suffered by Mr. AB, who can feel nothing at all. Furthermore, we are told that the outward symptoms of dying in such a way, which might otherwise cause distress to the nurses who care for

him or to members of his family who visit him, can be suppressed by means of sedatives. In these circumstances, I can see no ground in the present case for refusing the declarations applied for simply because the course of action proposed involves the discontinuation of artificial feeding. ...

Discussion End of life considerations

The end-of-life period is a very complex situation. Some approaches say that any right of a person is considered a ‘liberty’ and not an open permit to destroy and harm, even one’s self. According to this approach, a person cannot waive his moral right to life, even in situations where he has no dignity in it.

Another approach states that a person’s right to end his life with dignity is an inseparable part of his honor. Death is a part of life and a person should, therefore, within his basic right, be permitted to end his life in a dignified manner, according to his own values.

There are cases when a person’s ability to function is severely impaired, and his quality of life is considered very poor. Cases in which he prefers to end his life, rather than continue to ‘live’ in the existing condition, with no cognitive and/or physical capabilities and no dignity. In such cases, it must be determined whether he truly wishes to end his life, and if that is indeed his wish, his desire for dignity should be respected.

However, if we can not determine with full certainty his wish, we cannot assume that he wants to die, since that assumption is based on our point of view. It is acceptable, in the ethical world, to choose ‘life’ in cases where we cannot be sure what the patient’s wishes are, *‘if one is to err, err on the side of life.’*

Active euthanasia (which requires actual termination of life), is generally prohibited and stands against a physician’s primary obligation to advance the patient’s health and well-being. However, it seems that there is more willingness to enable passive euthanasia (the prevention of life-extending treatment), allowing the illness or the medical condition to run its own course and end the patient’s life.

The physician must seriously consider the best interests of the patient in such cases, and there are circumstances when the termination of someone's life is considered his 'best interest (according to people whose perception is that ending life is permissible).'

Among the most problematic cases are those where the patient did not explicitly express his wishes and it is not possible to ascertain what his real desires are. In such cases, one should try to learn more about the individual's perspective on life from letters, as much as such exist, statements made, or explicit behavior of that person, which can enlighten his real wishes.

Another issue we should address is the way in which we choose to end someone's life. Withholding food and water is considered an extreme practice, and society hesitates to use such means as a way to end one's life. However, withdrawal of medications is not considered as an extreme practice, and in many ways it is deemed acceptable. It might be a matter of cultural factors and principles; thus, we should ask ourselves whether there is a significant difference between withdrawal of medication and withdrawal of food or if it is just a matter of psychological perceptions.

CASE STUDY 9

Pain relief

Mrs. GC is a 28-year-old prison inmate. She was approximately seven months pregnant when she gave birth to her child. Prior to the delivery, Mrs. GC was transferred from the Correctional Facility for Women to the Medical and Classification Center (MCC) to facilitate closer monitoring of her pregnancy.

Mrs. GC had five prior pregnancies, most of which were pre-term deliveries. This fact was documented in the MCC records.

At approximately 7:00 p.m., Mrs. GC began bleeding and felt severe pain in her lower abdomen; she went to the Health Services and was seen by Nurse R. Without taking Mrs. GC's vital signs, performing a vaginal examination, or attempting to monitor the baby's heart tones, Nurse R sent Mrs. GC back to her living unit and told her to return when the contractions were six to seven minutes apart.

At approximately 9:30 p.m., Mrs. GC's pain worsened. She returned to Health Services and reported to Nurse R that she was still bleeding with severe pain in her abdomen, and her contractions were six minutes apart. Nurse R placed her hands on the exterior of Mrs. GC's abdomen and noted that she was unable to feel any contractions. Nurse R monitored the baby's heart tones, which were 142 beats per minute.

Despite concluding that Mrs. GC was in 'possible early labor', Nurse R sent her back to her living unit and instructed her to return to Health Services only if the bleeding increased or the contractions intensified in severity or regularity.

Following Nurse R's instructions, Mrs. GC returned to her living unit. She sat on the edge of her bed, her pain mounting, until 11:25 p.m., when she began to scream from the intense pain and moved to the cement floor, where she lay in a fetal position.

At approximately 11:45 p.m., Mrs. GC was transported from MCC to the hospital. Shortly after arriving at the hospital, she delivered a premature baby boy at 12:20 a.m. Neither Mrs. GC nor the baby suffered any complications during the delivery. The baby was later released from the hospital to the care of Mrs. GC's mother.

→ Based upon Mrs. GC's pain and suffering, should Nurse R have acted differently?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

NO Mrs. GC experienced nothing different from what most women endure during childbirth. Nurse R could not have done anything to reduce Mrs. GC's pain and suffering, even if she had sent her to the hospital. The fact that Mrs. GC gave birth to a healthy child without complications in the labor demonstrated that Nurse R acted as she should have.

YES Nurse R should have acted differently. She should have transferred Mrs. GC to the hospital at 7:00 p.m., so she could have received medical treatment to reduce her pain and help her give birth to her child with dignity and less pain. Nurse R violated Mrs. GC's human rights and dignity by her acts.

Notes about the case study

Court decision

This case came before the Court of Appeals for the country. Mrs. GC completed a complaint form used by prisoners to file complaints under the Civil Rights Act. It alleged that Nurse R had violated Mrs. GC's

right to freedom from cruel and unusual punishment through her indifference to Mrs. GC's complaints that she was in labor, thus causing her to suffer both physical and emotional pain.

The Court of Appeals affirmed the district court's decision which held that Nurse R's conduct deprived Mrs. GC '*of the minimal civilized measure of life's necessities afforded her by the Civil Rights Act*'.

Nurse R was accountable for Mrs. GC's pain and suffering between 9:30 p.m. and 11:30 p.m., when she was finally transferred to the hospital. The District Court further held that Nurse R's conduct in delaying Mrs. GC's transfer to the hospital reached the level of callousness and warranted punitive damages to prevent such an occurrence in the future, but the Court of Appeals reversed this decision.

Discussion Pain relief

'Respect of dignity' is a phrase that is yet undefined. Many believe that 'respecting one's dignity' means respecting one's autonomy, yet this is not the case. Although dignity is mentioned in many contexts, it seems that this phrase mostly relates to the need to protect the inherent value of every human being, whether a regular person or someone who committed a crime and is now in prison.

Respecting patient dignity does not only demand appropriate care for the patient, as the medical staff perceive it, but also requires physicians to heed patient desires, complaints and wishes, as the patient sees them (as far as possible), and as he would like to be treated.

Part of respecting a person's dignity involves alleviating his pain. Pain can be intolerable and individual pain thresholds may vary so that whilst one person may not feel any pain, another is unable to tolerate it. Therefore, it is important to relate to what a patient says, to consider his wishes and grant him the appropriate treatment.

When discussing vulnerable populations, such as prisoners, it is important to remember that they deserve to be treated as any other patient, maintaining their dignity at all times when coming into contact

with the healthcare system. Thus, assuring such dignity must receive full attention due to prisoners' vulnerability (vulnerable sectors of the population are also referred to in Article 8 of the *Universal Declaration of Bioethics and Human Rights*).

We would like to stress that, in cases where the medical staff is unable to treat the pain or deal with a patient's complaints, they must refer the patient to another medical institution or locality, where they will receive appropriate treatment.

CASE STUDY 10

Right of refusal

HA is confined to a correctional services medical facility, where he is serving a life term. On May 24, 1991, while he was in prison, HA jumped or fell off a wall. As a result, he fractured a cervical vertebra, rendering him quadriplegic. He lacks any physical sensation or bodily control below the shoulders.

HA suffers from a profoundly disabling and irreversible physical condition. Medical personnel must assist him with all bodily functions, and HA must cooperate with them when he is being fed and given medication. His condition not only makes him fully dependent on others for all bodily functions, but also renders him susceptible to illness and infection that require further medical attention.

Since October 11, 1991, HA has intermittently refused to be fed, causing severe weight loss and threatening his health. He has also refused necessary medication and treatment for his general care. Consequently, he is at substantial risk of death from possible pulmonary emboli, starvation, infection, and renal failure.

Staff psychiatrists have examined HA and found him depressed about his quadriplegic condition, but mentally competent to understand and appreciate his circumstances.

Dr. T, a staff member of the correctional services medical facility, who is the attending physician for HA, would like to give HA life-sustaining treatment.

► Should the physician force HA to get life-sustaining treatment?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES Dr. T has assumed an obligation to force-feed and provide other nonconsensual treatment as he deems appropriate and necessary because, although HA is competent, as a state prisoner he is subject to Dr. T's custodial care.

NO Regardless of his status, HA has the right to decline life-sustaining treatment, even if said refusal may hasten his death. By law, each individual is considered master of his own body, and if of sound mind, he may expressly refuse medical treatment. A doctor may well believe that surgery or some other form of treatment is desirable or necessary, but the law does not permit the doctor to substitute his own judgment for that of the patient's by any form of artifice or deception.

NO Since death is the natural conclusion of all life, the precise moment may be less critical than the quality of the time preceding it. Especially when the prognosis for full recovery is dim, the relative balance of benefit and burden must lie within the patient's exclusive jurisdiction.

Notes about the case study

Court decision

This case came before the Supreme Court of the State. The court concluded that a competent, informed adult has a fundamental right of self-determination to refuse or demand the withdrawal of medical treatment of any form, irrespective of the personal consequences, even at the risk of death. The right does not depend on the nature of the treatment refused or withdrawn; nor is it reserved for those suffering

from terminal conditions. Once a patient has declined further medical intervention, the physician's duty to provide such care ceases.

The right to refuse medical treatment is equally basic, fundamental, and integral to the concept of informed consent. We respect human dignity by granting individuals the freedom to make choices in accordance with their own values. The principle of autonomy is the moral basis for the legal doctrine of informed consent, which includes the right of informed refusal.

Considering the facts of this case, in the absence of evidence demonstrating a threat to institutional security or public safety, prison officials, including medical personnel, have no affirmative duty to administer such treatment and may not deny a person incarcerated in a state prison this freedom of choice.

Discussion Right of refusal

Respecting a person's choice means granting him opportunities to choose and act upon choices once made. The assumption that we must respect people's choice moulds the character of the society we live in. Respecting someone's choice not to live, when such choice is a result of a sound mind consideration, means accepting him as a human being.

The right to refuse to receive medical treatment, even if it is life-saving treatment, is expressed in the individual's right to autonomy and the need to obtain his informed consent to treatment. The fact that a person chooses not to be treated is also a reflection of his wishes and is an integral part of his autonomy. The patient's mere choice is an expression of his dignity and an expression of the respect which we, as a society, give him.

One of the reasons that an individual has been given a choice, is the fact that it is the patient himself who must bear the consequences of his decision, and therefore, the responsibility for the decision and its consequences are his, a fact which is expressed and reinforced in Article 5 of the *Universal Declaration on Bioethics and Human Rights*.

When a person decides to refuse treatment and this choice has a dramatic result, such as death, we must examine whether his decision was an informed and competent one, or whether it was made under emotional or other pressures. Just as it is the physician's obligation to ensure that consent to the treatment is 'informed,' so also must the patient's refusal to receive treatment be made with a recognition and understanding of all related implications.

We must remember that, even if we feel that the patient should have made a different choice, we might not be addressing the patient's personal considerations, his religious and social viewpoint. Only by taking into account all of these considerations can we bring about the right decision, which the physicians must then respect and assist the patient to realize.

In this case, we are talking about a prisoner who is, by definition, a vulnerable patient. Nevertheless, we must be sure to respect his wishes as much as we would do for a 'regular' person.

CASE STUDY 11

End of life

Mrs. SR is a 42-year-old married woman who is the mother of an 8 1/2-year-old son. Mrs. SR suffers from amyotrophic lateral sclerosis (ALS), commonly known as Lou Gehrig's disease. Her life expectancy is between 2 and 14 months, and her condition is rapidly deteriorating. Very soon she will lose the ability to swallow, speak, walk, and move her body without assistance. Thereafter she will be confined to her bed, unable to breathe without a respirator and unable to eat unless a gastrostomy tube is inserted into her stomach.

Mrs. SR understands her condition. She is aware of the trajectory of her illness and the inevitability of her death. Her wish is to control the circumstances, timing, and manner in which she dies.

Mrs. SR does not wish to die so long as she still has the capacity to enjoy life. However, by the time she no longer is able to enjoy life, she will be physically unable to terminate her life without assistance.

Mrs. SR wants a qualified medical practitioner to be allowed to install the technological means by which she can end her own life at the time of her choosing.

→ Should a medical practitioner be allowed to facilitate Ms. SR's wish to determine the time of her death?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES The right to live with dignity also encompasses the right to die with dignity. Therefore, as a terminally ill patient, Mrs. SR

has the right to choose the manner of her death and to get assistance from the medical staff in fulfilling her wish.

YES Mrs. SR's request is no different from shutting down a respirator to hasten a person's death. Therefore, the medical staff should be able to terminate her life when she is no longer able to enjoy it.

NO Euthanasia is forbidden, and the medical staff should not take any part in Mrs. SR's death, despite her wishes.

Notes about the case study

Court decision

This case came before the Supreme Court of the country. The court dismissed Mrs. SR's appeal. The court concluded that Mrs. SR's claim under Section 7 of the country's Charter was based on alleged violation of interests related to her liberty and the security of her person. These interests cannot be divorced from the sanctity of life, the third value protected by Section 7. Even when death appears imminent, seeking to control the manner and timing of one's death constitutes a conscious choice of death over life. It follows that life as a value is also involved in the present case.

Security of the person in Section 7 encompasses notions of personal autonomy (at least with respect to the right to make choices concerning one's own body), control over one's physical and psychological integrity free from state interference and basic human dignity.

The dissenting Judge concluded that Section 7 of the Charter granting citizens a constitutional right to life, liberty, and security of person emphasizes the innate dignity of human existence. Dying is an integral part of living and, as part of life, is entitled to protection under Section 7. It follows that the right to die with dignity should also be protected, as is any other aspect of the right to life. State prohibitions that would

force a dreadful and painful death on a rational, but incapacitated terminally ill patient are an affront to human dignity.

Permitting a patient of sound mind to choose death with dignity by refusing treatment is no different from permitting a patient of sound mind who is terminally ill to choose death with dignity by terminating life-preserving treatment, even if, because of incapacity, such act must be physically carried out by another person at the patient's instructions. Nor is there any reason for failing to extend that same permission so that a terminally ill patient facing death may put an end to his or her life through another person acting as intermediary. Since the right to choose death is open to patients who are not physically handicapped, there is no reason for denying such choice from those who are.

Discussion End of life

When dealing with people at the end of their lives, some relevant principles should be taken into consideration.

One of the most important considerations is respecting someone's choice, even if we would have chosen differently. A right is derived from entitlement, whose unique feature is that it can be waived by the individual. If we look at life as a right, we can argue that its fundamental feature is the ability to decide how and when to end it.

A very common argument in end of life discussions is the sanctity of life. Those who believe that life has value and that it is wrong to take steps to end it, will disapprove of any activity that shortens a person's life. Those who argue that a human being can and should control his life and death can make a distinction between actively killing someone and refraining from an action that may prolong or preserve that person's life. In a medical context, this distinction would mean that doctors may not administer a lethal injection to end one's life, but could withhold treatment that may sustain it.

Another issue we should address in situations like this one is the respect for autonomy, i.e. acknowledging the right of a patient to have control over his own life, including the decision on how his life should

end. A competent patient can express his wishes and define ‘quality of life’ according to his subjective point of view. Some would argue that, under these circumstances, we should help him fulfill his wishes, even if they are to end life, while others would argue that it is the same as assisted suicide, which is illegal in many countries.

The ability to choose and respect choices obligates society to deal with the implications of the choice. However, as long as the choice does not harm anyone, we should respect it.

We emphasize that, in any case, the doctor must not take such a decision alone or unilaterally. Physicians should refer to an ethics committee or another jurisdictional body to determine the best course of action on a case-by-case basis. Moreover, even if active euthanasia is permitted in a given case, this decision cannot obligate doctors to act in contravention of their own moral conscience, nor can medical staff be forced to perform such a medical procedure.

CASE STUDY 12

Forced treatment of the mentally ill

Mr. MR, Ms. FZ and Ms. FG had been involuntarily committed to a Psychiatric Center. Each was being retained pursuant to orders of the local County Court, which had found them to be persons in need of involuntary care and treatment, in that they have a ‘mental illness’ for which care and treatment as a patient in a hospital is essential to their welfare and their judgment is so impaired that they are unable to understand the need for such care and treatment.

These patients refused to be medicated with antipsychotic drugs. Their objections were overruled, and they were subsequently medicated with various antipsychotic drugs.

Mr. MR and Ms. FZ thereafter commenced a declaratory judgment action against the commissioner and officials of the Psychiatric Center. They sought to obtain an injunction against the nonconsensual administration of antipsychotic drugs and a declaration of their common law and constitutional right to refuse medication.

Ms. FG refused treatment with antipsychotic drugs, but was thereafter forcibly medicated. She alleged that the forcible use of antipsychotic medication violated her common law and constitutional right to determine her own course of treatment.

→ Should the hospital allow mentally ill patients to determine their own course of treatment?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES Every individual of adult years and sound mind has the right to determine the course of his medical treatment. This fundamental right is coextensive to mentally ill patients. The fact that patients at a state facility are mentally ill or have been involuntarily committed does not constitute a sufficient basis to conclude that they lack the mental capacity to comprehend the consequences of their decision to refuse medication and to understand that their refusal poses a significant risk to their physical well-being.

NO The right to reject treatment refers to patients of sound mind. The above mentioned patients seem to be impaired and to lack the capacity to make a reasoned decision with respect to proposed treatment. Therefore, these patients cannot determine the course of their treatment, and they should be treated with antipsychotic drugs for their best interests.

Notes about the case study

Court decision

This case came before the Court of Appeals of the country after the trial court had dismissed the patients' complaints, mainly, their right to refuse medication. In addition, the trial court determined that these patients were so impaired by their mental illness they were unable to make a competent choice in respect to their treatment. The lower court affirmed the dismissal, and the patients appealed.

The Court of Appeal reversed the ruling, stating that the individual must have the final say in respect to decisions regarding his medical treatment to insure that the greatest possible protection be accorded with his autonomy and freedom from unwanted interference with the furtherance of his own desires. This right extends equally to mentally ill persons, who are not to be treated as persons of lesser status or dignity because of their illness.

The court stated that the fact that the patients were mentally ill and were involuntarily committed did not constitute a sufficient basis to conclude they did not have the mental capacity to comprehend their decision. The court rejected any argument that the mere fact that appellants are mentally ill reduces in any manner their fundamental liberty to reject antipsychotic medication.

The court reversed the dismissal of the patients' action and remitted the case to the trial court.

Discussion Forced treatment of mentally ill patients

Respecting a person's dignity commits us to respecting his choices. Being mentally disabled does not preclude the right to choose and to be respected. A person's dignity is not embodied in his ability to choose, but rather exemplifies his existence as a human being. That being the case, it is not a question of respecting a person's choices and as a consequence respecting him, but rather respecting him, as a human being, and as a consequence respecting his choices.

Thus, mentally disabled people have the same degree of dignity as any other human being and their choices should be respected. For example, they have the right to refuse treatment. Every patient's decision must be examined in light of the specific circumstances. A patient who chooses to be hospitalized is not automatically considered to be a person who agrees to every treatment.

Denying their rights on the grounds that they are incapable of making meaningful decisions cannot serve as an excuse for forced treatment.

Furthermore, informed consent is a basic right that is based on the recognition of the patient's human status as a free man and on society's obligation to respect his dignity.

Refusing treatment is part of the patient's expression of autonomy and dignity.

In our case, there is no mention of whether or not the patients have a guardian. If they do, the guardian, who must act in their best interest, should consider whether or not to consent to the treatment. If they do not have a guardian, then they are probably somewhat competent and capable of making their own decisions, which we, in turn, must respect.

Protection of individuals who are unable to give their complete consent must be stronger and executed with as much caution as possible, so as not to take advantage of their impairment or to advance goals which are not worthy, as stated in Article 8 of the *Universal Declaration on Human Rights*:

In applying and advancing scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account. Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected.

It is important to stress that the obligation of the medical staff is intensified, owing to the impaired state of the psychiatric patient, but as long as he is not a danger to society, his desire to refuse treatment must be considered as an option.

The staff in charge is bound to act in the patient's best interest and in a manner which benefits the patient. However, the beneficence should be considered along with the patient's personal choice and view of the situation.

CASE STUDY 13

Bone marrow donation by a mentally ill patient

Y, a 25-year-old woman, severely mentally and physically handicapped from birth, lives in a community home. Until the age of 10, she lived with her parents and three sisters in a close-knit family and since moving to the home she has been visited regularly by her mother and sisters. Those visits are very important to Y, particularly because they maintain her link with the outside world, which is helpful to her and would otherwise be lost.

Her eldest sister, aged 36, is married and has one daughter, E, aged 6. Y's sister suffers from a pre-leukemic bone marrow disorder known as myelodysplastic syndrome. Her only realistic prospect of recovery is a bone marrow transplant from a healthy, compatible donor. Furthermore, bone marrow transplanted from a sibling is superior to a transplant from a stranger. Preliminary investigations show that of the three sisters, only Y would be a suitable donor. Without a transplant, Y's sister's prospects of survival are very poor and are deteriorating fast.

Due to her disabilities, Y is unaware of her sister's illness and unable to consent to the tests and surgical procedure entailed in donating bone marrow. Y understands her own basic needs but cannot understand the needs of others.

The disadvantages to Y from the harvesting procedure are very small.

→ Should Y be a bone marrow donor for her sister despite the fact that she is incapable giving her consent?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

NO Taking blood for testing and harvesting bone marrow from Y, who is incapable of giving informed consent, would amount to assaults upon her and would therefore be illegal.

YES Although the suggested procedure is not therapeutic for Y, it is in Y's best interests for such a procedure to take place. By helping her sister, Y will enable her family to continue visiting her, and in that way, Y's best interests will be served.

Notes about the case study

Court decision

This case came before the court which concluded that the test to be applied in a case such as this is to ask whether the evidence shows that it is in Y's best interests for such procedures to take place. The fact that such a process would obviously benefit her sister is not relevant unless, as a result of helping her sister, Y's own best interests are also served.

The death of Y's sister is bound to have an adverse affect upon Y's mother, who already suffers from major health problems. The mother's ability to visit Y would be significantly impaired, not only due to foreseeable deterioration in her health, but also by the need which would then arise for her to look after her only grandchild, E.

In this situation, Y would clearly be harmed by the reduction in or loss of contact with her mother. Accordingly, it is to the benefit of Y that she should act as donor to her sister, because in this way, her positive relationship with her mother is most likely to be prolonged. Further,

if the transplant occurs, it is likely to improve Y's relationship with her mother, who in her heart clearly wishes the transplant to take place. It is also likely to improve Y's relationship with her sister, who will be eternally grateful to her.

Therefore, donating bone marrow to her sister will benefit Y emotionally, psychologically, and socially.

Discussion Bone marrow donation by a mentally ill patient

Dignity, according to some traditions, is the intimate and symbolic care of the individual. Therefore, every individual has dignity and, in order to respect it, we grant rights, such as privacy and the ability to fulfill one's own desire. There are situations where the individuals cannot have any will, such as cases of mentally ill people. Nevertheless, this fact doesn't detract from the dignity, which one still has and which we still have to respect.

In considering invasive medical procedures for the mentally ill—who often lack self awareness and are dissociated from their surroundings—the proposed treatment must be evaluated solely on the basis of the patient's own welfare and benefit. Patient benefit is an important ethical principle in healthcare. However, the good, or benefit, in question is not the same to different individual patients. In fulfilling this obligation of beneficence, the medical staff, sometimes intentionally, practices without patient consent.

When relating to benefitting patients who cannot express their wishes, general (non-medical) issues can also be taken into account in evaluating the overall damages and benefits of treatment. In this context, we should include the emotional trauma that the patient might suffer due to the death of a close relative, the patient's attachment to that person, and reasonable expectations of the patient's ability to recover from the loss. It is important to examine all dimensions of the patient's life and not to isolate the medical consequences of treatment from other facets thereof.

Therefore, in situations where the expected harm to the patient is insignificant and the benefits are numerous, we might go on with this procedure, even without the patient's consent.

While evaluating overall benefits and damages, we should try to involve the patient as much as possible and explain matters to the best of their capacity for understanding.

CASE STUDY 14

Refusing life-saving treatment on behalf of a minor

DJ is six years old. He was diagnosed with a highly malignant tumor that, if not properly treated, will inevitably result in his death. Currently available treatment methods offer hopes for a cure; however, these methods necessitate the use of a blood derivative.

Both of DJ's parents were informed of these facts. Despite being Jehovah's Witnesses, they were aware of the seriousness of their son's illness and gave their consent to the treatment.

Three months later, the parents were told that a further round of chemotherapy treatment was needed to treat the illness.

Several days later the minor's condition worsened. He was admitted to University Hospital, where it was determined that another blood transfusion was necessary. This time the parents made a statement to the effect that they were aware of the seriousness of the illness. However, should the minor's treatment require any further transfusions of blood, they could not give their consent. Based upon their religious convictions and on health grounds as well, they were wary of the risks of blood transfusion.

Accordingly, they insisted that their minor child be treated solely with pain relievers. In continuing to refuse further chemotherapy treatments involving blood transfusion when no alternative treatment was available, the parents were denying DJ his one hope of a cure. Thus they were gravely threatening his health and life.

► Should DJ be treated with blood transfusion despite his parents' refusal which is based on their religious beliefs?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

NO The parents have a right to determine the course of treatment for their own child.

YES Although the parents have the right to determine the course of treatment for their child, they cannot deprive him of his only chance to live. Therefore, in this case the child should be treated with the life-saving treatment, including blood transfusion.

Notes about the case study

Court decision

This case came before the Constitutional Court of the country. The court affirmed the first instance decision. This decision concluded that in view of the fact that the parents of the minor child refused further chemotherapy treatment, they took from him the sole hope of a cure, thus gravely threatening his health and life. According to the Chief Physician of the Clinic of Child Oncology of the University Hospital, there was and is no alternative treatment offering the child any hope of a cure, and his parents are aware of this fact. In the opinion of the court, the parents, in maintaining their position on treatment, threaten not only the child's health, but also his life; thus, they have violated their parental duty, in particular their obligation to provide proper care for the health of their children.

The right to respect one's private and family life is not unlimited, as public authorities may interfere with the exercise of this right, though only if such interference is in accordance with the law and is necessary in a democratic society in the interests (among others) of protecting the health or the rights and freedoms of others.

Discussion Refusing life-saving treatment on behalf of a minor

Minors, as any other human being, have the right for dignity, which should be respected. Dignity also includes an aspect of cultural diversity. Where people in our society fail to abide to norms, due to their beliefs, we should respect them and their right to grant or withhold consent to medical treatment and avoid intervention.

Minors are generally considered unauthorized to grant informed consent to medical treatment. Therefore, their parents grant such consent on their behalf. In making decisions about their children's medical care, parents must consider the child's welfare and the maximum benefit that treatment can provide the child.

In situations where parents make decisions for their child, most of the problems arise when they make choices that seem to contradict their child's best interest.

There was controversy regarding what standard to use when defining goals of treatment. Today, the 'best interest' standard is most acceptable. However, it may be difficult to determine what is in a child's best interest, particularly when making value-laden choices, as in cases in which parental decisions involve core beliefs, religious faith, and other considerations. In principle, these considerations should be respected, as described in Article 12 of the *Universal Declaration on Bioethics and Human Rights*:

The importance of cultural diversity and pluralism should be given due regard. However, such considerations are not to be invoked to infringe upon human dignity; human rights and fundamental freedoms, nor upon the principles set out in this Declaration, nor to limit their scope.

However, there are exceptional cases in which parental beliefs are so extreme or strongly held that they may cause real harm. In these cases, it is important to determine if the parents' considerations are damaging to the child.

There are various conditions that must be met in order to override parental autonomy²:

- a. The medical professionals are in agreement with regard to the definition of the appropriate treatment in an individual case
- b. The expected outcome of treatment is a relatively normal life of reasonably good quality.
- c. The child would die without treatment.

Decisions to act in contrary to parents' opinion may be considered by an ethics committee or similar body, while giving primary weight to the child's needs and welfare.

² Gaylin, W.; Macklin, R. (eds.) 1982, *Who Speaks for the Child? The Problems of Proxy Consent* (The Hastings Center Series in Ethics), New York, NY: Springer.

CASE STUDY 15

A minor refusing life-saving treatment because of faith

LDK is a 12-year-old patient suffering from a fatal disease known as acute myeloid leukemia. After consulting with doctors at the Sick Children's Hospital, the family was advised that the recommended treatment was chemotherapy, which would necessitate blood transfusions. This treatment is both intensive and aggressive and could go on for a considerable period of time. No alternative treatment was offered.

Because LDK and her parents are Jehovah's Witnesses, they could not consent to any treatment that would include the transfer of blood or blood products.

LDK strongly objected to chemotherapy, with or without blood transfusions. LDK had been hospitalized together with other leukemia patients and had seen other children who were undergoing chemotherapy treatment. Some of these children lost their hair, cried out in pain and begged not to have any further treatment.

LDK has stated clearly that if an attempt is made to transfuse her with blood, she will fight that transfusion with all the strength she can muster.

All the family's efforts to obtain assistance at several hospitals around the world were in vain. LDK's condition began to deteriorate. Again, the only option offered was chemotherapy and blood transfusions, and again this option was unacceptable to LDK and her family.

LDK and her parents proposed their own treatment plan. The family would remove LDK from the hospital and place her in the home of relatives, where she would be treated with mega-vitamin therapy under physician supervision. There are no statistics on the rate of success of the mega-vitamin treatment.

LDK has wisdom and maturity well beyond her years. She has well-considered, firm and clear religious beliefs.

Should the physicians responsible for LDK's treatment force her to undergo chemotherapy, including blood transfusions?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

NO Although LDK is a minor, she is mature for her age and is capable of understanding the consequences of the recommended treatment, which not only contradicts her beliefs, but is also aggressive and painful. Therefore, the course of treatment should be the one suggested by her and her family, even though its therapeutic value is unclear.

YES Despite LDK's maturity, she is a minor; she cannot evaluate the risk of death. Her wishes should be heard, but the treatment cannot be motivated by her fear of painful treatment. Moreover, her religious beliefs cannot be respected if they deprive her of life-saving treatment. In addition, the treatment suggested by her and her family is not an alternative treatment because its therapeutic value has not yet been discovered.

Notes about the case study

Court decision

The case came before the Provincial Court of the state. The Children's Aid Society sought an order finding LDK to be a child in need of protection because she and her parents were unwilling to submit to treatment involving blood transfusions. The court concluded that the agency failed to reveal its legal onus to prove that this child is in need of protection.

The treatment proposed by the hospital addresses the physical disease only. It failed to address the patient's emotional needs and her religious beliefs. The emotional trauma she would experience as a result of any attempt of transfusion could have nothing but a negative effect on any treatment being undertaken.

LDK should be given the opportunity to fight this disease with dignity and peace of mind. That can only be achieved by accepting the plan put forward by her and her parents. Despite the lack of statistics regarding the rate of success with the mega-vitamin treatment, this treatment is still preferable. During this treatment, LDK will be surrounded by her family, and she will be free to communicate with her God. She will have peace of mind and can continue attempting to overcome this dreadful disease with dignity.

Discussion A minor refusing life-saving treatment because of faith

We use human rights to set global norms. However, there is a perception that, since these norms grew from historical and social circumstances, they are not relevant to societies and people who have different beliefs or cultures. A possible answer to that claim is that, although human rights have roots in a certain culture, they still have sufficient flexibility to suit cultural diversity.

We accept refusal to life-saving treatment in respecting a person's autonomy. A person's refusal to treatment, while taking personal responsibility for the outcome, is an expression of his dignity as a human being. The medical staff cannot replace the patient's inner feelings by their own considerations.

When this relates to a minor, who is legally incompetent and cannot refuse or consent to treatment, but on the other hand does understand the situation and its consequences, his wishes must be considered and he must be involved, as much as possible, in the decision. This issue is addressed in Article 7(a) of the *Universal Declaration on Bioethics and Human Rights*, and in the various health-related international instruments and UN conventions, such as in Article 12 of the *Convention on the Rights of the Child*.

The more mature the adolescent and the deeper his capability to understand, the more conscious we must be to respect his dignity and wishes. When the child has beliefs which do not correspond with our own or when he lives within a different culture, we ought to be flexible and consider his will as well.

The need to balance between the fact that the patient is a minor and that he has full understanding of the situation and is mentally competent, obligates the medical team to consider local regulations on the one hand, but also to pay attention to the minor's needs, on the other.

CASE STUDY 16

Refusing treatment due to religious beliefs

A, a minor aged 15 years and 10 months, became ill and was admitted to the hospital on September 8, 1990, where he was diagnosed with leukemia.

Conventional treatment for A's disease involves the administration of four drugs. The side effects of two of those drugs necessitate blood transfusions from time to time. This recommended treatment offers an 80% to 90% chance of full remission. The hospital was unable to follow this conventional course of treatment because A and his family are devout Jehovah's Witnesses, and blood transfusions are contrary to the tenets of their faith.

A expressed his refusal to receive the needed blood transfusion. His refusal was supported and continued to be supported by his parents, who likewise refused to give their consent, though they consented to all other hospital treatment.

An alternative treatment offers only a 60% chance of remission. Because the child indicated his refusal to receive a blood transfusion, and because he was supported by his parents, the hospital resorted to the alternative course of treatment. Within two weeks, the child's condition deteriorated to the point where his life was threatened.

According to local law, a minor who has attained the age of 16 years can lawfully consent to a medical treatment. In the absence of consent, treatment would constitute a trespass to the minor, as much as it would be if he were an adult.

► Should the physicians respect the wishes of A and his family not to receive any blood transfer?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES The physicians should respect A's wishes and his refusal of the treatment. A is almost 16, an adult patient with full mental capacity, so he has an absolute right to refuse treatment, even if the decision is considered to be misguided, irrational, or wrong according to medical or legal opinion, and even if the ultimate outcome is death.

NO A is a minor and therefore, by law, is not capable of deciding. Nevertheless, even if A were legally capable of determining the course of his treatment, his best interests are to receive the blood transfusion. Therefore, the physicians should act in A's best interest, even at the expense of A's own wishes.

Notes about the case study

Court decision

The above mentioned case was heard by the Family Division of the state, where the hospital sought the approval of the court to treat A as it saw fit, including the administration of blood transfusions. The court stated that although A was a boy with sufficient intelligence to be able to make decisions about his own well-being, his condition involved a range of decisions, some with implications beyond his ability to grasp. Nevertheless, the court was impressed by his obvious intelligence, his calm discussion of the implications, and his assertion that he would refuse even knowing he might die as a result.

In the court's view, A did not sufficiently comprehend the pain he was likely to suffer, the fear he would experience, the distress not

only occasioned by that fear, but also and importantly, the distress he would inevitably suffer as a loving son helplessly watching the anguish of his parents and his family. A did not fully understand all the implications involved in refusing the treatment.

The Judge added:

In my judgment, whether or not he is of sufficient understanding to have given consent or to withhold consent is not the issue for me. In considering what his welfare dictates, I have to have regard to his wishes. What he wishes is an important factor for me to take into account and, having regard to the closeness to his attaining 16, a very important matter which weighs very heavily in the scales I have to hold in balance.

In my judgment, A has by the stand he has taken thus far already been and become a martyr for his faith. One has to admire, indeed one is almost baffled by, the courage of the conviction that he expresses. He is, he says, prepared to die for his faith. That makes him a martyr by itself. Nevertheless, I regret that I find it essential for his well-being to protect him from himself and his parents, and so I override his and his parents' decision. In my judgment which has been truly anxious, I have endeavored to pay every respect and give great weight to the religious principles which underlie the family's decision to the fundamental human right to decide things for oneself. That notwithstanding, the welfare of A, when viewed objectively, compels me to only one conclusion, and that is that the hospital should be at liberty to treat him with the administration of those further drugs and consequently with the administration of blood and blood products.

Discussion Refusing treatment due to religious beliefs

Respecting cultural diversity is an integral part of human rights. Though we accept the axiom that every human being has the right to dignity and the right to life, we must also respect his choice to live in certain way and to hold certain beliefs.

The right to refuse medical, albeit life-saving, treatment due to religious and cultural beliefs is part of a person's dignity, and we should respect his choice, since we respect him as a human being with dignity and free mind. This is stated in Article 12 of the *Universal Declaration on Bioethics and Human Rights*:

The importance of cultural diversity and pluralism should be given due regard.

Avoiding treatment, even in cases which could lead to the patient's death, exemplifies the social-bioethical principle of respecting the patient's will, even when we believe that a different course should be taken, and the realization of his autonomy to decide for himself.

The right to refuse medical treatment is an aspect derived from the obligation to receive informed consent for every medical procedure. We accept that the patient can define what kind of life he wishes to live and when his life is so poor that it cannot be considered 'life' according to his beliefs and wishes.

It is important to ascertain whether a person, who refuses treatment, particularly if such treatment may result in significant improvement of the patient's well-being, fully understands the consequences of his decision and to ensure that he has come to this decision freely and out of his own accord.

With minors, especially those on the verge of adulthood, their point of view is most important. We must ascertain that they understand their situation and the consequences of their refusal, and we must hear their standpoint and wishes, and take them into consideration.

Local laws sometimes compel the provision of treatment, even without consent, and the physician must determine whether his patient falls into this category. In cases such as these, patients' failure to understand the situation and/or its consequences is usually accompanied by treatment options that can greatly improve patient health.

In cases of Jehovah's Witnesses, especially when relating to children, the courts often enforce treatment.

CASE STUDY 17

Informed consent

Mr. S, a 56-year-old male, consulted his family physician due to respiratory problems. After X-rays revealed patchy infiltration of the lung, Mr. S was referred to a respiratory specialist, who determined that the condition was bilateral and recommended an open-lung biopsy, which Mr. S refused to undergo.

After Mr. S's condition further deteriorated, he was referred to Dr. D, an internist specializing in respiratory diseases. Dr. D observed that Mr. S was exceptionally anxious upon examination. The doctor's initial diagnosis was progressive pulmonary fibrosis of the interstitial pneumonitis type, probably involving fibrosing alveolitis. A biopsy was required to confirm this diagnosis, but Mr. S continued to refuse to undergo an open-lung biopsy.

Dr. D then suggested an alternative procedure, known as a trephine lung biopsy. This procedure was inferior to the open-lung method, but in view of Mr. S's refusal to undergo the open-lung biopsy, it was an appropriate alternative. Dr. D explained to Mr. S that the procedure involved administering a local anesthetic and then inserting a special needle into the lung while the patient sat on the edge of his bed. He also told the patient the needle would be attached to a drill. Dr. D then outlined the procedure's risks, advising Mr. S that the procedure was usually virtually painless, but did have two possible complications. Dr. D did not mention to Mr. S that the procedure also involved risk of perforating the spleen or the liver, an uncommon risk but not as uncommon as death. Apparently Dr. D was not aware of this risk.

Mr. S consented in writing to the trephine biopsy procedure. Prior to the procedure, Mr. S was anxious, apprehensive, and nervous. He told Dr. D he could not afford to die. He was given atropine and sedated with normal and accepted doses of morphine. Once Mr. S had been sedated, Dr. D gave him instructions and demonstrated the equipment to him. After a local anesthetic was administered, the operation began.

At a critical juncture, Mr. S was directed to hold his breath. Instead, Mr. S winced and moved, causing his spleen to be perforated.

Dr. D told Mr. S that the required tissue sample had not been obtained, but did not yet disclose that the spleen had been perforated. When Mr. S asked Dr. D what he had obtained from the biopsy, he answered ‘something else.’ It soon became painfully obvious that Mr. S’s spleen had ruptured and had to be surgically removed.

→ **Taking into consideration that Mr. S was an extremely anxious patient, should the doctor have acted differently with respect to the explanations he gave to Mr. S?**

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES Dr. D should have acted differently than he did. The patient was inadequately prepared psychologically for his required role in the procedure. Since Mr. S was recognized as an unusually anxious person, Dr. D should have won Mr. S’s confidence through better and more effective communication. Dr. D gave instructions and demonstrated the equipment only after Mr. S had been sedated. The procedure should have been explained and the equipment demonstrated when Mr. S was in an un-sedated state. Furthermore, this particularly anxious patient should have been prepared for this procedure through careful rehearsal to teach him how to hold his breath and refrain from moving. The statement Mr. S made to Dr. D immediately before the procedure, that he could not afford to die, was a clear indication of his apprehension. At that point, Dr. D should have evaluated Mr. S’s willingness to proceed, which could have been tested only when Mr. S was alert and not under sedation.

NO Dr. D acted properly and did not breach his obligation to provide Mr. S explanations about the procedure. All the

explanations that should have been given before the procedure were provided. Determining that this behavior constitutes a breach of a physician's obligation to his patient would increase the liability on physicians to an intolerable level.

Notes about the case study

Court decision

Mr. S sued Dr. D for negligence. The alleged acts of negligence included a failure to obtain informed consent, a failure to perform the biopsy in accordance with a reasonable standard of care, and falling below a reasonable standard of post-biopsy care.

The court ruled that Dr. D failed to provide a reasonable standard of medical care. This very anxious patient had not received adequate psychological preparation for his required role in the procedure. His required cooperation should have been explained to him before he was sedated and should have been carefully rehearsed. Mr. S's expression of acute fear, even under sedation, should have led Dr. D to discontinue the procedure. Discussing the procedure further while the patient was not sedated might have elicited his agreement to undergo it.

The court determined that the physician-patient relationship in this case was less than satisfactory. Dr. D failed to take Mr. S into his confidence and provide him the information a patient is entitled to, as a matter of professional relations, if not a matter of law.

Dr. D had an obligation to inform Mr. S that his spleen had been perforated. Mr. S asked Dr. D what he had obtained at the biopsy. Dr. D's failure to be candid with Mr. S was a breach of obligation.

The cumulative effect of all these circumstances, even if most of them individually might be characterized as errors of judgment, is to establish liability for negligence on the part of the defendant.

Discussion What is informed consent?

Every medical treatment requires the patient's informed consent. The significance of this consent is that a person agrees to: the treatment, the 'invasion' of his body, understands the significance of his medical condition and the meaning of the treatment, the dangers and the benefits inherent in the treatment, and grants his informed consent willingly and without coercion, as determined in Article 6(1) of the *Universal Declaration on Bioethics and Human Rights*:

Any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information.

Informed consent is a doctrine which was developed by courts over the years and is anchored in law in certain western countries. This doctrine strengthens mutual physician-patient trust and respect by helping the patient reach an informed decision freely with respect to the treatment to be given.

In order to obtain an 'informed' decision, three elements must be determined:

- 1 Free will:** the patient's wish, without coercion or outside pressure.
- 2 Information:** The patient must receive all of the information regarding his condition and the proposed treatment, including alternative treatments, side effects and the effect of not receiving treatment.
- 3 Competence:** The patient must be competent to make an informed decision.

Consent will be valid only if it has been given in respect of the proposed treatment.

The obligation of the physician is to strictly adhere to the rules of informed consent, as part of the autonomy and respect he is obliged to his patient. Therefore, the physician must always consider the personal characteristics of the patient, such as anxiety, his special peculiarities, as much as such exist and his unique personality and relate to it by providing the relevant explanations. One of the challenges facing the medical staff is providing each patient with appropriate information.

CASE STUDY 18

Information required for informed consent

Approximately one month after her marriage, Mrs. NP went to Dr. A's clinic seeking help in becoming pregnant quickly. Shortly after being treated with ovulation stimulants, Mrs. NP conceived, resulting in a pregnancy with four fetuses. As the pregnancy advanced, the risk to the fetuses grew. Therefore, Mrs. NP was referred to the outpatient clinic of the local hospital, where her pregnancy continued to be monitored and treated.

Mrs. NP is a devoutly religious woman who prays every day. The hospital at which she was receiving treatment is also a religious institution.

The chances for such a pregnancy to reach term are low due to the risk of premature delivery and all the complications of such a delivery. To overcome these problems, several techniques have been developed in recent years to reduce the number of fetuses. Fetal reduction preserves the well-being of the other fetuses and extends the pregnancy to term. Such reduction techniques can be carried out during the first trimester and even at the beginning of the second trimester. Although this method is considered 'cruel', it has successful results. Nevertheless, fetal reduction carries a risk of killing all of the fetuses.

The hospital and the medical staff are opposed to this method because they believe it is forbidden by their religious beliefs. Therefore, the hospital does not perform such procedures.

Mrs. NP and her husband were not informed of the possibility of fetal reduction.

Due to complications in Mrs. NP's pregnancy, she delivered the four fetuses in her 25th week of pregnancy. All of the fetuses died shortly after delivery.

→ **Was the physician obligated to inform Mrs. NP and her husband about the possibility of fetal reduction, even though this procedure is contrary to their religion, contrary to the physician's conscience, and contrary to his own religious beliefs?**

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES The physician should inform Mrs. NP and her husband of all the possibilities even if they go against his conscience and his own beliefs. After receiving all of the information, Mrs. NP and her husband can decide what to do in accordance to their conscience. Depriving relevant information from Mrs. NP and her husband is a violation of their right to autonomy.

NO The medical staff believes that reducing fetuses is forbidden according to their religious beliefs. Therefore, they are not obligated to tell Mrs. NP and her husband about an option forbidden by their religion.

Notes about the case study

Court decision

This case came before the District Court of the state which concluded that according to local law, a physician is not obligated to perform a procedure if it goes against his personal conscience. In this case, Mrs. NP and her husband are religious people treated at a religious institution. Hospital personnel do not consider fetal reduction to be an option because they believe it goes against their religion.

It is the hospital's right to act according to its principles and values. However, the hospital should have informed Mrs. NP and her husband that such a procedure exists and should have allowed Mrs. NP

and her husband to decide about the procedure, even if the hospital is against it.

Discussion Information required for informed consent

Although dignity has a central role in bioethics, it is not a magic word and in order for it to become functional, it requires practical norms, such as informed consent. Informed consent is regarded as a right of all human beings, stating that any medical treatment may only be administered upon obtaining the patient's informed consent. The patient's power to grant informed consent is an integral part of his autonomous right to decide what shall be done to his body.

In order to grant informed consent, patients must receive all relevant information, including details of their medical condition and prognosis, the available therapeutic alternatives, and the repercussions of treatment or non-treatment.

In many instances, patients decide on a proposed course of treatment based on personal, subjective and non-medical, factors: emotional, religious, and others.

The doctor is obligated to provide patients with all of the relevant information, enabling them to reach a well-considered decision. Relevant information includes therapeutic alternatives that are more expensive or less accessible at the given location. The doctor should not replace the patient's consideration by his own to choose between therapeutic options. Even if the doctor knows the patient and his beliefs, even if the doctor thinks he knows what the patient will choose, this does not absolve the doctor's obligation to supply complete and current information so that the patient can independently decide on the option that is best for him.

On the other hand, the physician and the medical institute are also entitled to respect their own beliefs and norms. Accordingly, one must respect medical institutions which act according to religious beliefs or cultural tradition. Thus, we cannot force such an institute to perform a procedure which is against its faith; however, this alone cannot relieve

the institution from its obligation of informing patients of the existence of alternative procedures.

Doctors are not obligated to act against their own personal beliefs. For example, one cannot force a physician to perform an abortion if he believes it is wrong, just as we cannot force him to help a patient end his life if he believes that it is considered murder.

CASE STUDY 19

Information about alternative treatments

On 28 January 1991, Ms. X, a 53-year-old woman, was examined by a doctor, who then ordered a surgical biopsy. On 14 February 1991, the results of the biopsy showed she was suffering from breast cancer.

At the time, two treatment methods were available for treating Ms. X's disease. The first method, mastectomy, entailed surgically removing all of the breast tissue, while preserving the underlying pectoral muscle. The second method, known as the conservative treatment or breast-conserving surgery, involved removing only the tumor and a small amount of surrounding tissue. The doctor advised Ms. X that while the conservative treatment for breast cancer was being implemented, this method was not yet fully and accurately understood. The doctor also told Ms. X that her breast would be totally removed, but the pectoral muscle would remain.

At the time of the operation, the conservative treatment for breast cancer was not yet prevalent, and mastectomy was the primary method used. There were not too many reported cases of implementing the conservative method, results had only been observed for a short period of time, and the method of treatment had yet to be established. Nevertheless, at the time of Ms. X's operation, the doctor was aware that a sizeable number of medical institutions were using the conservative treatment for breast cancer.

The doctor operated on Ms. X on February 28, 1991 and removed her breast. Before the operation took place, Ms. X handed the doctor a letter outlining the complex sentiments of a woman diagnosed with breast cancer and faced with a choice between continuing to live and having her breast removed.

→ **Was the doctor under an obligation to inform his patient about the conservative treatment for breast cancer which at that time had not yet been strongly established?**

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES The doctor should have told Ms. X that alternative treatments were available. The breast is located prominently on the front of the body and is a symbol of femininity. Losing a breast in such an operation changes the patient's appearance and could seriously affect her mental and psychological state. The doctor should have given the patient the opportunity to determine the course of her treatment and not deprived her of information about an alternative treatment only because it has not yet been established.

NO The doctor did inform Ms. X that there was a way of preserving the breast. He did refer, more or less, to the alternative treatment method and mentioned its pros and cons and the prognosis after treatment.

NO Since the rate of implementation of the conservative treatment was low and its safety had yet to be established, the situation had not reached the stage where the doctor should have asked whether the patient wanted to try this treatment, despite the risk in its implementation. Therefore, the doctor's explanation was not insufficient as an explanation of the available alternative method of treatment.

Notes about the case study

Court decision

This case came before the Supreme Court of the country. The court concluded that if there are several established methods that all adhere to medical standards, the doctor, as a matter of course, is required to explain, clearly and explicitly, the differences between the treatments and their pros and cons so that patient can choose between them after sufficient consideration.

However, in cases where one treatment has already been established as adhering to the standard of medicine, while the other has yet to be established, it cannot be said that the doctor is always under an obligation to explain the latter treatment. On the other hand, it cannot be denied that there are instances in which a doctor is under an obligation to explain even such a non-established treatment. In this case, the treatment had been implemented at a sizeable number of medical institutions, a considerable number of operations had already taken place, and the results had been positively assessed by doctors who implemented this treatment.

The doctor was aware that the treatment might be suitable for the patient and that the patient was strongly interested in the suitability and applicability of this treatment to herself, despite his negative view of this treatment and his own refusal to implement it himself. Under such circumstances, the doctor is under an obligation to inform the patient, within the scope of his knowledge, about the content of the treatment, its suitability, its pros and cons, as well as the name and address of the medical institutions which offer this treatment.

The mastectomy surgery for breast cancer is an operation to remove the breast. Surgical removal of the breast can seriously affect the patient's mental and psychological state as a result of the change in her appearance. Such surgery has an impact on the patient's quality of life, indeed upon the whole manner in which she conducts her life. Thus, doctors are obligated to explain the conservative treatment for breast cancer as an alternative treatment before deciding upon surgical removal of the

breast tissue while preserving the pectoral muscle. This requirement is even stronger than in general surgery that does not have such an impact on the patient's appearance and quality of life.

Discussion Information about alternative treatments

Dignity is not a well defined notion and different sources refer to it with different meanings. In order to unify the definition of dignity, some 'practical rights' call for particular definitions, such as the right to approve medical treatment without 'informed consent'.

To effectively implement this right, the patient must have all of the information relating to the medical procedure, including information about alternative treatments. According to one approach, the physician must disclose every option available to the patient, even if it is not truly feasible, only then can the doctor be convinced that the patient will be able to make a fully informed decision. Another approach says that if the patient is unable to receive the treatment either because it is unavailable or he cannot afford an alternative treatment, the physician does not have to tell him about it.

The right of informed consent is an integral part of the patients' autonomy to determine the treatment most suitable for them, based on their medical condition, their general life perception, values, beliefs, and feelings. This autonomous decision is part of one's personal responsibility and it follows from the fact that patients will have to live with the consequences of treatment – whether it succeeds or not. This principle is expressed in Article 5 of the *Universal Declaration on Bioethics and Human Rights*:

The autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, is to be respected.

To obtain genuine informed consent, based on the patients' sincere and free will, comprehensive information relating to their medical condition, available treatment options, as well as benefits and risks involved in each of the treatment alternatives must be disclosed. Certainly, this

includes therapies that are less common or more expensive, as long as they are established and accepted medical protocols. Even if a course of treatment is infrequently applied or is highly costly, still it should be discussed with the patient, who may opt for that treatment despite its cost.

The right to informed consent is not absolute, and in situations where the patient might be harmed by the information, it is ethical to withhold certain information.

CASE STUDY 20

Acting without prior consent due to an unforeseen medical problem

When Mr. M, a 52-year-old male, was referred to Dr. C, he was in a very serious state. His symptoms included fever, headache, dry tongue, sinus infection, and general septic poisoning. Urinalysis indicated his urine was badly infected; he had stones in his bladder and a large stone in his kidney. Dr. C operated on Mr. M in May, draining his bladder and removing the bladder stones. The patient was subsequently treated with injections, and his bladder condition improved. He continued to experience severe pain on his left side and had also developed a hernia.

A second operation was performed to alleviate the patient's overall physical condition. Several months after the second operation, Mr. M gave his consent to have surgery to repair his hernia. A day or two after the operation, Mr. M was informed by Dr. C that his testicle had also been removed during the surgery due to potential problems it might have caused.

In response, Mr. M said he had not given his consent to the removal of his testicle and had never been informed that it might be necessary.

Three eminent surgeons supported the correctness of Dr. C's procedure. They stated that no surgeon could have anticipated the condition, and that further surgery had been necessary.

→ Should Dr. C have postponed the operation until Mr. M was able to give his consent?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

NO Removal of the testicle was a necessary part of the operation to repair the hernia, the need to remove the testicle could not have reasonably been ascertained before any surgery was undertaken, and consent for further surgery was implied in Mr. M's request to repair the hernia.

YES Mr. M did not give his consent to the removal of his testicle. Under these circumstances, a testicle can be surgically removed only if the procedure is considered an emergency or life-saving procedure. If it does not constitute an emergency, the physician must postpone the procedure until the patient gives his consent. In this case, however, it must be assumed that the condition of the patient's testicle was not considered to be so serious as to immediately endanger the patient's life or health, and that there was reasonable opportunity to obtain the patient's consent for surgical removal of the testicle.

Notes about the case study

Court decision

The case came before the Supreme Court of the country. The court stated that in an ordinary case where there is opportunity to obtain the consent of the patient, it must be obtained. A person's body must be held inviolate and immune from invasion by a surgeon's knife if an operation has not been consented to. Such surgery can only be performed with the patient's consent; if performed without such consent, it is technically an assault. Every human being of adult years and sound mind has the right to determine what shall be done with his own body.

A surgeon who performs an operation without his patient's consent has committed an assault, for which he is liable in damages. This is true except in cases of emergency where the patient is unconscious and where it is necessary to operate before consent can be obtained.

In the case at bar, the judge found that Dr. C, after making incisions in Mr. M's body, discovered conditions that neither party had anticipated and that the defendant could not reasonably have foreseen; in removing the testicle, he acted in the interest of his patient and for the protection of his health and possibly his life. The removal in that sense was necessary, and it would have been unreasonable to postpone the removal to a later date. The Judge came to this conclusion, despite the absence of express and possibly implied assent on the part of Mr. M.

Discussion Acting without prior consent due to an unforeseen medical problem

In respecting one's human dignity, we respect his autonomy and require informed consent before performing any medical procedure. The patient, who will bear the consequences of the procedure, whether it is successful or not, must grant his informed consent prior to the performing of the medical procedure.

To verify the 'informed' component of informed consent, it is essential to ensure that the patient understands his present condition, the proposed treatment, and all of the possible consequences, as opposed to other treatments, or to not having treatment at all. If the patient is not aware of this information, his consent cannot be considered 'informed.'

Nevertheless, there are situations where it is impossible to obtain the patient's consent, but he is still treated and everything is done to help him to improve his condition. An example of such a situation is the treatment of a person injured in an accident. Sometimes we are able to obtain the patient's consent to the treatment, but in order to do so, the patient would have to undergo some kind of additional treatment. For instance, it is possible to imagine a scenario where a patient is under anesthesia and we discover that there is an additional problem

which was unknown in advance, and for which we would need to conduct a different procedure, for which the patient had not given his informed consent.

This problem can be solved in advance if the patient appoints a legal representative, who may decide on his behalf, and/or if the patient is aware of such a possibility before the beginning of the treatment and gives his informed consent to an optional procedure in advance.

According to the common point of view, if the patient is not in possession of the information in advance and did not give his consent to the matter, the 'new' treatment must not be given and the patient's consent must be obtained. However, another approach claims that if the person authorized to grant informed consent on behalf of the patient is a parent or partner (especially spouses) then there is no need to stop the procedure. This view is acceptable in societies where the family plays a great role in the individual's life.

It should be stressed that if there is a real and immediate danger to the patient's life (if the 'new' treatment is not given), then such treatment is permitted.

CASE STUDY 21

Special importance of informed consent for irreversible procedures

Ms. SK, an unmarried 44-year-old woman, visited the clinic of Dr. P complaining of prolonged menstrual bleeding for the past nine days. Dr. P examined her and advised her to undergo an ultrasound test on the same day. After examining the ultrasound report, Dr. P advised Ms. SK to come the next day for a laparoscopy test under general anesthesia to make an affirmative diagnosis.

Accordingly, the next day Ms. SK went to Dr. P's clinic with her mother. On admission, Ms. SK signed a consent form for hospital admission and medical treatment, and a consent form for surgery. The admission card showed that admission was for diagnostic and operative laparoscopy on 10 May 1995.

Thereafter, Ms. SK was put under general anesthesia and examined by laparoscopy. While she was still unconscious, Dr. P's assistant came out of the operating room and asked Ms. SK's mother to give her consent for a hysterectomy on the pretext of saving Ms. SK's life. Thereafter, Dr. P performed an abdominal hysterectomy (removal of uterus) and bilateral salpingo-oophorectomy (removal of ovaries and fallopian tubes).

→ **Should Dr. P have performed the operation as he did without Ms. SK giving her consent to the removal of her reproductive organs?**

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES Ms. SK's mother gave her consent to the removal of Ms. SK's uterus. There was nothing wrong with Dr. P's actions.

NO No one can consent to the removal of reproductive organs on behalf of a patient, except the patient himself or herself. This irreversible procedure deprived Ms. SK of her fundamental right to become a mother and have a family. No one can make this choice for her, including her mother or her physician.

Notes about the case study

Court decision

This case was heard before the Supreme Court who concluded that, unless the unauthorized additional or further procedure is necessary to save the life or preserve the health of the patient and it would be unreasonable to delay the further procedure until the patient regains consciousness and can decide, a doctor cannot perform such a procedure without the consent of the patient. No emergency or life-threatening situation developed during the laparoscopy.

Where the patient has given consent for a particular surgical procedure, this cannot be construed as consent for an unauthorized additional procedure involving removal of an organ, only on the grounds that such removal would be beneficial to the patient or is likely to prevent some danger from developing in the future, when there is no imminent danger to the life or health of the patient.

The consent form referred to a diagnostic and operative laparoscopy. Signing this form does not amount to giving consent for OH-BSO surgery to remove the uterus, the ovaries and the fallopian tubes. Ms. SK did not give her consent to a hysterectomy and bilateral salphingo-oophorectomy. Consent given by Ms. SK's mother cannot be considered as valid or real consent.

Discussion The special importance of informed consent for irreversible procedures

Part of a patient's dignity is expressed in the medical team's obligation to obtain informed consent to the proposed medical procedure, as stated in Article 6(1) of the *Universal Declaration on Bioethics and Human Rights*:

Any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information. The consent should, where appropriate, be express and may be withdrawn by the person concerned at any time and for any reason without disadvantage or prejudice.

The importance of this principle is realized in the obligation to obtain informed consent for each procedure. A broad-ranging informed consent is not ethical and should not be considered as genuine consent (with the exception of life-threatening emergencies, where it is impossible to obtain the patient's informed consent to the medical procedure).

However, consent is an expression of human dignity and there can be situations where obtaining consent can harm the patient and detract from his dignity. Therefore, every situation and every patient should be regarded individually and according to the particular circumstances of the case.

For example, there are societies where it is acceptable for close relatives (parents, spouses) to take part in the decision-making process and where talking to them about the patient is part of the culture.

Another situation arises when an irreversible medical procedure, with far-reaching implications, is involved. One might think that the need to obtain informed consent from the patient himself becomes even more valid and vital, as the relevant procedure has dramatic ramifications and it is only logical that the person who will be forced to deal with the consequences should decide whether or not to consent to or refuse the procedure.

Therefore, in cases of irreversible procedures, the patient's wishes must be properly verified, even if this involves a certain unpleasantness on the part of the patient such as: the need to awaken him from surgery, in order to obtain his consent and then re-operate or the need to reveal details of his disease, etc.

CASE STUDY 22

Assumed consent of an unconscious patient

Ms. C, a 31-year-old woman, was admitted to the Intensive Care Unit of a hospital after suffering a massive intra-cranial hemorrhage. As a consequence, she sustained irreversible brain damage. She remained unconscious, and her life was dependent on a ventilator and the skills of the physicians and staff who attended her.

At the time, Ms. C was pregnant. Her husband was strongly in favor of maintaining Ms. C's life support systems until the fetus became viable and the child could be delivered. It was his stated opinion at that time that his wife would also have desired that her life be sustained until the fetus was viable. If her life had to be sacrificed in any case, at least her child should be given a chance to live.

Ms. C's physicians agreed that an attempt should be made to maintain Ms. C on life support so the fetus would have the chance to develop and become viable. The decision was made not only because it was considered medically possible, but because, taking into consideration what the mother's wishes would have been, it was believed to be in her best interest to sustain her life in order to deliver her child.

Accordingly, Ms. C was kept on advanced life support systems in the Intensive Care. By the time the pregnancy reached 32 weeks, Ms. C's survival and that of the fetus had been achieved with some difficulties. She had suffered '*multiple infections and other physiological and metabolic complications associated with prolonged life-support in the presence of such severe cerebral damage*'. The time had come when delivery by caesarean section was fully feasible.

The operation had to be carried out without delay. Each day of delay would further endanger the child, and the longer the delay, the greater the danger.

The husband, however, strongly opposed what he believed to be a premature delivery. The husband had been told by his spiritual guide that further time was needed to marshal spiritual healing powers, and it was therefore essential that the birth be delayed at least another ten days. He believed that only a further delay would equally ensure the welfare of the mother and the child.

➔ **Should the hospital perform the caesarean section to save the fetus, despite the husband's strong objection and in the absence of Mrs. C's explicit consent?**

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES Ms. C's wishes were very clear. She wanted to be kept alive so her fetus would have a chance to be born and live. Therefore, by performing the caesarean section, the hospital would be fulfilling her wishes. The husband's objection should not be considered when Ms. C's wishes are loud and clear.

NO Ms. C's husband did not give his consent to perform the operation. Since Ms. C did not explicitly consent to such operation, the operation should not take place.

NO The hospital should not risk its patients life for that of an unborn child when explicit consent has not been given.

YES Ms. C is being kept alive only for the purpose of giving birth to her unborn child. Therefore, the operation should take place even at the price of risking Ms. C's life.

Notes about the case study

Court decision

This case came before the court of the country. The court concluded that in tragic circumstances of this kind, with the mother so severely brain damaged and the life of an unborn child at stake, it is perhaps natural to directly consider the interests of that unborn child, assuming that those interests must be a vital factor in the decision. However, up to the moment of birth, a fetus does not have any individual legal interests that should be taken into account by a court considering an application to perform a caesarean section on the expected mother. In short, a court does not have jurisdiction to issue a declaratory judgment solely to protect the interests of the fetus.

The court must first consider the will of the mother. If the mother is incapable of expressing any such will, then, and only then, the mother's best interests should be considered.

In the present case, it was not in any way disputed that Ms. C, having sustained severe cerebral damage and being in a deep coma, was incapable in any way of either giving or withholding her consent to the caesarean section. In light of the circumstances of the case, it was necessary to consider the best interests of Ms. C. Those best interests were not limited simply to what was necessary to keep her clinically alive, but rather encompassed a broader range of factors, especially what she herself would have wished.

Under these circumstances, it is in the best interests of the patient to undergo an operation to try and ensure the birth of a healthy child. Apart from all other constraints, not to take any risks which might endanger the life of the child, one should take extra care to regard the fetus without life in the womb of the mother.

The declaration was granted, but not because the mother and the fetus had different interests. Ms. C and her fetus could no longer be considered as one entity because the fetus was a unique organism, having the potential for a full and independent life. The available

evidence indicated that the mother's wish, if she had been able to express it, would have been to deliver a healthy child. Under all of the circumstances, delivery clearly was in her best interest.

Discussion Assumed consent of an unconscious patient

Every human being has the right that his will shall be respected, as part of his dignity. One question we ask ourselves is; who is considered a human being? There are several forms of human life and some perceptions (Catholic, for example) argue that all forms of human life are considered human beings and thus, are entitled to protection. Other views argue that only a 'born man' is considered a human being. Another question addresses the obligation towards people who are dependant on artificial life support with no chance of recovery, and the obligation towards fetuses, especially where one right might clash with the others.

The first step, in situations where there is more than one person involved, is to determine who the patient is. One might say that the fetus has no rights and we should not consider its interests. Another might say that, although the fetus does not have legitimate rights as a human being, we should still consider its best interest, as long as we don't harm the mother. However, if the mother is a patient, we have to act according to her best interest as she sees it.

Where there's a conflict between the interest of the mother and the fetus, a balance must be found between the two. When considering such a balance, we must take into account the interests of each of the patients from the point of view of that particular patient.

The importance of upholding a person's honor; whether a mother or fetus, stresses the centrality of the autonomy which we as a society feel towards her ambitions, desires and the respect which we give her when materializing this wish. Part of upholding a person's honor is the execution of his wishes with regard to his medical treatment, even if in other cases, with other patients, the physicians may have used different procedures. For example, prolonging life for many months only in order to serve as an incubator for the birth of a child, is not necessarily

respecting the patient. However, if this is her wish, and the purpose for prolonging the patient's life is to create life, then the medical staff is obligated to carry out that person's wishes.

CASE STUDY 23

Irreversible procedures performed on mentally disabled patients without consent

F is a 36-year-old woman suffering from a serious mental disability. She has been hospitalized, with the approval of her mother, as an inpatient since she was 14 years old.

F's mental disability is marked by arrested or incomplete mental development. She has the verbal capacity of a 2-year-old child and the general mental capacity of a 4- or 5-year-old. She is unable to express her views verbally, but is able to indicate what she likes or dislikes. She experiences emotions such as pleasure, sadness, and fear, but is prone to express them differently than other people. She is liable to become aggressive. Her mother is her only relative and visits her regularly. There is a strong bond of affection between them.

F has made significant progress due to treatment administered during her hospital stay. She has become less aggressive and is allowed considerable freedom of movement around the hospital grounds, which are large. There are, however, no prospects for any improvement in her mental capacity.

F has entered into a sexual relationship with a male patient, P, whom she meets around twice a month. The relationship is entirely voluntary on F's part, and she probably derives pleasure from it. There is no reason to believe that F does not have the ordinary fertility of a woman of her age.

Medical evidence indicates that it would be psychiatrically disastrous for her to become pregnant. All ordinary methods of contraception were found to be ineffective in her case, either because she would be unable to use them effectively or because they posed a risk to her physical health.

The medical staff in charge of F, with the approval of her mother, decided that the best course was for her to be sterilized by ligation of her fallopian tubes.

→ **Should a sterilization operation be allowed in the case of an adult woman of childbearing age who is mentally unable to give or refuse her consent to the procedure?**

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES Even though F is incapable of consenting to the operation, the evidence shows that pregnancy might cause harm to her mental health. The operation will be performed to prevent F's physical and/or mental health from deteriorating. Therefore, sterilization is in her best interest; it is unavoidable and consequently it is legitimate.

NO Such an operation can take place only if performed as curative or prophylactic treatment. In F's case, the proposed sterilization is not to treat diseased organs. Rather, this procedure is to be performed on a woman with healthy reproductive organs in order to prevent pregnancy. Under such circumstances, sterilization cannot be considered either curative or prophylactic. Therefore, it is not in F's best interests to undergo this surgery. Furthermore, as a society, we must search for a way to protect those who cannot protect themselves from the insult of unnecessary sterilization, as in this case.

NO Sterilization has a number of unique characteristics. First, the operation is in most cases irreversible. Second, due to the operation's general irreversibility, the almost certain result will be to deprive the woman one of her fundamental rights as a woman, namely the right to bear children. These unique characteristics demand that the hospital seek some other solution.

Notes about the case study

Court decision

This case came before the Court of the country. Because of F's mental disability, she does not have the capacity to give her consent to the operation. Her mother, acting as her best friend, sought a declaration asking the court to rule that the absence of F's consent would not make her sterilization an unlawful act.

It was declared that the proposed sterilization operation to be performed on F was in her best interests under the existing circumstances, and thus could lawfully be performed on her despite her inability to consent to it.

Discussion Irreversible procedures performed on mentally disabled patients without consent

A very common mistake regarding mentally disabled patients is that we do not respect their dignity because we believe they do not have the ability to choose. The truth is that dignity refers to what one is and not what one does. However, sometimes the person chooses to do things that might harm him and society, and at this point, one should consider where and when, if at all, he should be stopped.

Every medical treatment or study conducted on human beings must, first and foremost, consider the best interests of the subjects and where they are particularly vulnerable, these interests should be protected, as stated in Article 8 of the *Universal Declaration on Bioethics and Human Rights*:

In applying and advancing scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account. Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected.

It is important to note that ‘best interests’ are not necessarily the same for all patients; they are specific to the patient and circumstances. Therefore, a medical procedure can be considered in the best interest for one patient, but as a very harmful action to another. The medical staff is obligated to consider the best interest of the specific patient under the certain circumstances.

When dealing with people whose ability to make choices is doubtful, we should take extra precautions to make sure that we are not ignoring someone’s right, just because we believe he is ‘incapable of choice (in many countries women did not have a right to vote because of this reason).’

In addition, every medical intervention requires the patient’s consent, whether for healing or preventative purposes. This informed consent expresses society’s respect for the individual, the patient, in terms of how treatment, if any, will be provided.

There are cases where patients are unable to grant informed consent. In such cases, the action taken toward ensuring the patient’s best interest becomes even more important and must be handled with increased sensitivity. One should act in accordance with the maximum benefit of such a person in mind, and try, as far as possible, to involve him in the decisions concerning his well being, as detailed in Article 7a of the *Universal Declaration on Bioethics and Human Rights*:

Authorization for research and medical practice should be obtained in accordance with the best interest of the person concerned and in accordance with domestic law. However, the person concerned should be involved to the greatest extent possible in the decision-making process of consent, as well as that of withdrawing consent.

Treating a patient who is unable to grant informed consent requires, on the one hand, particular sensitivity on the part of the medical staff and expresses, on the other hand, our obligation, as a society, to act for that person, for the benefit of his interests whilst safeguarding his autonomy and ability to make an informed decision in accordance with his personal capabilities.

CASE STUDY 24

Respecting patients' decisions

Mrs. M came to the Hospital complaining of some stomach disorder.

She was admitted to the hospital, and after some weeks of treatment, the house physician, Dr. B, discovered a lump which proved to be a fibroid tumor. He consulted the visiting surgeon, Dr. S, who advised an operation.

The physicians explained to Mrs. M that the character of the lump could not be determined without examining her. To this end, she needed to be anesthetized by the administration of ether. She consented to such an examination, but according to her claim, she told Dr. B that there must not be an operation.

She was taken at night from the medical to the surgical ward and prepared for surgery by a nurse. She repeated her wish not to be operated on. In the morning, she was anesthetized by the administration of ether, and while she was unconscious, a tumor was surgically removed.

▶ Should the physicians have performed the surgery despite Mrs. M's explicit objection?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES Mrs. M was already under anesthesia and the tumor had to be removed, if not at that time, then in the future.

NO Not only did Mrs. M not consent to the operation, which should have been a sufficient cause not to perform the operation, but

she was also very clear in expressing her objection to undergoing surgery. The physicians should have respected her decision.

Notes about the case study

Court decision

This case came before the Court of Appeals of the country. The court concluded that every competent adult human being of sound mind has the right to determine what shall be done with his own body and that a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable for damages. The exception is in cases of emergency where the patient is unconscious and where it is necessary to operate without being able to obtain patient's consent.

Discussion Respecting patients' decisions

An indispensable aspect of honoring the rights of a person undergoing medical treatment is the requirement for their freely granted consent to the suggested course of therapy. The need for this agreement, known as informed consent, is established in Article 6(1) of the *Universal Declaration on Bioethics and Human Rights*.

The doctrine of informed consent is based on the recognition of each person's autonomy in deciding what shall be done to his own body. The understanding that every person has an individual personality leads to the conclusion that any physical injury or intervention requires his consent, and must be performed with respect to his independent existence.

However, this perception, which is quite common today, was not always under complete consensus. The other, more paternalistic, perception claims that the doctor knows what is best for the patient and that the patient is not always capable to consider the consequences of the treatment. Moreover, in many cases, the patient is unable to fully

understand all of the information and so, accepting his opinion may be harmful. In such cases, when a decision detracts from one's dignity, the physician should be the one who takes the decision for him.

One possible response to this opinion is that the individual, as an entire human entity, reaches medical decisions not just on the basis of his medical condition, but also on the basis of his religious beliefs, worldview, and personal desires. These wishes are unknown to the doctor, and only the patient himself can give them proper weight as he reaches a decision. It is not ethical to perform a medical procedure on a person who has not yet reached a weighted decision based on the available options and who has not yet granted willing consent to the suggested treatment.

We should note also that the patient has the right to refuse treatment. Such refusal is part of his autonomy, and the medical staff members, by not treating him, are expressing their respect for his dignity.

CASE STUDY 25

Equality in providing health services

Mr. S is a 41-year-old unemployed male. He is diabetic and suffers from ischaemic heart disease and cerebro-vascular disease, leading to his stroke in 1996.

In 1996, his kidneys failed as well. His condition is irreversible, and he is now in the final stages of chronic renal failure. His life could be prolonged by regular renal dialysis treatment. He has sought such treatment from the renal unit of the public hospital; however they can only provide dialysis treatment to a limited number of patients.

Because of the shortage of resources, the hospital follows a set policy regarding the use of its dialysis resources. Only patients suffering from acute renal failure that can be treated and remedied by renal dialysis are given automatic access to renal dialysis at the hospital. Those patients who, like Mr. S, suffer from irreversible chronic renal failure are not automatically admitted to the renal dialysis program. Access to dialysis treatments for patients like Mr. S is given only to those eligible for a kidney transplant. Mr. S suffers from ischaemic heart disease and cerebro-vascular disease, and is therefore not eligible for a kidney transplant. Therefore, the hospital has been unable to provide Mr. S with the treatment he has requested.

Mr. S has managed to receive dialysis treatment from private hospitals and doctors, but his finances have been depleted and he claims he is no longer able to afford such treatments.

→ Should the state provide the desired treatment to a person such as Mr. S who lacks the means to afford such treatment?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES It is the state's obligation to provide appropriate medical treatment for those who cannot afford the treatment on their own. By not providing the treatment, the state discriminates against those who cannot pay for medical treatment, in effect, condemning them to death.

NO Because the state has limited resources, it cannot provide all desired medical treatments to everyone. A dialysis program is in effect, with specified criteria determining who is eligible for the treatment. It is unfortunate that Mr. S is not eligible for this program.

Notes about the case study

Court decision

This case came before the Constitutional Court of the country. Mr. S based his claim on a Section of the Constitution, which states that *'No one may be refused emergency medical treatment'* and another Section, which stipulates *'Everyone has the right to life.'* The court dismissed Mr. S's claims.

One can only have sympathy for Mr. S and his family, who face the cruel dilemma of having to impoverish themselves in order to secure the treatment that Mr. S needs in order to prolong his life. The hard and unpalatable fact is that if Mr. S was a wealthy man, he would be able to procure such treatment from private sources. But he is not wealthy, and therefore must appeal to the state to provide him with the treatment. The state's resources, however, are limited, and Mr. S does not meet the

eligibility criteria for admission to the renal dialysis program. Unfortunately, this is true not only for Mr. S, but also for many others who need access to renal dialysis units or to other healthcare services.

Discussion Equality in providing health services

The question of equality in providing health services is one of the most difficult medical issues. There is considerable literature on the topic of inequality in health matters. The UNESCO *Universal Declaration on Bioethics and Human Rights* addresses this issue as an obligation of countries, organizations, and institutions, to act equally, as determined in Article 10 of the Declaration:

The fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably:

Another issue we should address is the issue of distributive justice, by which society should distribute the rights and the resources among all people who belong to the society. Some questions arise from that principle. For example, what are the resources that are distributable? One theory distinguishes between rights such as: freedom, political right, etc., that should be distributed equally and welfare such as: health, shelter, money, etc, that cannot be distributed freely to all people. Therefore society should concentrate on the distribution of rights and not welfare.

According to another perception, society should distribute all resources in a utilitarian manner. In that case, we can defer treatment from one person and give it to another who is in the same condition, because it is more useful for the latter. This system is not considered as being equal for everyone.

Equality is a basic principle in healthcare systems operating in democratic countries. Treating people equally respects their dignity and honor. However, lack of resources is a problem which society cannot ignore, and we should pay attention to whether discrimination in withholding treatment derives from disrespecting one's dignity or rather from a lack of resources.

Upholding a person's dignity also means treating him politely, patiently, considerately, and without humiliation. Therefore, blocking the right to medical treatment for some of the patients in effect harms and humiliates them, and thus is unethical.

One more note we should consider is that selectively preventing treatment from patients could be considered as discrimination, actively contradicting Article 11 of the *Universal Declaration on Bioethics and Human Rights*:

No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms.

CASE STUDY 26

State's obligation to provide emergency medical care

Mr. HS fell off a train at about 7:45 p.m. on July 8. As a result, he suffered serious head injuries and brain hemorrhage. He was taken to the local Primary Health Centre. Since necessary facilities for treatment were not available at the Primary Health Centre, the medical officer in charge of the Centre referred him to the nearest hospital for better treatment.

HS was taken to the hospital at about 11:45 p.m. on July 8. The emergency medical officer in said hospital, after examining him and taking two X-rays of his skull, recommended immediate admission for further treatment. Nevertheless, HS could not be admitted to the hospital, as no vacant bed was available in the surgical emergency ward and the regular surgery ward was also full.

He was thereafter taken to another hospital at about 12:20 a.m. on July 9, but he was not admitted there, on the grounds that no vacant bed was available. He was then taken to another hospital at about 1:00 a.m. on July 9. He was not admitted to that hospital on the grounds that the hospital has no ENT emergency or neuro-emergency department. At about 2:00 a.m. on July 9, he was taken to another hospital, but was also not admitted there because no bed was available. At about 8:00 a.m. on July 9, he was taken to an Institute of Neurology. Upon examining the CT scan, performed at a private hospital after payment, the doctors discovered a hemorrhage in the frontal region of the head and determined this was an emergency case that could not be handled at said Institute. At about 10:00 a.m. on July 9, the patient was taken to yet another hospital, but was also not admitted there on the grounds that the hospital has no neurosurgical facilities.

Ultimately, he was admitted to a private hospital, where he was treated as an inpatient from July 9 through July 22.

► **Was it correct for the abovementioned hospitals to refuse to provide medical treatment to HS and to transfer him to another hospital?**

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES Most of the aforementioned hospitals administered first aid to HS, but could not provide him appropriate treatment due to their lack of facilities and medical services to handle complicated situations such as in this case. It was better to transfer HS to an institute that could handle such conditions.

NO Depriving a person of medical treatment in an emergency case is actually depriving that person of his right to live and his right to live with dignity.

Notes about the case study

Court decision

This case came before the Supreme Court of the country, during which the state government appointed an enquiry committee to investigate this chain of events. The committee has suggested remedial measures to rule out recurrence of such incidents in the future and to ensure immediate medical attention and treatment to patients in real need.

The court reasoned that the constitution envisages the establishment of a welfare state at the federal level as well as at the state level. In a welfare state, the primary duty of the government is to secure the welfare of the people. Providing adequate medical facilities for the people is an essential part of the obligations undertaken by the government in a welfare state.

The government fulfills this obligation by running hospitals and health centers which provide medical care to the person in need of

those facilities. The constitution imposes an obligation on the state to safeguard the right to life of every person. Preservation of human life is thus of paramount importance. The government hospitals run by the state and the medical officers employed therein are duty bound to extend medical assistance for preserving human life. Failure on the part of a government hospital to provide timely medical treatment to a person in need of such treatment results in violation of his right to life, guaranteed under the constitution. In the present case, HS's said right, guaranteed under the constitution, was breached when he was denied treatment at various government hospitals, even though his condition was very serious at that time and he was in need of immediate medical attention.

Indeed it is true that financial resources are needed for providing these facilities. But at the same time, it cannot be ignored that it is the constitutional obligation of the State to provide adequate medical services to the people. Whatever is necessary for this purpose has to be done. In the context of the constitutional obligation to provide free legal aid to a poor person, this Court has held that the state cannot avoid its constitutional obligation in that regard on account of financial constraints.

Discussion A state's obligation to provide emergency medical care

A State, which strives to give its citizens quality health services and wishes to advance healthcare within its region, whilst being obligated to accepted ethical principles, should act to uphold and strengthen the dignity of sick people.

However, the State does not always have the ability to provide quality health services to all, due to lack of resources. The gap between the moral right of an individual member of the society to receive health-care services (as part of his dignity and as much as this right exists) and society's ability to provide it, is a problem that many countries have to deal with.

A suitable solution would be to distinguish between moral and legal-rights and then to determine their economic consequences. One position is that the right to healthcare is not greater than the right

to property, and therefore, the state cannot tax rich people in order to provide health services to all. Another position is that the right to healthcare is a basic right that enables one to acquire many other rights and therefore, it is ethical to take money from people who have it and provide quality health services to all.

Another question relates to situations in which the State provides limited quality of health services, while private organizations provide better health services. In some countries, all residents are entitled to the same quality of health services and even if one has money, one cannot purchase better healthcare. Other countries provide healthcare services to some extent, but the individual is free to seek better services elsewhere. Another attitude is that the individuals must buy their own level of health services according to their ability, and the State provides health services only to poor people.

However, the obligation of a State and health institutions to provide suitable treatment, is in addition to the patient's right to continue receiving appropriate treatment. As such, when there are units such as intensive care that are filled to their maximal capacity and it is impossible to add beds without harming the current patients, the ethical obligation to the 'new' patient clashes with the obligation to provide appropriate treatment to existing patients. The balance between these two rights creates a difficult dilemma.

Beyond all this, efforts should be made to increase resources to enable appropriate medical treatment for all.

CASE STUDY 27

Claim of 'wrongful life'

Prior to her marriage, A consulted a genetic counselor. She wanted to know whether her future descendants were at risk of developing a particular hereditary syndrome known as Hunter's disease, which ran in her family. If she were to discover that her descendents were at risk, she was determined not to give birth to boys, as the disease primarily affects males.

Due to negligence in carrying out the tests or in interpreting the results, the genetic counselor determined that there was no risk of A's descendants being afflicted with the disease. Based on the consultant's opinion, A became pregnant and gave birth to a baby boy with Hunter's disease. The disease severely damaged his physical and mental development.

It should be noted that there were only two possibilities for A's son: to be born with this disease or not to be born at all. There was no other medical option to enable him to be born without this hereditary disease.

→ Should a situation in which not existing at all (as distinguished from death) will be regarded as better than living?

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES There may be cases, although rare, in which it can be determined that it would be better for someone not to be born than to live with severe disabilities.

NO Living with defects can never be compared to not having a life at all. Every person has the right to live, not the right not

to live. There can never be a situation in which not existing is preferable to living with defects.

Notes about the case study

Court decision

This case came before the Supreme Court of the country who considered, *inter alia*, the question of whether it can be determined that not existing is preferable to living with defects.

One of the justices' opinion stated that the problem in this case revolves around the following assumption: acknowledging the child's right requires comparing the child's condition after the consultant's negligence and his condition if the consultant had not been negligent at all, *i.e.* before his birth, by concluding that not existing is better than living with a defect. Such a comparison cannot be made, for it arouses philosophical and moral issues that can never be solved.

The court cannot compare between life and non-life. Even if the minor were to claim that he preferred non-life over life with defects, still the court cannot heed this claim for the child's right is the right to life, not the right to non-life. Therefore, there is no need to compare the value of not existing at all to the value of living with a defect.

The damage caused by the genetic consultant is the damage of living with a defect. The damage does not refer to causing or preventing life. Therefore, the phrase 'wrongful life' is inappropriate and deceptive. The claim is not against life, and the alternative is not non-life. The claim is against life with defects, and the only alternative is life without defects. The genetic consultant was negligent in causing life with defects and is liable for this damage.

Discussion Claim of 'wrongful life'

Every person has the right to live with dignity. This right is fundamental and inherent in each human being, as established in Article 3(1) of the *Universal Declaration on Bioethics and Human Rights*:

Human dignity, human rights and fundamental freedoms are to be fully respected.

There are situations in which babies are born with genetic deformities unrelated to medical procedures. Some will describe this as an act of God, others will call it fate, but it is clear that the defect was not caused by an act or omission by the medical staff or anyone else. However, if this disability was not detected by the physician during pregnancy, when he should have found it, the child may sue him.

In these cases, the disability can be so severe that the afflicted person claims that it would have been preferable not to exist, rather than to live with their deformity.

This claim raises complicated philosophical and legal dilemmas. Such claims by patients are now accepted in cases of extreme dysfunction and suffering. We can understand this as being analogous to the situation in which patients decide to discontinue invasive treatment and end their life with dignity. Similarly, we must honor someone who claims they would rather not have been born than to have been born with their defect. On the other hand, accepting such claims raises an ambiguous issue, since this human being, the child, would be unable to sue the medical staff if he was not born. The only possibility for him to sue was the mere fact that he was born. Hence, if he was not born, as he claims, he would not be able to sue since he would not have been a 'human being.' By suing, he cuts the branch he sits on, and therefore, we cannot accept such a claim.

Another issue concerns the sanctity of life. Does a human being have the ability to choose to be born? One who argues that a human being has no right to choose whether or not to be born, either because it is God's will or because he has no wish until he is physically born, cannot

accept the concept of 'wrongful life.' One who argues that the decision to be born or not is a right of every human being, will accept such a claim, since it is an inherent part of his autonomy to decide whether to come to this world or not.

One of the most serious ethical questions in these cases is the need to evaluate the harm to the child. On one hand, the child suffers from a disability. On the other hand, the child didn't have the choice of being born without the disability or not being born at all. That is why it is very complicated to evaluate the damage, since we cannot compare him to a healthy child, but must rather compare him to a 'no child' entity.

CASE STUDY 28

Obligatory vaccination

Mr. B and his wife have two young children, L, a 10-year-old, and K, a 3-year-old. Mr. B and his wife are vigorously opposed to vaccinating their children and to vaccination in general, either as a private or a public health measure.

In Mr. B's view, not only is vaccination harmful, but it is also a useless procedure with perhaps disastrous side effects. He asserts that he and his wife have a fundamental right to decide whether or not to vaccinate their children. It follows that he rejects the proposition that vaccination is a measure that is reasonably necessary to protect the public's health.

L and K were refused entry to a child care center run by the Council on the grounds that they were not medically immunized.

From at least 1976, the Council has had a policy that any child seeking to attend a child care center controlled by the Council must be medically immunized before acceptance. Proof of immunization is required on enrollment and after each immunization update. The standard immunizations required are stated as being 'per current Health Authority recommendations.'

Mr. B and his wife are unyielding in their refusal to vaccinate their children.

→ **Is the Council entitled to discriminate against L and K by not allowing them to enter to the child care center because they are not vaccinated?**

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES The fact that the children are not vaccinated puts the other children at the child care center at risk. For the benefit of the other children, the children of Mr. and Mrs. B must be barred from attending the child care center.

NO Discriminating against the children of Mr. and Mrs. B by barring them from the child care center is unlawful. Every person has a right to determine whether or not to be vaccinated.

Notes about the case study

Court decision

This case came before the Human Rights and Equal Opportunity Commission of the country. The court concluded that the decision of the Council to exclude the children from the child care center is one that is reasonably necessary to protect public health.

The incidence of serious infectious disease in a community is a matter relevant to public health. Experience has shown that an individual or a group of persons may fall victim to some ailment which, by its very nature, is considered to be infectious. One person's illness may be the source of infection in another. The seriousness of the illness and the potency of the infection process may be such as to affect the health and well being of the wider community. On the other hand, the level of morbidity in the case of a less serious infectious illness may be considered not to raise public health issues because it is within the capacity of the individual to take appropriate remedial or preventative action.

It is for these reasons that vaccination has been proposed as a public health measure, and the advocates of vaccination, through publicity and education programs, are intent on raising the so-called 'herd immunity' level, of a community in relation to various potential infections. The required level of 'herd immunity' would be defined by experts in the field of infectious diseases and public health as the percentage of

the target population that must be vaccinated in order to develop immunity, and thus block the transmission of the target disease.

An integral feature of the Council's case is that the decision to exclude Mr. B's children, and any other unvaccinated children who are included in the extended definition of 'disability' in the act, was indeed a discriminatory decision. Yet, it was a decision reasonably necessary to protect public health. In short, the Council's insistence that the children not be admitted to the child care center unless vaccinated, whilst discriminatory, is reasonably necessary to protect public health.

In the process of balancing the risks, it is unquestionably desirable that all children, except those who are sick or who have pre-existing neurological or genetic conditions, be routinely immunized. The resultant benefits will be shared not only by the individual person, but also the public, through increased herd immunity.

Discussion **Obligatory vaccination**

One of the arguments addressed by human right theorists is that of 'cultural imperialism,' i.e. people can live their lives according to their beliefs, and society should respect them and avoid forcing them to believe or do what they don't want to.

However, although those human rights were conceived with the individual in mind, there was a strong trend towards collective rights, and the second and third generations of rights issues, such as the right to education, the right to peace, the right to a healthy environment, etc.

That being said, we understand that individuals have the right to refuse vaccinations, and that society has the right to vaccinate its citizens in order to promote health. Usually, as stated in Article 3(2) of the *Universal Declaration on Bioethics and Human Rights*:

The interests and welfare of the individual should have priority over the sole interest of science or society.

However, there could be circumstances in which individual interests do not take priority over public interests.

Vaccination, considered the most effective treatment for some diseases today, is a privilege, not an obligation. Therefore, people who do not desire vaccination will usually not receive it but they must remember that there may be consequences to non-treatment, and be willing to bear them.

Governments are responsible for public health, as established in Article 14(1) of the *Universal Declaration on Bioethics and Human Rights*:

The promotion of health and social development for their people is a central purpose of governments that all sectors of society share.

Vaccination of the population reduces rates of illness and therefore it is expected that public interest dictate policies that encourage vaccination. Preserving public welfare and reducing diseases are important values, and when they conflict with the individual's right to refuse treatment, a balance must be struck between the rights of the individual and the public.

Each situation should be evaluated on its own merits and each society, country, and government must define a balanced policy based on its values, provided it gives real weight to the rights of the individuals.

The considerations that we should think about, when balancing such values could be:

- 1 The seriousness of the disease
- 2 The imminence of the threat
- 3 The number of people that are not vaccinated
- 4 The potency of the infection

CASE STUDY 29

Protecting a prisoner's dignity

B is a prisoner serving a 20-year sentence handed down in 1996. The jury convicted B of the offense of conspiring to commit an act of terrorism, and he is considered a high-risk prisoner.

In August 2006, B was referred for medical treatment after being diagnosed with testicular cancer. B was handcuffed on the way to and from the hospital for treatments.

On several occasions, prison officers were present at B's medical consultations and treatment, despite the sensitive nature of his condition.

B had an operation to remove one of his testicles. He was handcuffed when he went into surgery, and still handcuffed when he awoke from the anesthetic. He was also handcuffed on his way back to prison.

Moreover, B has allegedly been required to supply samples, including semen samples, while in the presence of prison officers. On other occasions, he allegedly had to provide semen samples with one hand handcuffed.

B refused treatments that he felt were humiliating.

B claims that during his various medical consultations and treatments, he felt humiliated and demeaned and suffered from pain and discomfort. His privacy was invaded at a time he was feeling vulnerable.

► **In situations in which a patient is handcuffed or is unable to obtain privacy during medical treatments, should the physician interfere?**

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES One of the basic principles of medical ethics is the physician's obligation to his patients. The patient's dignity and right to privacy during consultations or medical treatment should be respected at all times. Whenever these rights are denied, the physician should pursue appropriate measures to assure them.

YES Withholding B's rights to privacy during medical treatment or consultations with his doctor destroys the patient-doctor relationship. The patient loses his confidence in his physician, possibly harming the quality of the treatment. For example, B's refusal of treatments demonstrates such possible harm.

NO B is a high-risk prisoner and the physicians should not interfere with the security arrangements. All they are obligated to do is their utmost as physicians so that B receives the appropriate treatment under the circumstances.

Notes about the case study

Court decision

This case came before the Court of the country. B, the claimant, challenged the decision regarding security measures that were taken while he received medical treatment.

No claim was made against the physicians in this case. The claimant argued for breaches of Articles 3 and 8 of the Convention on Human Rights. The court stated that B failed to show that the decisions taken were wrong, perverse, or irrational; or that there had been a breach of

the claimant's Article 3 or 8. The Judge also noted that there was no complaint made by the medical staff regarding this matter. There was no indication that any confidential information had been leaked, and, given the factors which have already been set out at some length, any interference was not disproportionate.

Discussion Protecting a prisoner's dignity

To what extent should we respect someone's dignity? The basic claim is that everyone is entitled to be respected just for being human. What about people who do not respect the dignity of others though, such as: terrorists who have murdered men, women, and children? One can say that we should respect their dignity, since it is not about what you do, but rather about what you are. Moreover, the fact that a person is a prisoner does not negate his basic rights and he is entitled to them just like any other person.

Others will say that since he failed to respect others, he is not entitled to be respected, and that he has actually surrendered his dignity by killing and failing to respect people's rights to life. However, even if we accept that approach, what would we do if he only planned to perform an act of terror, but did not execute it? On the one hand, he did not demonstrate disrespect for people's lives and dignity, but on the other hand, he planned to carry out a terrible attack, and if he hadn't been caught, he would have succeeded.

Another question to be asked: if we decided to restrain his dignity, how far should it be restrained? Should we act in a way that humiliates him? Should we withhold medical treatment? Should we treat him without pain-relief? Who can set the boundaries?

One thing we know is that prisoners comprise one of the weakest groups, unable to stand up for their rights on all issues of medical treatment. The *Universal Declaration on Bioethics and Human Rights* deals with vulnerability, however the Articles relating to vulnerability (Preface, 8, 24) address issues of human vulnerability, such as people who are uneducated, handicapped, etc.

According to the approach that high-risk prisoners do not deserve the same extent of dignity as every other human being, reducing their right to privacy is justified. According to the other point of view, because he has the same extent of dignity and can be classified as vulnerable, the medical system must pay even more attention to its contacts with him and other prisoners and to the treatment provided to them.

Another issue we should address is the safety of others. A person's right, as with most of our privileges, is not decisive and can be superseded by other interests, such as: keeping public peace or safety. When a prisoner is concerned, one must examine exactly how dangerous it is to leave him alone during his medical procedure when he is under anesthesia and, when possible, to guard him from afar. For example, it is more appropriate to examine a prisoner without guards, in a windowless room with one exit guarded from the outside, than it is to do so inside a clinic or a larger ventilated room, with an accompanying guard who is present during the entire examination.

Physicians may find themselves treating patients under difficult circumstances, and they face a challenge of providing the best treatment they can under these circumstances.

CASE STUDY 30

Unauthorised sperm extraction for spousal infertilization

MAW and GAW were married on 29-July-1993.

They decided not to have children until they got on their feet financially. From time to time, they had discussed the possibility of having children, but decided not to do so, at least not for some time.

On 20 April 2000, GAW was involved in a motor vehicle accident. While crossing the road, he was hit by a heavy vehicle, fitted with a bull bar in front. As a result, he suffered brain damage, went into a coma, and was in imminent danger of dying. His life expectancy was very short, approximately 48 hours.

MAW pleaded to obtain an interim order to extract sperm from GAW. Her intent was to reserve the option for future conception using her husband's sperm. She would not make any use of her husband's sperm until she felt capable of making an informed decision. She felt that conceiving a child using her husband's semen was the only way to 'have part of him.' She wished to maintain that option because at the present time it was what she wanted and she saw it as a way of keeping her husband with her, despite his death.

GAW had given no actual consent for removing, storing, or using his semen.

The Director of Reproductive Medicine at the hospital explained that GAW's sperm must be collected while he was still alive, since once the patient died, the sperm would no longer be viable.

→ **Should the hospital act according to MAW's wishes and extract GAW's sperm while he is in a coma, without his explicit consent?**

Here are a few, but not all, possible answers. Discuss them, as well as other possible answers. Identify ethical issues and decide which answer applies to you most, giving your reasons.

YES Even if GAW did not express his explicit consent for such a procedure, MAW can use her husband's sperm. It is inherent to their status as a married couple to conceive and have children.

NO Without GAW's explicit consent, this procedure, which involves surgical intervention, cannot take place.

Notes about the case study

Court decision

This case came before the Supreme Court of the country. The court concluded that it is not appropriate to infer any consent on the part of the patient to the taking, preserving, and use of his semen to impregnate his wife, and more particularly, to do so after his death.

The court's decision made a reference to the potential child. The court stated that under these circumstances, such a child's best interests would not be served by being brought into existence in the manner, at the time, and in the circumstances contemplated by MAW. Such a child would never have the prospect of knowing his or her father. Such a child would come to recognize that he was not sought to be procreated during the life of the father. Such a child would not have rights of succession under state law or rights under the Compensation to Relatives Act, arising out of the circumstances giving rise to the death of his or her father. Furthermore, should the circumstances of the child's conception come to be known, people in the community might tend to regard the child as different, not a happy situation, especially for a child. These considerations mitigate the decision against approving the possibility of conceiving a child in the present case.

Discussion **Unauthorised sperm extraction for spousal infertilization**

When a woman wants to use her late husband's sperm for spousal fertilization, there are several 'human beings' involved:

- 1 The woman herself:** We must ask ourselves if it is in the best interest of that woman to initiate a process of pregnancy that will end with an orphan baby, raising him through difficulties of no support of a spouse. One could say that it might be dreadful for this woman, while others would say that she has the right to decide how to live her life and how to grieve over her husband.
- 2 The late husband:** There are two major questions: first, should we consider this person as a 'human being'? Most authors in ethical literature consider dead people as human beings. As such, they have dignity and we have to consider their wishes. Another approach argues that dead people are not forms of human life and as such, they have no dignity. Therefore, we do not have to consider their wishes and best interest, since they are nonexistent. The other question is if we say that this late man still has dignity, how do we know if extracting his sperm is in his best interest? Does he want a baby if he cannot raise him? Does he want a child with this particular woman?
- 3 The future baby:** Is he a 'human being'? Should we consider his best interests? Article 1 of the United Nations *Declaration on Human Rights*, 1948, states that: '*All human beings are born free and equal in dignity and rights...*' One can argue that since this future child is not born yet, moreover, it is not even an embryo, it has no rights, no dignity, and we cannot and should not consider its interests. But even if we agree to recognize his dignity, it is impossible to evaluate the benefits and disadvantages in his future life.

Another issue we have to consider is how to obtain informed consent?

Any form of medical intervention requires informed consent and every effort should be made to ensure that the consent, if given, is explicit, as expressed in Article 6(1) of the *Universal Declaration on Bioethics and Human Rights*:

Any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information. The consent should, where appropriate, be express and may be withdrawn by the person concerned at any time and for any reason without disadvantage or prejudice.

The agreement expresses the patient's wishes and demonstrates that we are acting to intensify the patient's honor, as an inseparable part of the autonomy to which he is entitled. It is important to stress that in carrying out the relevant wishes, the goal must be seen from the patient's viewpoint; this must be taken into account when executing a medical intervention.

Nevertheless, it is not always possible to obtain the patient's specific or explicit consent. In such cases, we must try to ascertain what his wishes would have been, through evidence based on his lifestyle, statements which he made, and from people close to him who knew what he would have wanted. Therefore, it would be ethical, in cases where the patient is unable to express his informed consent, to learn from outside sources as to what his wishes were and execute them in accordance to what he would have wanted.

It is important to stress that in cases of 'planned orphan-hood' where the intervention occurred after the death of the father, a distinction must be made between the sperm extraction and insemination procedure. On one hand, there is a narrow window of opportunity enabling such extraction, in cases where it is possible to definitely assume that the person would have wanted to have a child. On the other hand, the decision is carried out during a period of intense pressure, when there are strong feelings and it is impossible to reach level-headed decisions. Therefore, only if we enable the extraction which is ensued by a debate regarding insemination, consequences to the future child, etc., we will later be able to carry out an in-depth debate about the technical option of impregnation from the deceased's semen.

As to the child's interest, some would say that since the child is not born yet, we cannot consider his benefits and harms. However, we should try to think whether it is his best interest to 'come to life' without a father.

Furthermore, one can argue that ‘coming to the world’ as an orphan is harmful for the child, while others might think that being alive at all, even if you live without a father, as many children around the world do, can be perceived as a benefit and better than not being alive.

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