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## Introduction

This text was written upon the request of Prof. Carmi and Feinholz for the first UNESCO course for teachers of ethics in medical schools. The text aims at providing the reader with updated key bioethical subjects, organized in a set of units internally coherent, and expressed with a unified language currently used in bioethics, medical law, public deliberation and academic circles. Emphasis is given to the common denominators, the values, jargon and practices that unite medical ethics and law. Even though the very choice of language and concepts is not value neutral, at familiarity with the prevailing modes of bioethical thinking, combined with one's own cultural background, personal experience and critical judgment may suffice for the cultivation of mature moral reasoning that can actively contribute to practice, education and regulation. Indeed, the chief purpose of this text is to familiarize the reader with contemporary modes of reasoning in bioethics, and to explicate medical ethics within the broader context of democratic governance, which is committed to human dignity and rights. More specifically, this text intends to help the learner play an active role in bioethics related activities, such as teaching, contribution to public and professional debates, participation in ethics committees, and drafting of ethics chapters in research proposals. Ethical conduct is a way of life and professional practice; bioethical reasoning is the style of thought and the vocabulary of accountability.

Morality is a universal enterprise of learning from local cultures, as well as informing and even reforming certain local practices. However, the reader is advised to be familiar with the law, culture and moral values of his or her own specific territory of practice. The implementation of ethical studies requires prudent and informed integration of general principles and modes of reasoning, such as the contents of this document, with local law, habit and personal wisdom.

## Human dignity and rights

## What is the role of "human dignity" in bioethics?

Human dignity is the overarching ethos of shared and basic moral values in contemporary democratic societies, international law and medical ethics. Human dignity provides the motivation, direction and fundamental meaning for our legal systems and moral values. By a United Nations Resolution (120/41, 1986), all human rights declarations and documents are explicitly committed to the value of human dignity; over 160 countries recognize "human dignity" in their constitutions. Most countries have revised their constitutions as to adapt better to international standards of human dignity and rights.

#### What is an ethos?

An ethos is a loosely arranged set of ideas. It is rich and informative, but not necessarily consistent, well-founded, and clear as legal documents and professional guidelines are. Yet an ethos is widely recognized and broadly accepted. It allows ethical, legal, and political deliberations within its framework. An ethos is expressed in narratives and metaphors; it evolves and grows by means of hermeneutics (=interpretation). An ethos is the product of long and complex processes involving many contributors and their cultural environments. For example, romantic love is an ethos. We all know more or less what it means, and can talk in length and depth about the affectionate feelings and mutual conducts of such love. Many cultures and traditions have contributed to the ethos; but no one culture or tradition yields an authority over the meaning of "romantic love". It is not canonized (encoded) in any formula or book. We all seem to care about it, but we often debate its boundaries, meanings and normative implications. Two people may have very different views about love, and yet, one may understand very well when the other says "I am in love with someone". We may also observe that the laws on

marriage, as diverse as they are in different cultures, relate very strongly to the ethos of romantic love. In a similar manner, human rights derive their meaning and motivational force from the ethos of human dignity.

## Origins of the ethos of human dignity

Human dignity originated in both the monotheistic religions (the idea that humans were created in the Image of God) and the secular-pagan traditions, mainly the Stoics. When "human dignity" emerged as the common value in international law (mid twentieth century), many cultures and religions have found within their own traditions very similar values and modes of reasoning.

There is a very broad consensus that the moral ethos of human dignity is a sort of **human universal**, which is a cultural feature that exists in all known societies, even if they use different languages to describe it, and employ very different practices in relation to it.

### What is the idea of human dignity?

Human dignity means that all humans share a special moral standing solely because of their humanity. Because all human beings are equally human (There are no people who are more or less human than others are), all humans deserve equal treatments in terms of human dignity. All humans are equally obliged to respect the human dignity of all other humans. In many cultures, this special moral status of humans relative to the animals' sanctions the use of the latter by the former. But the shared ethos of human dignity does not have to go thus far. It forbids the treatment of humans as if they were animals and it rejects the preference of animal interests to basic human needs.

In many traditions, human dignity entails a set of moral expectations of people, and standards of behavior that people should abide by, such as personal self-care and polite speech. However, the contemporary ethos of human dignity is centered on the moral status of human individuals, not on moral expectations of people. The dignity of all people must be respected

even when they fail to respect their own dignity and the dignity of others. Respect for human dignity is not a reward for the respected person, but a duty incumbent on all others, as well as on the person himself or herself. Although we often find expressions such as "he lost his dignity", according to the ethos of human dignity, it is impossible to either erode or erase the dignity of either self or others. The most severely humiliated and abused victims and the most horrendous criminals both share equally in human dignity. Fighting, prosecution and punishment of every crime and criminal conceivable must be conducted with respect for the dignity of all persons involved.

## What are the normative implications of the value of human dignity?

The normative dimensions of human dignity are divisible into distinct categories.

Special regard for human life and the protection of the life of every single human individual is the first of them. Similarly, protection from extreme suffering and disability are at the heart of human dignity. However, the life cherished by the value of human dignity is never restricted to the biological dimensions of existence (*bios*). Humans can survive and even thrive biologically, if put in a cage and treated like zoo animals, for example. But such life is offensive to human dignity. The ethos of human dignity informs us that some values, such as freedom from enslavement and degradation, are no less important than life itself.

Respectful treatment. Nobody should be subjected to humiliation and to any form of treatment that may imply that he or she is less human than others are. Every person deserves to feel as bearing a potential to moral excellence and personal growth. Even those whose mental capacities are very flimsy are treated respectfully, as belonging to human society, solely because they are human. People may vary in honors (the praise society may esteem their social status and achievements), but are equal in dignity (their human status in society). Respect for dignity is

especially related to people's image (physical appearance, reputation) in their socio-cultural contexts. This public image or public face is not about each person's differences in character, capacity, background and achievement (social recognition of all of these is a matter of honor), but about a basic standard of being a human person in society. One typical example is the universal habit of greeting persons. Some culture-specific examples are, "Sir", "Madam", handshakes, eye contact and a bow, use of the third person pronoun and the like). Key to the person's image is personal control over exposure of body and personal information. Hence, exposure of the body and other intrusions into private life are disrespectful of human dignity. Medical, genetic and other personally attributes of the person are especially protected from unwanted exposure. (See chapter on privacy). The WHO considers reducing waiting times and other measures that render healthcare services friendlier as dignity related as well. Even if no-harm is involved, inefficient and impolite health care services are undignified.

The ethos of human dignity has always celebrated the <u>free will and rationality</u> of humans as social creatures. Especially in the medical contexts, the locus of expression of this free will and rationality is the live human body (which is also the embodied person). By means of rationality and free will, people exercise dominion (i.e. some influence) over themselves, their property and the rest of the world. However, human dignity confers a privileged status to the conscientious decisions of the person regarding his or her own body and personal life, to the dominion of the person over his or her self, his or her autonomy. Hence, respect for human dignity entails respect for the conscientious choices of individual humans that pertain to one's own body, and self. Even though, democracy values personal choice and opinion about almost every matter, the special moral calling of human dignity grants a unique power only to personal choices and values regarding one own self only. It follows that freedom of expression, religious

practice, political convictions, association with others and choices regarding the coping with health care are at the heart of human dignity. According to the ethos of human dignity, no human being should be subjected to the arbitrary free will of another human. Whereas some traditions and philosophers behold human rationality as more central than personal free will, others esteem free will more than rationality. The notion of human rationality entails modes of thinking common to all humans and the values they consequently share, such as esteem for life and dignity. The notion of personal free will underscore individual choice even when not accompanied by justification and quite idiosyncratic. Hence, when people freely choose in ways that appear to others not consistent with his or her human dignity, some people tend to respect the choice, despite its disagreeable content, while others maintain that respect for human dignity cannot uphold choices that undermine it. For example, think of a cancer patient who refuses evidence based curative treatment because he believes in spiritual healing only. Those who bend towards the primacy of common rationality will be more inclined to push that patient towards compliance with scientific medical care; those who bend towards the primacy of free will are more willing to respect pre-meditated choices of competent and free persons, however bizarre. Most jurisdictions will tend to avoid coercion of care on such patients because of the offensive nature of coercion.

Another dimension of human dignity is protection of bodily and sexual integrity of the person. Unwanted manipulations of and intrusion into the body are incompatible with human dignity. Usually, such interventions (e.g. medical care, male circumcision) are culturally specific, not harmful to health and life and are presumably desirable by the person. Protection of sexual integrity is even more sensitive, as all known human cultures regard intrusive sexual behavior as extreme disgrace. Hence viewing of private parts of the body, gentle touch of genitalia and sexist

language are condemned despite lack of clear physical harm and even in the absence of long term consequences. Separation of the sexes in hospitals, in the use of toilets and fitting rooms and the like embodies the special sensitivity to the sexual integrity of the person. This sensitivity applies to issues of sexual identity, sexual orientation and sexually related diseases.

Respect for human dignity involves many <u>culturally specific symbolic treatment of humans</u>, <u>including dead persons</u>. The use of personal names, clothing, care for hair and nails, and numerous other practices are tokens of respect for the humanity of people and are practiced whether or not the person is capable of appreciating them. Hence, proper clothing and personalized care for severely and irreversibly retarded children or old people are acts of respect for human dignity, even though the persons involved are not aware of such treatment.

Lastly, the ethos of human dignity esteems <u>relationality</u>, or Personal, I-Thou, interaction as end in themselves. Persons, even those who lack mature mental faculties, should be treated as persons, as conscious, sentient, emotional and thinking humans. Whenever possible, people should be addressed directly, and benefit from personal attention, especially when they cope with suffering, danger and injustice. Hence, personal attention is preferable to automated services. People must not be treated as mere objects or raw data. Every person, no matter how needy and socially low, may claim his or her rights with dignity, as a deserving person, not as an object of pity and mere charity.

## **Human Rights**

Human rights are an instrument or set of instruments that contain declarations, laws, conventions and systems of monitoring and enforcement. The fundamental human rights document is the UN Universal Declaration of Human Rights, proclaimed in December 1948.

All human rights documents and institutions are committed to the value of human dignity. But human rights do not aim at the protection of all dignity related issues, for example,

respectful treatment of the dead/ Human rights do not cover all moral issues either. Not every injustice and misconduct violates human rights. Human rights target the most basic human values, such as life, health, gainful employment, freedom of religious devotion, political expression and artistic creativity.

#### Human rights address the basic needs of live human individuals.

Human rights protect life, freedom of expression, devotion, association, trade and movement, integrity of the person as well as access to basic needs such as safe and adequate food, water and basic healthcare. Human rights protect persons from humiliation and discrimination.

Human rights serve rhetorical and trumping roles. The rhetorical role raises awareness to the severity and urgency of a human right issue; the trumping role help resolve conflicts.

Whenever a human right is in conflict with other interests and values, human rights shall prevail.

When human rights seem to collide, for example, when protection of life clashes with privacy, the instrument of human rights does not tell us a priori which right or value takes precedence over the other. Case by case deliberation is required in order to make specific decisions in such conflicts. In well-ordered societies, the key role of human rights is to set limits even on reasonable and legitimate laws, majority power and any other action that may violate the dignity and basic needs of any human individual, including aliens (non-citizens), foes and criminals. In relation to failed-states and evil regimes, human rights shed light on the duty to protest (and later persecute) most serious and urgent crimes.

Human rights are commonly divided into "first" and "second" generation. The first generation rights, or "negative rights", proscribe action. They set limit on anybody wishing to deliberately or indirectly violate the right protected values, mainly life, integrity of body and

person, liberty of the person to work, practice religion, associate politically, create artistically and otherwise develop interests and passion, alone or in society. Protections from arbitrary foreclosures, dispossessions and unequal standing in the marketplace count as well.

Second generation rights, or "positive rights", refer to the active duty of society (mainly the state and the international order, which is based on the state system) to provide for basic needs such as basic healthcare, gainful employment and education. The Universal Declaration of Human Rights contains a mixture of first and second-generation rights. However, there are many controversies regarding the extent and power of second generation rights, especially regarding the state's power, and possible duty, to impose taxation and markets regulation in order to finance and promote structures of positive rights, such as an expensive and universal healthcare system.

#### Controversies

Because human dignity is an ethos, we expect it to be widely received, but passionately contested. Human rights, on the other hand, owing to their formulation in declarations, laws and conventions, are more specific and leave much less space for diversity of interpretation.

However, constitutional and international law allow for a "margin of appreciation" (the principle of subsidiarity), which is a range of diverse interpretations of human rights in different jurisdictions.

Much of "human dignity" is not contested at all. Universal agreement prevails against the discrimination and humiliation of any person on grounds of ethnicity, age, creed, and medical condition. The U.N. has spoken against discrimination on the basis of sex and sexuality. All cultures and legal frameworks contain duties to provide lifesaving and similarly urgent assistance to people in need, regardless of age, sex, religion, ethnicity or medical condition. Key medical values such as respect for privacy, taboo on non-consensual use of the person, protection of life

and health and medical neutrality are also a matter of consensus and international humanitarian law.

## Respect for personal autonomy

The topic of autonomy as a moral value involves five leading questions:

- 1. What is "autonomy"?
- 2. Why is it morally valued?
- 3. Who is competent to be autonomous?
- 4. Which behavior and choice are autonomous?
- 5. How is autonomy respected?

This section is concerned with outlining answers to these questions, whereas the sections on benefit, consent and privacy elaborate further how respect for human dignity is embodied in beneficial care that is guided by respect for personal autonomy.

#### On the nature of autonomy

Autonomy means "self-rule". The expression of "self-rule" captures the notions of human rationality (without which no rule is conceivable), and dominion over the body and self. The synonym "self-determination" highlights will-power as key to autonomy.

We respect personal autonomy because it embodies three fundamental elements of human dignity: The first is self-control (dominion), the second is human rationality, and the third is personal free will. It implies that it is very difficult to benefit a person without respect for his or her autonomy. Indeed, numerous well-intentioned attempts to benefit people failed spectacularly because of insufficient regard for their autonomy. Hence, respect for autonomy is instrumental to the values of benefit and respect for human life. The autonomous person exercises his or her free will and rationality in the service of making the important decisions of his or her life and living accordingly. The responsible person acts freely in choosing goals and orchestrating them (e.g. development of family, social relations, career, hobbies and the like).

The wise person actually chooses and behaves in line with his or her autonomous choices in real

life. He or she is also capable of logically explaining them (even if not exhaustively) to others (this is **accountability**), and ultimately be peaceful with them; in this manner he or she is **responsible** and **conscientious**. Typically, autonomous decisions fit with and coalesce with a grander "rational life-plan", of the person.

Autonomy is a prime moral value because it unifies (or at least connects meaningfully) many elements of identity, personal interests, chosen goals, and regard for others in a four-dimensional abstract structure—it has the depth of personal integrity, the breadth of myriad concerns, the coverage of significant time spans, and value-driven rational organization. As an overarching, organizing faculty, autonomy prioritizes values and brings the self into coherence with the judgment of the conscience and the feedback coming from like-minded people. Such a person unifies dignity as a moral standard of behavior (=the behaviors expected of people on the sole basis of their human dignity) with dignity as a moral status (the duties owed to people solely because they are human). This is a life-long process of personal growth, character development and the consolidation of identity. However, in real life, clinicians and policy makers cannot (and must not) ponder whether each person shares this ideal of autonomy and conforms to it. In bioethics, whenever a person expresses behavior along with some reasoning and consistency, and from what seems to be a responsible disposition, he or she is regarded as acting autonomously.

Respect for personal autonomy is especially prized in medical ethics, because there is hardly anything more important *and* personal than one's own body, identity and mind. Respect for personal autonomy is also a highly sensitive value, because there is hardly anything more vexing and humiliating than the control of one's body, person and health by others, their benevolence notwithstanding.

Many medical traditions of the past tended to believe that serious sickness clouds autonomous judgment, and that, consequently, caregivers must protect the sick from disturbing information and decide for him or her, until the patient gets better. Empirical research has dispelled this premise. Today we know that, with the exception of few cases, humans, including the old, frail and sick, can and wish to exercise their autonomy, even in the face of extreme physical and social conditions. We also know that it is almost impossible to benefit a person without due respect for his or her strongly held wishes and values, even if the person is not fully autonomous. Hence, in most healthcare situations, respect for autonomy and the value of beneficence overlap and are not in tension with each other. Whenever possible, shared decision making in healthcare is also the straightest way to medical benefit and minimum harm.

It is widely accepted that the treatment of an adult as lacking in mental competence requires clear evidence of either serious derangement of higher mental faculties (e.g. memory, concentration, abstract thinking) or overtly rigid adherence to perceptions and factual beliefs all others deem absurd, impossible or blatantly false (i.e. hallucinations and delusions leading to psychosis).

Ideally, respect for personal autonomy goes much beyond "live and let live" and mere tolerance (also known as "**negative liberty**"). Respect for autonomy entails **recognition**.

Recognition occurs when either a person or society communicates to another person that his or her choices are autonomous and morally valuable as such. When the wishes of the person are met, recognition is essential for demonstrating that he or she is treated as a person, not instrumentally (i.e. merely in order to get from them something or use them). Recognition is in place even if others disagree and would choose differently from the person in similar circumstances, or when it is just impossible to honor the person's choice.

Indeed, recognition is associated with "positive liberty" and "positive rights", which is a social commitment to help and assist the person in the fulfilment of his or her choices. Social life provides structures for mutual recognition within a frame of shared values. Recognition may be expressed at three different levels. The most basic one is recognition in the humanness and human dignity of a person. The second is recognition of autonomous conduct, or at least, a genuine attempt to live responsibly and in light of human values, even of these values are alien to society and are contestable by many. The third level of recognition focuses on specific choices — recognizing them as conscientious, even if for other reasons (e.g. lack of resources, harm to the environment) it is either impossible or undesirable to support them actively. Most specifically, healthcare professionals do not have a duty to (We believe that they must not) provide autonomously chosen services that the healthcare professional considers as either futile (see below) or harmful to the patient's health.

Many jurisdictions allow for "conscientious objection", which occurs when the professional's own set of values (e.g. religious beliefs) strongly object to an autonomously chosen intervention (e.g. possibly by a patient not sharing this religious teaching). Some authors believe that in the absence of an alternative source of service, and if non-intervening may result in a significant personal distress to the patient, the altruistic commitment of the physician should prevail over his or her conscientious objection.

#### Degrees of self-rule and respect

Full autonomy and genuine respect for autonomy are ideals. Short of these ideals, there are gradations of self-control and respect.

**Self-directedness** is the capacity of animals and humans lacking in mature mental competence to move and act by their own natural means. Many self-directed persons can experience **resentment**, which is the anguish produced by coercion and disregard for one's

desires. Because self-directedness is part of the human nature of incompetent people, and because they can experience resentment, it is immoral to restrict self-directedness without a proportionate moral cause. Safety, such as prevention of accidents and protection of property, may justify restraining incompetent people. However, any restraint on self-directedness should be as mild as possible; and full of respect for the dignity of the person. It is immoral to tie a patient to bed, if it is possible to achieve safety by removal of sharp objects from the room, or locking the window only.

Adolescents and many other persons, such as people suffering from mild dementia, benefit from relatively mature mental faculties, even though they are not considered legally competent. Because, these people are almost autonomous, and some are either in the process of becoming autonomous (adolescents) or are reclaiming their autonomy (patients in rehabilitation), there is an even stronger moral obligation to involve them in personal decisions, to inform them about their medical conditions, and to allow them to participate in care related choices.

Some legal systems allow minors to make difficult and controversial choices, such as the prescription of contraceptives without parental knowledge. These laws do not necessarily embody only respect for autonomy, but may consider also an overall estimate of the situations, including possible outcomes, that may results from lack of personal freedom in such matters (e.g. unplanned teen pregnancies).

Human adults are considered autonomous unless proven otherwise. Usually, there is no reason to question people's autonomy. Usually people exercise self-rule by means of rationality and free will. Autonomy related problems do not arise when sick people seek treatment for their conditions, when they choose which doctor or medical service to consult and when they opt for one of a few alternatives presented by their healthcare professionals. Sometimes, people opt for

choices that seem immoral, may be self-harmful, or are considered contrary to mainstream reasoning (the range of choices ordinary persons choose in very similar circumstances). In such cases, the most appropriate course of action would be to address the issue at stake through an open conversation with the person with the aim of clarifying the question. Often misunderstandings are at the origin of unexpected or counterintuitive choices. The intervention of intermediaries (such as a family member or a religious leader) may improve communication. However, one may be aware of some individual's need for independence from such interferences and for protection from familial and cultural pressure. Overall, the above describe efforts should be proportionate to the nature of the healthcare issue at stake. When circumstances allow, consistency (or lack of it) along a span of time may also reveal or disprove the authenticity of the choice. For example, mandatory waiting periods prior to endorsement of live kidney donations are means for authenticating and enhancing autonomy, not restrictions on it.

Respect for autonomy is not absolute. Disrespect for the autonomy and interests of others is one reason for setting limits on autonomy (i.e. Mill's **harm principle**). In the name of human dignity and public order, some societies have legislated certain limits on public autonomous expression and behavior. The social nature of science and medicine sets some other limits. For example, a person is not empowered to participate in medical experiments that have not been approved by an ethics committee (IRB). A fully autonomous choice by a participant and a researcher is insufficient.

In sum, respect for personal autonomy is primarily an attitude of recognition. In medicine, this recognition takes place within the frames set by the state for healthcare.

Recognition goes beyond interpersonal, clinical relationship. It encompasses public participation, especially by the relevant consumers, in the planing and governance of basic social goods. In

addition to respect for individual autonomous choices, they also facilitate expansion of available` choices and facilitate circumstances of conscientious and informed reflection on healthcare choices.

#### Autonomy, truth, and difficult choices

Not only do humans detest resentment profoundly, but they also behold disregard, manipulation and coercion in personal matters as offense to their human dignity. Consequently, dishonest conduct and even subtle forms of manipulation and inducement of choice and behavior are morally problematic. Lying to and withholding personal information from people offend against their autonomy and are almost always prohibited. Rare situations in which truth telling is very likely to harm patients significantly (e.g. induce suicide), involve a conflict between two basic values – life and respect for autonomy.

The ultimate test of autonomy comes with **transcendent choices**. Such choices occur when a person faces a dilemma that pities one basic value against another. For example, a patient may have to choose between a life full of untreatable suffering and rejection of care that leads to an early death. Both - life and freedom from extreme agony - are basic human values, associated with human dignity. Because human dignity is a pluralist ethos, it is up to the affected person to decide for himself or herself whether to fight for life (and suffer) or die. Sometimes, people choose against a personal objective good, such as health, for the sake of a non-personal value, such as religious devotion or even altruism (e.g. a frail person undertaking difficult pilgrimages and fasts, or donation of a kidney). When a devout Jew insists on fasting against the advice of his or her doctors (and sometimes, even in defiance of the rabbis!), and when a diabetic Muslim insists on undertaking a long and taxing pilgrimage to Mecca, and an ageing athlete tries to run one more marathon, they all make transcendent choices. A third kind of transcendent choices pertains to sexuality, which is a specially protected aspect of human dignity. Because it is not

possible to tell objectively whether it is good for a person to have sex, beget children and perform other sexually related acts, sexual and reproductive choices transcend considerations of beneficence. Hence, according to the ethos of human dignity, only the affected person may decide conscientiously whether to engage in sexual acts (e.g. sexual relationships, choice of having children, infertility treatments, sterilization etc.).

When transcendent choices are at stake, medical ethics and law insist on the verification of full mental competence and elaborate (but not burdensome and degrading) procedures of verification. Patients who refuse life-saving medical care, people who donate organs or ask for radical procedures, such as sex-change surgeries, should be evaluated, talked to, offered support and understanding while the authenticity and duration of their choices are put to test.

#### Summary

We respect everybody's autonomy equally. However, when people's autonomous choices in healthcare deviates significantly from ordinary expectations, there is also a moral cause for respectful evaluation of the authenticity of the choice made. On the other hand, there is also a strong moral motivation to empower and respect unusual autonomous choices. (The majority and ordinary need much less protection!) Such diversity reflects the richness of human lives, reasoning and values, and may inspire novel ideas, life-plans and social progress. Respect for personal autonomy is a delicate balance of a triangle whose ends are:

- (1) A genuine commitment to respect the other person, no matter how different and challenging his or her rationality and free choice make themselves manifest.
- (2) A commitment to protect persons from harm and folly, from behavior that is not autonomous. This perspective involves a delicate balance of autonomy as individual, independent and free faculty on the one hand, and people's need for social interaction and cultural background for the construction of mature psychological capacities and

- responsible autonomous selves. At any rate, respect for human dignity is very strongly disposed against direct confrontation and against deliberate manipulation of persons.
- (3) The common good, imposes restrictions of justice (e.g. harm to and burden on others and public order. Every claim laid by individuals to the healthcare system entails compliance with professional standards and the overall social structure that regulate medicine as a public good, even in private, fee-for service, medical services.

Because the value of respect for personal autonomy is restricted to self-dominion, respect for autonomy is relevant to personal decisions regarding one's own body and self (e.g. whether I shall have surgery tomorrow), and becomes less and less compelling morally when decisions grow less personal (e.g. whether the healthcare services offer surgery on holidays). Respect for personal autonomy is manifested in democratic governance, when each person's freely chosen vote in the election counts as much as any other, and every person benefits from an equal and effective access to the public sphere (e.g. be active in politics, elected as public official, choose a trade and business, media and the like).

## Benefit and harm

## "Benefit", "medical benefit" and "the good"

The notion of benefit in bioethics has a few meanings. The first is holistic. It means that to benefit a person is to promote the overall of his or her interests in just and respectful manners. Whereas a holistic (or "bio-psycho-social") approach to medicine strives to take into account all relevant aspects to the patients' well-being, it is self-evident that healthcare's primary commitment is to health, rather than financial, social and other interests.

A more useful conceptualization of "benefit" in healthcare is medical benefit. This would entail the overall-promotion of health in respectful and just ways. Yet, since it may be possible sometimes to cure the patient while treating him or her disrespectfully and unjustly, the third and narrowest definition of benefit is focused precisely on the biological aspects of medicine.

Hence, the proper, technical, use of the notion of "benefit" as a bioethical value among others (mainly, respect for autonomy) is the promotion of objective healthcare targets. This means that health, strictly speaking, is universally recognized as a human good, and that most usually, it is possible to assess such promotion. If a person has fever and pneumonia, we know that he or she is sick, that cure is good for the patient and that it medicine may realize this by the prescription of a certain treatment.

Sometimes, the objective benefit of medicine, may be either non-beneficial to or undesirable by a particular patient. Perhaps, a particular person has trouble at work and prefers to benefit from a sick leave for a few weeks; perhaps the patient is a musician who prefers to suffer a protracted illness rather than risk the possible side effects of treatment on his or her hearing. It might also be possible that the use of antibiotics may boost resistant strains of germs. Such scenarios illustrate the role of benefit in ethical and clinical problems. The first challenge is to

answer the question: what is actually good for the person? Is it possible that it is better to suffer a long illness and escape boring work (perhaps make more money trading stocks at home)? Is it sound to risk untreated pneumonia in fear of a subtle hearing impairment? The second challenge is to decide on a course of action. The clinician's first decision is what to recommend to the patient. The second is what to do, should the patient insists on a different course of action, especially when benefit seems to collide with other values, such as health (the prisoner who prefers to be sick) or justice (the risk of benefitting a patient while risking others by inducing resistant strains of germs).

We may observe that benefit related problems begin with a biological (hence objective) assessment of the **medical good of the person** (in public health – the health indices of society). Then, we move on, exploring personal considerations (e.g. it might be better for a musician to exercise extra-caution in the protection of hearing), as well as subjective preferences (even if the objective risk of hearing impairment is very minor, a musician might care about it and suffer anxiety related to it), and non-medical factors (e.g. the economic burden of the "best treatment" on patient and or society). Altogether, medical benefit is medicine *default practice*. With the absence of a compelling reason to act differently, healthcare professionals opt for saving life and prompting health. They also strongly recommend compliance with beneficial medical care, and educate patients accordingly. However, sometimes, there are sufficient reasons to deviate from default practice. Sometimes this happens when the patient's own values and situation is unique (e.g. the sensitive musician mentioned above); at other times, competent patients insists on refusing beneficial care. Patients' choice cannot force doctors to harm; but it may stop doctors from provision of unwanted care.

Every medical intervention must be part of a plan whose ultimate goal is the medical benefit of people. These goals are either preventive, curative, palliative or rehabilitative. It is unethical and unwise to do something that either has no clear clinical goals or has very low chances of achieving a clinical goal.

#### **Futility**

Futile medical intervention is a medical intervention that is unlikely to contribute to a clinical goal. For example, research has shown that even though terminal cancer patients suffer from anemia and from weakness, correction of hemoglobin to levels above 8mg% improves neither quality of life nor survival. Hence, professional guidelines advocate against such infusions. They achieve a physiological goal (hemoglobin levels are nearer to normal), but no clinical goals. Principally, blood transfusion in these circumstances if futile. It is not administered even upon the patient's autonomous request, even if it is neither harmful nor burdensome on society (There is enough portions in the blood bank and the patient pays). Perhaps, an individual patient may be especially sensitive and responsive to higher increments of hemoglobin. If genuine clinical observations made on a specific patient actually support this exceptional course of action, blood transfusion to this patient is not futile. It promotes a clinical goal, even if for a single, exceptional case.

When the chances of clinical benefit are very low (usually less than 1-2%) and when the justification of treatment comes outside of biomedical knowledge (e.g. many forms of "alternative" treatments), intervention is considered futile as well. Even when a particular physician has great faith in the "alternative" modality, he or she has the duty to disclose to the patient the difference between the perspective of biomedicine, and "alternative" approaches. Treatment that is not objectively established and accepted by the medical community is not "medically beneficial" strictly speaking.

The notion of futility does not cover value judgments. Futility is about the attainability, not desirability of a clinical goal. For example, some people believe that it is not necessary (even wrong) to prolong the life of irreversibly comatose patients. However, a medical intervention that can prolong such life is not futile. Preservation of life is a clinical good, even if it is not in line with the overall good or wish of the patient. Assessment of futility is limited to the value of medical beneficence, not necessarily to a comprehensive moral evaluation of the problem in hand.

#### The common good

Medical interventions, especially in public health, should aim at the common good. Typically, the common good is the common interest of the people involved. The proper definition of the common good is the good, for which the public (the "common") should strive. Hence, even though the preservation of the environment and privileges to disabled people do not promote the interests of most people, these goals are part of the common good. When the interests of an individual patient are incompatible with either others' or the common good, we face a problem of justice. In societies that respect human dignity and human rights, the public's interest must not overcome the substantial medical good of an individual human (e.g. life, integrity of the body, freedom from physical suffering). Put in other words, the common good never entails deliberate harm of the health of an individual human being. Society does not sacrifice the health of a person for the sake of anybody's interests.

#### The rule of rescue and the defense of necessity

The rule of rescue is the secular name given to the ideal of the **Good Samaritan** (Luke 10:25-37, Leviticus 19:16), which is also found in numerous cultures and religions. In contemporary philosophical terms, it may be said that the rule of rescue contains the following conditions:

1. A human being is in immediate danger to life or other basic interest (e.g. blindness, rape).

- Another person or persons can act and rescue the victim with a very high probability of success and marginal personal risk.
- 3. Typically, the potential rescuer and the victim are physically close to each other.
- 4. There is a moral (and in certain jurisdictions is also legal) duty to act and save.

This rule embodies the values of human dignity and solidarity in relation to the most basic issues of harm and benefit. The moral calling of rescue is blind to differences such as ethnicity, religion, political affiliation and sexual identity and practice. It is the moral tenet behind the universal standard of providing emergency medical care to every needy person, including uninsured and illegal persons. The rule of rescue is pro-active. It does not tolerate inaction. But intervention may entail risks, especially rapid response in the face of emergency. Hence, in the face of regrettable error (clinical, moral and otherwise), those who take action may benefit from the **defense of necessity**, which is also quite universal, but has legally developed within Common Law, and which cover situations other than rescue as well. This defense requires the following conditions:

- 1. An extreme and unexpected situation
- 2. Usually, the agent himself or herself is under much risk and pressure.
- 3. All of the open courses of action are morally problematic (i.e. a dilemmatic situation).
- 4. The agent acts in good faith and is free from bias.
- 5. The agent does his or her utmost in the given circumstances.
- 6. In case the action taken is found wrong, the agent benefits from the defense of necessity and is not liable to punishment or shame.

For centuries, this mode of reasoning has protected doctors who had to make hard choices such as the management of hard labor (childbirth) or surgery in dire and poor conditions. However,

the evolution of scientific medicine, modern medical education and the rights-based legal systems has entailed the shrinkage of this defense. Today, in affluent societies, healthcare professionals are well equipped and well educated. Rarely do they face an emergency unprepared. An obstetrician cannot excuse himself or herself for failing to act upon the prevailing guidelines. For the obstetrician, childbirth is a routine, not an unexpected emergency. But every medical practice is rife with surprises. Even the most experienced obstetrician may invoke the defense of necessity upon handling a difficult crisis in the management of a very rare case such as conjoined twins. In sum that the non-professional (and the professional facing a dilemma outside his or her turf of expertise) had better not act than risk harm while acting without preparation. But the professional had rather act in the face of danger, do his or her best to avoid harm and rely on the defense of necessity should things go wrong. All the while, the defense of necessity is a defense, not justification. After the fact, when things calm down, a decent and critical evaluation of the case (debriefing) is conducted. The direct purposes of this debriefing is learning and quality improvement. The broader goal is respect for the dignity of the patients involved. Actions affecting people's life and integrity, directly and significantly, call for deliberative evaluation, even if only after the fact.

#### Harm

Avoidance of unjustified harm is a leading moto of medicine (*primum non nocere*). Yet, it must never be the primary one. Healthcare is about scientifically directed human action, not passive resignation. Because healthcare is about the promotion of health and struggle with disease, the surest way to avoid harming – inaction – is unacceptable in medical practice. Moreover, failure to deliver standard treatment is negligent and harmful. The doctor is accountable for the harm he or she could have prevented had he or she acted professionally. Evidently, doctors are barred from maleficent use of the medical arts (e.g. medical participation in torture and development of

biological weapons are crimes against humanity). The issue of harm usually comes to the forefront in relation to accidents, non-maleficent errors, and side effects, resulting from medical activity.

The practice of **risk management** arose in contemporary healthcare settings as an endeavor at risk reduction based on optimization of management techniques, systems of monitoring, ergonomics and social psychology. An emergent trend in risk management and medical education is the "**no-shame**, **no blame**", organizational culture, within which practitioners openly and promptly report on errors and mishaps in order to facilitate processes of harm and risk prevention. The "no-blame no-shame" reflects two ethical attitudes on nosocomial harm (i.e. healthcare induced). The first is acknowledgment that error is a human weakness, often resulting from circumstances (e.g. misunderstandings, cognitive bias, unexpected deficiencies in engineering, stress). If physicians and patients fear harm too much, they might forego active and daring interventions. Vulnerable and high-risk patients who wish to fight for their health and life might be especially harmed by fear from failure and side effects.

The second ethical attitude proclaims prevention of future harm to patients as more valuable morally than considerations of retributive (=punishment) and corrective (=compensation) justice. From the perspective of victims of error and negligence, the "no-blame, no-shame" policy might be unjust; but it is just within the paradigm of distributive justice – the provision of optimal safety to all future patients.

#### The principle of double effect

Many ethicists maintain that, whenever the prospects of an achievement (e.g. cure of a disease) is clouded by the risk of a significant side effect, the **choice of the lesser evil** should be made. A typical example is a decision to amputate a cancerous limb. Pending informed consent, the great benefit of saving life justifies the lesser harm of amputation. Sometimes, the dilemma is less

obvious. Suppose a vaccination program is likely to immunize a million people against an infectious disease, but to cause the death to a few. Can one say that the lesser evil of few dead people is a price worth paying for the health of the many? Such a statement is clearly disposed against the value of human dignity.

Many ethicists invoke the principle of double effect in order to evaluate the morality of side effects. Rooted in the Middle Ages, and still blighted by debates regarding its proper formulation, the principle has matured into the following definition:

- 1. A good action (the "major effect")
- 2. A foreseeable bad outcome of the same action (the "minor effect")
- 3. The bad effect is not the means (or: more immediate) to achieve the good one.
- 4. There is no intention to achieve the bad effect.
- 5. There is a proportionate balance between the good and bad effects.
- 6. Best reasonable efforts are made in order to avoid and reduce harm.
- 7. It is also widely accepted that the actors have the moral duty to undertake active measures to reduce harm (e.g. adopt a surgical method that is more costly, but associated with less risk). This is known as **the principle of double intention**.
- 8. Although not part of the principle, in actuality, informed consent of the patient is necessary.

Conditions (1) and (2) define the situation (i.e. the double effect); conditions (3) through (8) define the conditions that render the deliberate choice of the action moral. For example, the protection of the many from an infectious disease is the good effect, while the foreseeable death of the few is the minor, negative effect. The death of the few is not the means by which the many gain protection. Indeed, the immunization program would be pursued even if nobody is harmed.

Evidently, there is no intention to kill the victims of side effects. The prevention of serious infection among millions is proportionate to the accidental death a very few. A hypothetical immunization program against a minor problem such as hair loss does not commensurate with loss of a few lives. Even when the benefit is significant (prevention of numerous serious infections), the authorities have the duty to invest resources in harm reduction, such as screening for vulnerable people and spending on even safer vaccinations. Lastly, the democratic governance of society stands for the informed consent of the public to its public health programs; the informed consent of individuals is also requested prior to every immunization. Because infectious diseases are often contagious and pose risk to others, some advocate mandatory immunization plans (or other sanctions against non-compliers). Non-immunization may exemplify a clash between a personal perception of benefit and harm and the common good.

#### The precautionary principle

This text encourages doctors to dare and try to treat, upon informed consent, patients who conscientiously wish to fight for their lives and health. Patients have the right to know of treatment options based on solid medical science and practice, including experimental and novel approaches.

Many people believe that when life and other basic goods are not at stake, and when public policy is involved, such as the development of new genetic technologies, society has to be less daring. According the precautionary principle, a novel technology must be carefully assessed for potential harm, and be avoided until its safety is well-established.

## Privacy

The Hippocratic Oath mentions two privacy related issues: sexual propriety and medical confidentiality. Perhaps the oldest aspect of privacy is **prudery**, which is the sense of particular sensibilities associated with the private functions of the body, mainly sexuality and toilet. One's own medical condition and care is also a matter of prudery. Prudery is a universal value (=shared by all known human societies), which is culturally constructed (e.g. some cultures allow exposure of body parts that other cultures consider inappropriate). Because healthcare professionals must often observe exposed body parts and ask questions about intimate issues, and because many patients cannot observe the norms of prudery (e.g. they may be helpless and confused), protection and promotion of patients' privacy are at the very heart of medical ethics and the foundations of trust in medicine as well as its practitioners. Observation of prudery norms is a moral value regardless of the patient's awareness of the situation. It is immoral to disclose the medical file of demented people as well as to allow them lie in bed immodestly exposed. Medical information contains information that is unique to the particular person; prudery is about coverage of something that is common to all humans (e.g. the genitalia) and is not "information" at all. Two metaphors help understand the notion of privacy. The first metaphor is spatial. Privacy is about an enclosed space, access into which is not public and must be under the control of the autonomous person. The other metaphor is the mask. Indeed, the word "person" is etymologically derived from the Latin word designating the theatrical mask. Privacy allows each person to control his or her image in society, to "keep his or her face". From this perspective, exposure of some intimate parts of the body may not be wrong in its own right, but wrong only in societies whose norms are incompatible with such behavior. Within the framework of the mask metaphor, the violation of privacy is not necessarily intrusive but

primarily disruptive. It is the forcible removal of a mask the person keeps as a respectable member of society.

In medicine, unavoidable intrusion into privacy is codified. For example, patients' bodies are never fully exposed; only the part under examination is. Healthcare professionals use gloves when touching intimate parts of the body. Specific permission is needed in order to publish medical data, which must also be anonymized.

Most patients are capable of noticing disrespect for their privacy and they usually suffer deeply unwanted exposure and intrusion. The violation of privacy is humiliating regardless of the harm done. Patients resent the act of exposure, even if the information disclosed is of little practical consequence.

Sometimes, the information is fateful. For example, information about sexual orientation or carriage of certain diseases and genes. In many circumstances, publicizing such facts may render people vulnerable to the loss of a job, a partner, a chance for a business transaction, their social standing. The latter concern is relevant in contexts of **stigmatization**, in societies where prejudice and derision of people with certain medical conditions are rife. This often happens in relation to sexuality and to the **abject**. (The abject is a term referring to the "unpleasant" and "offensive" functions of the body, especially the products of the body – odors, sweat, vomit, pus, menses and the like). Hence, concerns about stigmatization coalesce with prudery. Because many sexually acquired conditions tell about the person's past choices (i.e. to have sex), biographic privacy may be involved as well.

An especially sensitive aspect of privacy is **biographic privacy**. It is the life of a person as an agent – the things he or she communicates (in words, behavior etc.), does (e.g. chooses where to be and with whom), and happen to him or her personally. In the absence of confidence

in one's own privacy, a person cannot mature and develop independent choices, judgments and personal conscience. The person cannot maintain the emotional, cognitive and social individuation necessary for having an autonomous personality. The person needs to act as the gate-keeper of this separation, deciding what, with whom and how privacy may be shared. Hence, privacy is not limited to protection from intrusion and exposure; it is no less also about the power to open up and invite persons into the private sphere.

In many circumstances, the healthcare system faces conflicts between protection of privacy and protection of patients' wellbeing. A person may not wish to tell his or her family members about a genetic condition, even though they might benefit from early screening. People diagnoses from sexually transmitted diseases are often not happy to share this with their sexual partners, even though this might save their partners' lives. It is customary to grant priority to the wellbeing of potential victims (i.e. sexual partners), but to delegate the disclosure to a public health official, not the patient's care giver. The balance of people's privacy with non-victims (i.e. family members who share the same genetic pool, but are not harmed by the patient) is controversial.

Privacy and transparent deliberation can co-exist peacefully. Very private matters, such as psychiatric clinical records, may be subjected to the critical scrutiny of a highly selected and small group of people, such as the regional chief of psychiatry, a state prosecutor and the local ethics committee. Additionally, every competent person has the right to review his or her clinical records and share them with his or her people of confidence.

In the era of IT (information technologies), a new privacy related concern has emerged. If I walk in the street, enter a shop and buy some fruit, I know that my actions are public.

Everybody may see me and peek into my basket. However, if someone (a commercial company,

a governmental agency) tracks all of my movement in public space and keeps track of my shopping, adding it all to a huge data bank of people's actions, I may feel concerned. The triviality of daily activity and its lack of deep meaning have been replaced by "Big Data" that transform my privacy in the sense of inconsequential events that concerns nobody into minute cogwheels in a gigantic mechanism which is under the control and in the service of ulterior goals. In a similar vein, DNA sequences that [to the best of our knowledge] carry no specific information (i.e. "junk DNA", "noncoding DNA"), such as on genetic status, may become a locus of concern when accumulated and analyzed by sophisticated, large scale data-banks. The management of high-tech rich healthcare is blighted by a tension between easy and rich flow of medical information in ways that enhance safety and high quality practice on one hand (e.g. if every emergency department can access the list of drugs taken by every person, diagnosis of side effects and avoidance of untoward interactions may be enhanced significantly), and worry about abuse and misuse of the IT systems in ways that may violate privacy, harm many vulnerable people, and erode trust in health care.

We have made a full circle. We have found privacy in the human dignity of people who are at the bare minimum of human existence (e.g. persistent vegetative state), and we have found privacy as precondition to the fulfillment of human autonomy. We have found it in relation to common humanity (e.g. the naked body), and to individual events, mental states and expressions that differentiate one person from another. Privacy is pivotal for both independent identity and participation in society. A third, emergent dimension of privacy issues pertains to situations in which somebody (an individual, a social institution) holds extensive information about a person or population, regardless of the value of each piece of information.

### Informed consent

Human dignity and rights: from democratic governance to formal informed consent The basic value of dignity and the instrument of human rights imply that all decisions related to people's salient interests be made consensually. The protection of people from harm by others (mainly crime, warfare and the spreading of disease) are the only recognized justification for coercion. This kind of democratic coercion is restriction on liberty; it forbids action, but it does not impose intervention on body and person.

Democratic governance runs by means of the indirect consent of elected delegates.

Those, whose choices are in the minority, are not in a state of absolute non-consent, because they have consented to the majority's vote. This is the case regarding impersonal matters, such as road safety laws, the resources allocated to transportation, and other aspects such as whether people with neurological deficits may drive cars. Personal decisions about one's own body and self are subjected to the direct informed consent of the person involved. Consequently, democratic procedures may deny driving license from people with epilepsy; but democracy is incapable of imposing on them medical treatment.

Democratic governance is responsible for the **framing** of events of informed consent. For example, the availability of medical services, and the designation of certain decisions as either "**opting in**" or "**opting out**" (e.g whether consent is required for organ donation from the braindead or consent may be presumed unless explicit refusal has been expressed). The closer is the service to personal well-being, the greater is the duty of the government to frame it along lines of **deep public participation**, and choice among alternatives by the consumer (patient). This means that the public, and especially the needy that depends on services, may have a voice in its design and regulation. For example, psychiatric patients need be active in decisions regarding opening

hours of clinics, regulations about choices of doctors, regulations on confidentiality and the like. Since medical care requires interpersonal trust and individualization of care, allowing choice in healthcare is a moral value. Society does not deny any person the power to choose a healthcare professional privately. Incorporation of some measures of choice in public and insurance-based services is highly valued. Ultimately, all of the above issues only frame the setting for personal decision making in healthcare. Every specific clinical procedure, even mild, must be subjected to the paradigm of informed consent, which is the consent articulated by the relevant patient in relation to the specific modality of care, as temporarily close to its performance.

## The legal, "thin" conceptualization of informed consent.

In medical law, the definition of valid informed consent is "thin", as to enhance simplicity and transparent judicial arbitration. According to the thin conceptualization of consent, a person giving consent must be mentally competent, free from overwhelming duress, and properly informed about the decision in hand. Laws and regulation often set additional formal requirements, such as a dedicated form of informed consent signed by the patient, a second signature by a witness, and the communication of the information by the responsible physician. A patient's expressed choice, made in the specified conditions, is considered a valid informed consent. In biomedical law, provision of medically beneficial care without informed consent is medical negligence. The imposition of medical care against the refusal of the patient may count as battery (assault).

At times, the expressed choice is implicit, rather than explicit. When a patient checks himself or herself to a hospital, he or she communicates consent to numerous medical procedures, from compliance with hospital regulations to various blood and urine exams.

However, sensitive procedures, such as testing for HIV, and risky, invasive ones (e.g. surgery)

always necessitates explicit and real time provision of information along with obtaining explicit consent.

It should be noted that whereas informed consent to medical care has developed within common law and medical ethics, informed consent to research is the product of post-World War II regulations and conventions. Despite many similarities in relation to consent and to the fiduciary duties of doctors and scientists, the key difference between the two kinds of consent is the universal requirement of an approval by a dedicated local research ethics committee (Institutional Review Board) of the research protocol prior to the participant's personal consent.

## The three elements of informed consent

As said, the three pillars of informed consent are mental competence, freedom from excessive duress and adequate information. This section will explicate these three conditions.

Competence: Roughly speaking, competence is holistic psychological maturity and integrity that enables the person to understand the relevant situation, process new information about it, weigh options against each other, and make a coherent choice. It is universally assumed that healthy adults are competent (the age of maturity varies culturally, always during teenage). When adults manifest very bizarre or erratic behavior, and when we know that they already suffer from conditions that tend to cloud the mind, there is a duty to examine and verify competence, especially before honoring unusual choices, such as refusal of apparently beneficial care. However, because the notion of personal autonomy compels respect for individual choices and even idiosyncratic preferences and opinions, competence is never evaluated by the content of choice. A wish to die, a preference of seemingly unsound methods of care, and profession of culturally deviant values cannot serve as sole evidence of incompetence. On the other hand, signs of significant lapses in memory, concentration and extreme mental rigidity associated with delusions or hallucinations are good reasons to determine non-competence.

On the brink of legal capacity, adolescents manifest quite developed mental maturity.

Other patients, who are not "competent", are still capable of elaborate emotional and cognitive processing. Legally, they are not capacious and guardians make decisions for them. But morally, there is a duty to have them involved in their own care, inform them about the situation and elicit their consent to treatment. Consent by quasi-competent persons is referred to as **assent**. Its absence does not stop caregivers from the provision of essential care; but omission of reasonable attempts to obtain assent is negligent and disrespectful of human dignity.

Many legal systems grant the power of informed consent to adolescents, usually in relation to very specific issues, mainly sexuality. Such policies may reflect recognition in the maturity of minors in relation to the issue in hand; but often they reflect a utilitarian consideration, recognizing that it is both impractical and harmful to impose in such matters parental involvement. A typical example is the power of adolescents to discuss sexual issues with their healthcare professional, and have contraception prescribed without anybody's involvement.

Freedom from duress. Evidently, consent given under threats is invalid. Although in clinical contexts we hardly find guns pointed at patients, subtle but no less disabling forms of coercion exist. Often, they are not deliberate. A twenty-year-old woman, living with his parents, may not feel free to refuse an HIV test when her parents participate in the interview with the doctor. While everybody (patient, parents, doctor) may act in good faith, the de-facto imposition of choice between privacy, shame and health does not allow free space for autonomous choice. Similar considerations apply to vulnerable populations such as prisoners, illegal immigrants, and the homeless. As borne out by the example of the teenager and the HIV test, vulnerability may

be context-related. An adult man brought to medical care by his employer following a work accident may not feel free to provide full information in the presence of his boss.

In the past, it was believed that serious, life-threatening illness induces terror and confusion as to render patients unable to deal with his or her condition. Along with the presumption that confrontation with threatening information may break the patient's spirit, this psychological presumption was at the heart of medical paternalism. Contemporary medical knowledge and ethics maintain that, unless a disease process interferes directly with mental processes (e.g. a stroke affecting memory), even in extreme medical conditions, people are capable of informed consent. In many cultures, the proper exercise of autonomy is contextualized within decision making within a family (e.g. the old father with his adult children). Especially in such cultures, patients should be given the choice to incorporate supportive persons in the informed consent process, and to have the choice of solitary decision making with their doctor, in case they prefer to opt out of the cultural standard. Information. Data is mere facts. Information is context-relevant presentation of data that empowers a person to make judgments regarding the situation. Hence, while a medical text might be highly informative to doctors, it may be impervious, even misleading to lay persons. Excessively detailed information (e.g. listing the statistics about every reported side effect of a drug), and information given in haste or in compromised circumstances (e.g. noise) is not "adequate". In relation to valid informed consent, the adequacy of information is assessed by the ordinary patient standard – what an ordinary person with similar cultural background to the patients' may expect to have in order to perform an informed choice. Research shows that doctors tend to under-inform patients, and that patients tend to expect doctors to avoid showering them with all relevant information. It is not an easy task to find the amount of information and

style of presentation that meets patients' expectations. As a matter of fact, the cargo and conduit set of metaphors in relation to medical information may be quite misleading. Information is not a quantity of something to be transferred from the medical side to the patient's side. The provision of medical information is an elaborate interpersonal process. It typically entails repetition and elaboration, a time span for processing as well as social and emotional contexts for interiorization and incorporation, with autonomous decision-making processes.

Ordinarily, clinical advice and instructions are part of the information communicated. Whenever medical benefit and harm is at stake, the doctor is expected to be **directive**. He or she does not say, "If you treat your hypertension, you are less likely to suffer from stroke", but "You have to take the hypertension medicine prescribed in order to reduce your risk of stroke". The less confident is the doctor in the overall benefit of the intervention (e.g. when state of the art medical knowledge is ambiguous), the less directive he or she should be, and more open to the need for a second opinion and ancillary modes of counseling. When the choice contains a significant moral aspect (such as genetic testing during pregnancy), medical ethics prefers **non-directive** counseling, during which the doctor tries to avoid signaling a preferred mode of action.

## Exceptions to the informed consent standard

Medical law recognizes three exceptions to the practice of informed consent, prior to any action performed on or in personal relation to any human being:

1. The emergency exception: When a person faces a sudden and unexpected catastrophe, such as severe injury in a road accident, he or she are not capable of informed consent to his or her emergency care. The emergency context of decision-making bars the patient from full participation. However, if a patient was able to contemplate in calm the reaction due in a future emergency, such as a patient with chronic renal failure contemplating an acute need for dialysis, then the emergency

exception does not obtain. In the dialysis example, the decision about an emergency was made calmly, whereas the emergency exception is about an unexpected and urgent need to make a decision in a situation of emergency. Once the emergency is over, the patient must be informed as befitting his or her condition and be recruited to care by full informed consent.

Doctors universally provide care to unconscious patients who attempt suicide. The practice originated when suicide was considered a horrendous and damning crime, and when medicine was more paternalistic and vitalistic. However, the high rate of contemporary suicide patients who are grateful for the treatment that saved their lives, gives support to the contemporary practice of presumed consent to life-saving measures following suicide.

- 2. The therapeutic exception: Rarely, the provision of information is expected to harm a patient directly (e.g. induce him or her to suicide). Exclusion of patients from informed consent on therapeutic considerations may need a specific approval by an expert panel and / or and ethics committee or a judge. The patient must be informed about the care policy once the exception (e.g. risk to life) has passed.
- 3. Waiver: Sometimes a patient chooses not to participate in his or her own care, thus delegating decision making to a trusted person or the medical team. Because waiver of self-rule is disposed against human dignity, waivers are quite restricted in scope (e.g. a competent person cannot sign off responsibility over self to others completely and in an unlimited manner). Because autonomy is so highly prized morally, and because it is at the heart of human dignity, healthcare professionals never initiate (i.e. suggest to the patient) to waive his or her unique power of informed consent. A

Waiver is acceptable in extreme conditions, such as of a diabetic patient with renal failure and heart failure, much of his suffering is incurable. The patient may retract the waiver at any time. Actually, especially when circumstances improve, caregivers should try to encourage the patient to resume full responsibility over body and self.

Even though all three exceptions omit the duty of formal informed consent prior to the provision of care, the exceptions are still loyal to the notion of informed consent. It is assumed that people consent to the omission, should they encounter an emergency; that they would rather be spared information that is clearly and severely harmful; and, evidently in the waver situation, that the patient has asked for the omission of specific informed consent.

# Proxy decision making.

Respect for human dignity requires that every significant and personal decision be made rationally (rather than frivolously or arbitrarily) and from a position of benevolence and good faith. Because incompetent people cannot make such choices, someone else must. The values of human dignity and solidarity compel the conclusion that there is no person on earth who is in human company (to be distinguished from people trapped and stranded alone), and, yet, nobody is responsible for,in time of need. When two people are in a situation in which one of whom is incompetent, the **rule of rescue** renders the competent person the guardian of the other, differences such as of age, gender, faith, race or political affiliation notwithstanding. In situations of need, every human being can be the guardian of any other. In the absence of known guardian, the caring physician is the guardian of the patient. Parents are the **natural guardians** of their minor children. Family members are often the de-facto guardians of incompetent relations (e.g. wife in relation of her demented husband). However, most legal structures require a formal, judicial nomination of guardianship. It follows that parents need no nomination in relation to their minor children. Doctors are the guardians of their incompetent patients until guardians are

either found or nominated. Formal nomination is sought in order to validate de-facto guardianship. Even though every human being with good will and mental competence may act as the guardian of another, judges prefer to nominate a kin or friend as guardians (e.g. a brother). There are a few reasons for such preference. Close people are likely to know the person better, are more likely to dedicated the efforts and resources needed, are often already committed and available, and are likely to behold care for kind and friend as a cherished moral duty. Care for a needy human, especially a family member, a neighbor or a friend, is a prime manifestation of human dignity as a moral standard (i.e. what it means to behave in dignity) and moral status. All this said and done, every competent and well-intentioned person may act as the guardian of any other needy human being. Only practical barriers (e.g. a brother living remotely) may render a person unsuitable for guardianship.

Many legal structures empower people facing incurable conditions to sign "living wills" / "advance directives", nominating specific persons as their future guardians or as future proxies for specific fateful decisions (e.g. "do not resuscitate" orders).

Usually a proxy decision maker should ask himself or herself "How would the patient wish to be treated in this situation, should he or she were competent?". In the absence of a reasonable answer to this question, one should ask oneself, "How should I wish to be treated if I were in the patient's place, and he or she decide for my?". Both formulations articulate the **golden rule** in interpersonal relationships.

#### The special status of medical informed consent

It is possible to behold biomedical informed consent as a kind of a waiver pertaining to a human right. Thus, by giving an informed consent, a person relinquishes temporarily the human right protection against interference with his or her integrity of body and person. Even though the waiver model suffers from some limitations, it helps examine the unique features of biomedical

informed consent relative to other process of consent and waiver, mainly in business and politics. One key difference is the **real time** condition. A patient may revoke his or her informed consent to a medical procedure at any time he or she pleases, with no duty for giving explanations and with impunity. Another constraint is the value of medical benefit. Healthcare professionals do not have a duty to honor an informed consent (even an explicit request) if they are convinced that the act in question is harmful to the patient. Doctors must never propose, on their own initiative, to consent to biomedical interventions that are not directed towards the good of the patient. This is a striking difference from business and political conduct, where a party may propose to a person to consent to actions that are in the benefit of the proposing party, but not at all in the benefit of the consenting person. (The recruitment of patients to biomedical research will be discussed separately). One more key difference relates to the waiver exception to the standard of informed consent. Whereas people may often relegate decision making over their property to others (e.g. managers, lawyers), the value of human dignity and the structure of biomedical law substantially restrict the possibility of willful transfer of decision making power over body and self to others, no matter how well-intentioned and knowledgeable they are.

In certain situations, there is no choice but to allow the doctor to make the final decision within the limits delineated by the informed consent. One example would be a patient heading to a surgical removal of an abdominal tumor. Decisions about the extent of surgery depend on the histological analysis performed during surgery. Because performance of two surgeries is much riskier and more cumbersome, the surgeon discusses with the patient in advance what should be done in either scenario – malignancy or benign.

#### The ethical ideal of informed consent

So far, we have explicated the principle behind the "thin" or legal conceptualization of informed consent. Medical ethics envisions a moral ideal that is founded on two concepts that are beyond judicial arbitration - sincerity and deliberation.

Whereas in business, politics and many other domains of life, there is no need to go beyond the formal conditions of consent (i.e. competence, freedom and adequate information), healthcare professionals are bound by the duties of beneficence and fiduciary. They must strive to verify that a sincere psychological event of consent actually takes place, and they must not accept consent to care that they find clearly and significantly harmful to the patient's wellbeing. Moreover, doctors are morally bound to seek genuine consent, the best possible signs of the mental state of mind of consent, made in situations of realistic decision making among the relevant alternatives, and not content themselves with mere formal evidence, such as a signature on a legal form.

Behind the laws and practices of informed consent, one also finds the notion of interpersonal moral deliberation. Deliberation is a rational interpersonal conversation whose aim is to reach a joint decision of a significant moral character. The social and rational character of the human person entails the moral significance of interpersonal deliberation prior to fateful decision making. Hence, the informed consent process is a situation in which a healthcare professional presents the information to the patient and discuss with him or her the proper action. Even though the patient may be adequately informed through searches over the internet and conversations with expert friends, the ethics of informed consent requires interpersonal conversation. This is a clear token of the moral difference between business transactions, political moves, and medical care. The latter depends on interpersonal communication between patient and a responsible healthcare professional, regardless whether the "content" of

communication may be "transmitted" by alternative modes. The physician who is directly responsible for the procedure at stake is the ideal person for the processing of the informed consent. The ideal structure of informed consent is **shared decision making** by the responsible physician and the patient, within a context of clinical relationships. The proper process of informed consent is a meeting point of different, complementary responsibilities – the professional responsibility of the doctor and the personal self-care of the patient.

In sum, whereas the law requires that the patient expresses his or her preferences regarding personal healthcare choices (usually by means of signing a dedicated form) in conditions of mental competence, freedom from duress and having received the relevant information, medical ethics expects the responsible healthcare professional to seek genuine consent, through a process of shared decision making, coming from interpersonal deliberation.

## Deliberation

# What is ethical deliberation?

Deliberation is an interpersonal, free and rational discussion whose aim is justifiable (defensible rationally) practical decision, acceptable to the participants. There are different kinds of deliberation, each with its own codes and habits of practice. Business deliberation is about the promotion of each party's economic welfare. It allows to use all sorts of tricks and manipulations during sale-promotion and negotiation. A salesperson may boast, "My product is the best in the world" and may hint that the product is associated with celebrities. However, a doctor must not say, "I am the best doctor" and hints that his or her care is associated with celebrities. Deals are at the heart of politics. A parliament member may tell another, "I will vote with you on issue A, if you vote with me on issue B". But is it unacceptable for a member of an ethics committee to similarly propose, "I will support your anti-abortion position, if you support my position on conflicts of interests"? In a clinical discussion, the chair of department may declare, "I have heard you, and this is my decision". Can he or she talk like this in an ethical discussion, resorting to authority, experience and knowledge in order to bring deliberation into closure?

The ethical deliberation in the public sphere, and specifically bioethical deliberation in the medical realm, entail different ideals of practice. In an ethical deliberation, a decision with a significant moral character is at stake. Participants are expected to be sincere and avoid manipulation. Ethics committees, such as hospital ethics committees and IRBs, practice public ethical deliberation with additional commitment to transparency (protocols, even when kept confidential), representation (e.g. of diverse stake-holders), and commitment to formal structure (e.g. the committee's charter). Within the healthcare setting, ethics committees are also committed from a stance of joint responsibility for the patients' good (beneficence) and the values of medical ethics in general. Usually, ethics deliberations are advisory in nature.

Deliberation is initiated by a stakeholder, who seeks practical advice related to a difficult problem of healthcare delivery. Even though the participants deliberate from a stance of personal care and responsibility, the ultimate responsibility for the action take is the actor's. In the healthcare setting, the actor is the professional responsible for the decision. In sum, moral deliberation is an act of conscientious sharing; bioethical deliberation is moral deliberation that aims at an action within the healthcare setting from positions of professional responsibilities.

Within medical education and healthcare, we find diverse deliberative practices: events of informed consent and patient education; Balint groups whose chief goal is self-reflection and support within an intimate collegial circle; clinical and managerial meetings, activities dedicated to cultural awareness and other forms of social communication through recognition of "others". The ideal of bioethical deliberation is an egalitarian (no hierarchy of power and authority), sincere, and free conversation among diverse people (not only healthcare professionals), who share medical values and, from a stance of responsibility, seek a reasonable course (or courses) of action in a practical problem posed by one of the participant. The problem might be a clinical case (i.e. what do with a particular patient in a given situation) or a question of policy (what should be the standard or law in a kind of situations).

Precisely because deliberation is such a widespread and universal human activity, people are at risk of confusing bioethical deliberation with many other deliberative practices. Our daily and old habits of deliberating among friends dealing with questions such as choice of a gift to a beloved person, arrangement of a sport activity, creation of a business strategy and the like, might cloud biomedical deliberation. Indeed, as people learn how to deliberate through continuous practice (e.g. conversations with friends since early childhood) and simulation (e.g. reading stories, watching drama shows), healthcare professionals need practice in order to

cultivate the proper skills of bioethical deliberation. Moreover, by means of deliberation and related activities (e.g. preparation of clinical, theoretical and other material), practitioners as well as involved citizens (or stakeholders) hone their ethical and democratic skills and, hopefully, attain moral self-growth. However, moral growth, as well as any other personal and institutional gains (e.g. academic publication) are never the intended goals of deliberation; only possible by products.

Every person knows how to sing; and every person can reason and act morally. But people differ much in talent and performance. Every human skill requires continuous practice in appropriate setting. At the heart of education in bioethics and medical ethics is the practice of deliberation, orally and in the writing.

## The process of deliberation

Bioethical deliberation may occur any time and any place. When two or more healthcare professionals, one of whom is responsible for a decision, sincerely discuss a practical problem with significant moral dimensions, searching for a course of action, they deliberate. Ethics committees have formal modes of deliberation. Their members are pre-nominated, and, when necessary, they care to include in the discussion (or parts thereof) stakeholders not represented in the nominated panel. The chair usually has experience, training and education in either ethics or law. Committee members are also committed to study and growth in bioethics. The setting is tranquil, encouraging both solemnity and open-mindedness, in respect of the often-tragic human situations under consideration and the goal of taking proper action.

Deliberation begins with case presentation by the initiator of the session. Usually, participants have already read the case and related materials, as to allow productive deliberation in the time of the meeting.

The presentation of the case is followed by clarification of relevant facts. At the beginning, the deliberants avoid ethical discussion and raise *factual* questions (such as on the clinical situation, the law, social issues and whatever other fact is relevant in the eyes of the participant to know in order to have a clear picture of the case). Then, each participant is expected to self-reflect and self-search for personal biases and prejudice. Perhaps he or she has been personally traumatized by a similar scenario (e.g. a frail parent in intensive care), or is implicated in gender or class related bias. Such prejudices and biases are no necessarily "negative". Rather, personal experience and perspective may contribute to the deliberative process. However, one had better been aware of them and of their *potential* to create untoward and unnoticed influence.

In the next stage, the deliberants focus on one specific issue, usually the one that motivated the request of opinion, in the first place. In fact, a clinical case offers many issues to discuss, but efficient deliberation can be done only once the main problem at stake is defined and all the participants agree in discussing that and not others. The definition and delimitation of the problem is a key step.

The ethical heart of the deliberative process is value centered. Ethics committees operate within the paradigm of applied ethics and deliberative democracy. This paradigm aims to incorporate diverse opinions and culture sensibilities in a deliberative process, which does not aim to resolve "big questions" (e.g. whether God exists), but only to address some practical problems arising in a shared context and offer a reasonable way to overcome them. Experience shows that even "moral strangers" (i.e. people coming from very different cultural backgrounds and moral convictions), usually share some basic values and know how to behold human situations through their prism. Indeed, the leading bioethical values are universal and found in

almost all human societies. Among these leading values, we find truth telling, justice, fiduciary, benevolence, avoidance of harm, special regard for the vulnerable and weak, respect for human life and for persons, and reciprocity. Differences in opinions arise in relation to the precise formulation or conceptualization of values, their content, the prioritization of values in conflict, and the modes by which a moral conflict is conceptualized and narrated.

Consequently, at this stage of deliberation, the participants point out the relevant values at stake in the specific issue in hand and explore diversity in their conceptualization and in the relationships among them (e.g. "life" v. "autonomy"). Following this exposure, deliberants begin to explore possible courses of action and the diverse reasoning behind them.

## Reflective equilibrium

The most common theory of deliberation draws on John Rawls's idea of "reflective equilibrium". Rawls built on a set of insights. The first insight is that abstract moral theory, as precise and elaborate as it might be, is prone to produce unpalatable recommendations. One famous example is Immanuel Kant's conclusion that a person hiding innocent people from an evil regime must not lie to the police when they come to ask about fugitives at his or her home. Kant and many other ethicists with strong convictions expect people to overcome their initial moral revulsion and internalize the theoretically established moral "truth". People may undergo a process of moral conversion, and change their hearts following abstract moral teaching. The equal moral worth of all people regardless of gender, race and creed is one such teaching, which almost nobody in the past found conceivable. However, whereas we expect our intuitions to adopt to scientific findings, for example, to know that the earth is round even though the land looks to us flat, we do not similarly wish to abandon all moral conviction in the face of powerful philosophical argumentation. In ethics, and not in the sciences, people's conscientious opinions, their considered judgments, have a special moral authority. Rawls realized that neither the mere voice

of conscience nor well-argued abstract theory is sufficient for sustaining morality. We need both of them to reflect on each other and check each other in order to come up with balanced moral conclusions. In the absence of scientific certainty, the highest degree of confidence people can aim at in morality may come through examination and modification of theory in light of conscience (or some other personal sense of conviction or judgment), and the examination of conscience opinions and feelings in the light of theoretical arguments. This cross-examination produces opinions that are closer to theoretical argumentations, and theoretical argumentations that are closer to opinions. The process of reflection goes on until some equilibrium is achieved, and, even though some gaps may remain between conscientious feelings and abstract reasoning, the deliberant is capable to accept a direction of action.

The three main modes of reasoning are **specification**, which is the application of rules or principles to particular situations, **casuistry**, which is rich and in-detail examination of the nuances of the case and diverse narratives construcint it, and **balancing of values**.

We may now observe that the process of reflective equilibrium occurs in parallel at few distinct levels. It is primarily a personal way to examine critically and conscientiously on a moral problem. Reflective equilibrium takes place in the interpersonal sphere, when every deliberant raises issues and marshals arguments. Ultimately, sessions of deliberation, on diverse cases, accumulate into moral growth through critical and interpersonal reflection on the human condition from a stance of responsible and beneficial engagement. This growth is part of the professional aspiration to excellence and to the cultivation of the virtuous personality as a human excellence. Yet, we have to keep in mind that people who deliberate in order to satisfy a personal need and doctors who treat for the sake of fame and achievement fail the ideal of medicine.

If ethical deliberation was about a joint search for an absolute moral truth or the best decision, it is unlikely that reflective equilibrium might achieve these goals. It is unlikely that deliberants coming from very different cultural backgrounds and personal convictions may be able to reach a joint conclusion; even people who share background and values tend to have quite different personal approaches and opinions on particular moral issues. Hence, ethical deliberation is not about absolute truths and best choices, but about reasonable courses of action within a range of an overlapping consensus in a pluralistic society. Moral deliberation is conducted with the purpose of helping the needy, mainly by means of helping those directly responsible for the care of the needy, to develop moral decisions. People who participate in deliberation in search for some personal gain (including moral growth), the promotion of an ideology and other purposes, miss the ideal of ethical deliberation, and probably distort the process. So are participants who are not sincere (i.e. what they say does not fit the things they really believe in), and who are not open to modify or change their minds to a certain degree. Obviously, a deliberant may remain quite convinced in his or her original opinion. He or she should not modify their position unless they are sincerely persuaded to do so. In each single event of deliberation, it is impossible to tell the morally brave, who does not bends his or her truths in spite of many thinking differently, from the dogmatic foolhardy, who never listens to alternative ways of thinking, no matter what. Deliberation depends on a personal capacity to listen from some openness to persuasion. Ideally, the person is no less open to listen and be receptive to creativity and other ideas than self-reflect, self-express and influence others.

Some ethics committees operate within the constraints of local laws, or the hospital's values (e.g. a religious hospital), which quite constrain the possible courses of action. However, deliberation should remain open to a diversity of opinions and contending points of view,

especially if they are shared by some of the stakeholders (e.g. a caregiver or a patient professing different creeds).

## Accountability for reasonableness

Another deliberative method, especially useful in overcoming significant cultural and personal gaps is especially suitable for policymaking. Inspired by John Rawls, Norman Daniels describes an approach he calls "accountability for reasonableness". Since it seems that the most universalistic moral value is fairness (i.e. lack of bias), a fair process of decision making is being constructed on the principles of rationality, transparency and revisibility (i.e. It is always possible to revisit and revise earlier decisions). Transparency refers to the data, premises and reasons behind each decision, as to show lack of bias and leave opening for criticism, modification and revision. Whereas each case deliberation is somehow unique and invites much attention to casuistry, accountability for reasonableness is especially suitable for policy-making (e.g. on distribution of resources, on conflicts of interests).

#### Closure of the ethical deliberation

After the deliberants have clarified the facts, become aware of potential bias, put the main question and the values at stake related to it on the table and reflected on opinions, arguments and narratives, they may be ready to discern a range of possible actions within fuzzy boundaries of what they perceive is reasonable. When participants understand that deliberation is not a tug of war between opposing directions, each of which lays claim to "rightness", they can perceive the reasonable mode of action as a range of synthesis, creativity and re-interpretation. Work on the range of reasonable actions, help delineate "red lines" that must not be trespassed, and delineate intermediate courses of action that may limit as much as possible the loss to the values in conflict. At this stage, the committee analyses and discusses different possible courses of action, in order to establish an order of preference among them. Once the committee agree on

one or two reasonable alternatives, and explicitly reason and justify such a choice. Deliberants attempt to double check these emergent suggestions, asking questions about possible impacts on public opinion, on unrepresented parties, especially vulnerable minorities, and find out their impact on other domains of action, no last their legal compatibility. At this stage, the deliberants do not seek to improve their conclusions but to make sure they do not miss something important.

The recommendations of the ethics committee must be accompanied by a written justification, where will be expressed also dissenting opinions and should contain referral to moral residues. The committee's report includes the minority's opinion or opinions.

Seldom do deliberants hand down irreversible recommendations. There is usually time for re-examination and revision. Even when time is pressing, there is an opening for retrospective revision of the decision ultimately made.

In ethical deliberation, neither a vote nor a consensus of opinions is the modality of choice. In the absence of agreement, the majority opinion may be presented first, and may be presented as the majority opinion. But majority as such does not render a choice "more" moral than the alternative. When opinions are sharply and closely divided, it does not matter whether voting, if held, resulted 5:7 or 7:5. In the absence of further considerations and developments, that responsible doctor may choose to follow the majority; but not because voting settles ethical questions, but because, in the other of any other consideration, it is even less reasonable to follow the minority. We should keep in mind, that since the responsible actor might be on the minority side, and since the ultimate moral responsibility is his or hers, he or she might follow their own conscience, relying on the support of a significant number of participants in the minority and their respective reasoning. Our teacher, Diego Gracia, used to say that a close count is a sign of unsuccessful deliberation, and the whole process should be restarted all over.

Deliberation does not aim at consensus about the course of action chosen, but does aim at sharing the process with all the participants, no matter the outcome.

Consensus is not the goal of ethical deliberation. It is impractical and it fails the ideal of moral deliberation as a joint attempt at reasonable recommendation or recommendation in a pluralistic society. Even those who are unhappy with a particular outcome of deliberation cannot claim that action taken following that outcome is the subjection of a person to the arbitrary will of another. On the contrary, all affected parties will know that decision has been made sincerely, fairly and solemnly, applying the best means available for appropriate moral reasoning.

# Summary: a scheme for ethical deliberation

- 1. Presentation of the case
- 2. Clarifications of the facts (medical, psycho-social, legal, institutional)
- 3. Attention to potential bias
- 4. Elicitation of relevant values
- 5. Formulation of the practical question (or questions in hand)
- 6. Reflective examination of opinions, arguments and narratives
- 7. Delineation of a set of reasonable courses of action
- 8. Evaluation of acceptability
- 9. Attention to moral residues
- 10. Recommendation

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