Topic 3

Life and health are the main values of bioethics

Part 1

Human dignity and human rights

Human dignity as an intrinsic value of the person capable (at least potentially or as a member of natural kind) of reflection, sensitivity, verbal communication, free choice, self-determination in conduct and creativity

- Human dignity is an end in itself
- Equality in dignity of all human beings
- Respect and care
- The interests and welfare of the individual are prior to the sole interest of society
- Human dignity as a foundational concept

Ethical aspects of health care provider-patient relations in regard to human dignity and human rights

- The problem of paternalism
- In treatment of children, elderly persons, and mentally handicapped individuals
- In palliative treatment of terminal patients and patients in 'vegetative state'
- In treatment of embryos and foetuses

There are several concepts of dignity in the history of ideas

Classical antiquity. Common understanding of dignity as deserving of honour and esteem according to personal merit, inherited or achieved. In ancient Greek philosophy, particularly of Aristotle and the Stoics, dignity was associated with human abilities of deliberation, self-awareness, and free decision-making.

In many world religions human dignity is considered to be predetermined by the creation of human beings in the image of God; those who are weak in body and soul have dignity equal to those who are robust and sturdy.

Modern philosophy proposed secular understanding of human dignity and progressively associated this concept with the idea of human rights. In different teachings human dignity was presented as an aspect of personal freedom (Giovanni Pico della Mirandola) or an embodiment of one's public worth (Thomas Hobbes), or as universal virtue, unconditional and incomparable worth determined by one's autonomy rather than origin, wealth, or social status (Immanuel Kant). One of Kant's basic principles of ethics – to treat any other person always at the same time as an end, never merely as a means (categorical imperative) – has been accepted by moral and political philosophy as the actual basis for the conception of human rights and in this sense it is a foundational concept.

In contemporary international law, national constitutions, and other normative documents, human dignity is strongly connected with human rights.

i According to Art. 1 of the Universal Declaration of Human Rights (1948), 'all human beings are born free and equal in dignity and rights.' The Declaration establishes human rights (like freedom from repression, freedom of expression and association) on the inherent dignity of every human being.

ii The European Convention on Human Rights and Biomedicine in Art. 1 declares protection of 'the dignity and identity of all human beings and guarantees everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine' as its main purpose.

The notion of human dignity expresses the intrinsic value of the person capable (at least potentially or as a member of natural kind) of reflection, sensitivity, verbal communication, free choice, self-determination in conduct, and creativity.

Unlike material values, or financial prices, human dignity has no external equivalent; it is an end in itself. Unlike merit as an embodiment of publicly recognized personal achievements, a person is dignified as a human being as such.

All human beings are equal in dignity irrespective of gender, age, social status or ethnicity.

Recognition of a person's dignity presupposes active respect for her human rights, self-esteem and self-determination, as well as care for her privacy, protecting her from illegitimate intrusions and preserving her valid public space.

A society or a community should respect each of its members as a person or a moral agent on the basis of the notion of human dignity. This notion also requires that the interests and welfare of the individual are considered as prior to the sole interest of society, community, or any particular kind of publicly wholesome activity. The emphasis on 'the sole interest of science or society' is important. It implies that because of his/her human dignity, the individual should never be sacrificed for the sake of science (as has happened in medical experiments during the Second World War) or for the sake of society (as has happened in totalitarian regimes). But 'sole' also implies that there might be exceptional circumstances in which the interest of others or the community as a whole are so important that infringing upon the interests of individuals is unavoidable in order to save others or the community. An example is the threat of a deadly pandemic.

Human dignity is a foundational concept and it is theoretically and normatively inappropriate to reduce it to functional characteristics of person's activity, ability to decision-making or to taking into account her autonomy. Respect for dignity means recognition of other's intrinsic worth as a human being.

In a comparative view, human dignity has diverse forms in different cultural and ethical traditions (for example, Confucian, Judeo-Christian, Muslim) and is respected in various ways in different types of societies (traditional, modern, totalitarian, democratic). It is less respected in totalitarian societies and more respected in modern and democratic societies. Regardless cultural, confessional, and political varieties human dignity is universally based on the person's self-awareness and appropriate respectful treatment towards her. As it is emphasized in Declaration, the regard to cultural diversity is 'not to be invoked to infringe upon human dignity, human rights and fundamental freedoms' (See Article 12).

From the point of view of ethics, the person's dignity and rights are proved by others' obligation to treat a person respectfully, that is to cause no harm, not to abuse, to be fair, not to impose unwelcome models of personal good and happiness, not to treat her merely as a means, and not to consider the interests and welfare of the individual as subordinate to others' interests and welfare, to 'the sole interest of science and society'

Health care provider-patient relations are just one kind of human relations, presupposing all ethical requirements.

However, historically these relations used to be considered as unequal. A physician was associated with an active role of decision-maker, providing medical care, taking responsibility. Hence, he or she was higher in status. A patient was associated with a passive role of recipient, being in need, not responsible for his or condition and, hence, lower in status. In this paternalistic model of health care provider and patient relationship the patient used to be in a dependent position.

Actual inequality in the status of the health care provider and the patient may be aggravated in special cases when patients are children, handicapped individuals, elderly persons. Particularly risky are cases of patients who are mentally handicapped.

Special attention in regard to human dignity and human rights is required in palliative treatment of terminal patients and patients in 'vegetative state'.

Though there is no consensus either in public or in the expert community concerning the ethical and legal status of embryos and foetuses, the latter should be treated with respect and care.

The principles manifested in articles 4–15 of the Universal Declaration on Bioethics and Human Rights give a proper framework to respect patients' dignity and rights and clarify the specific context of human rights in bioethics

Part 2

Benefit and harm

How do we evaluate benefits and harms in practice?

- Dimensions of comparing harms and benefits in individual patients
- Significance of these dimensions for making treatment choices

What is a health benefit?

Begin by analyzing the various interpretations of 'health benefit' proposed by the students. Various possibilities can be mentioned:

i relief of suffering

ii care

iii prevention of disease, illness, disability

iv health

v enhancement

vi psychological benefit

At first glance it does not seem to be problematic to identify health needs. We are all only too familiar with the common reasons we have for going to see our doctor. Perhaps we have an unexplained pain or we are short of breath or we simply feel dreadful and find we have no energy to do anything. We expect the doctor to diagnose some kind of problem associated with disease, either trivial or serious. We are told that we have an infection, or that our condition demands further investigations which will involve sophisticated investigative work to determine whether we are developing a malignant tumour, or rheumatic joints or a stomach ulcer or whatever. There is a standard classification of diseases to which doctors refer when conducting these investigations. It is tempting therefore to conclude that to be healthy is to be free from any of the diseases detailed in that list and being unhealthy is to suffer from one or more of them.

Once we have determined the disease state of a person then, it seems, we have also identified their health needs. Absence of disease means no health needs and therefore no possibility of health benefits; disease means there is a need for

treatment and the possibility of treatment leading to either a cure or the palliation of the effects of the disease, each of which counts as a health benefit.

A narrow concept of health

Attractive though the above story is, it is only part of the truth. A cursory glance at the practice of medicine will show that health benefits are available to people who do not presently suffer from any disease. These are provided by prophylactic treatments or disease prevention programmes such as vaccination against whooping cough. To be protected from the onset of a disease clearly constitutes a health benefit. Indeed it has been argued by health economists that these are the cheapest forms of health benefits to achieve. Most people would also prefer that their health practitioners enable them to avoid suffering diseases rather than have to treat those diseases when they occur. However, conceding this point does not move us far from the disease model of health in that the range of health benefits is still exhausted by either the treatment or the avoidance of disease.

If we look more closely at health care delivery we will see that non-disease conditions are also part of the remit of medicine and surgery. The most obvious treatments which go beyond the disease related conditions are bodily dysfunctions arising from traumas, such as broken legs and brain injuries. Restoring proper physical functioning by treating the results of non-disease events are clearly part of the remit of health care provision. But the practice of health care professionals might go far beyond restoring normal bodily functions in the face of such events. When such restoration is impossible, health care professionals might still have a role in providing health benefits to those who suffer impairments of function. For example, the provision of prostheses to people who have suffered the loss of arms or legs in accidents is doing nothing to restore normal bodily functioning nor to treat or ameliorate the effects of disease.

It is to treat a social dysfunction insofar as the new limb enables its wearer to engage in a wider range of social activity and the affairs of life than would otherwise be possible. No-one would hold that this was not to provide a health benefit. Such an extension of the definition of health benefits demonstrates that

simply widening the disease model of health to one related to physiological function is also inadequate. Here the social context of a physical condition becomes significant.

Further reflection will soon bring us to a consideration of mental health problems. Only a very few people would assert that such problems always originate from or are explicable in terms of physiological functioning. Even though there has been vigorous debate amongst psychiatrists and philosophers about the application of terms like ‘illness’ to mental conditions, it is generally accepted that many behaviours and psychological phenomena fall under the umbrella of health. Indeed mental health is a major segment of health care delivery. Whilst there are some advocates for physiological explanations of mental problems, including genetic determinists, most practitioners disagree. If, for example, an apparent psychopathy can be explained by the existence of a brain lesion, a physiological explanation, then it is described as a ‘pseudo-psychopathy’.

Discuss the WHO definition of ‘health’: ‘a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity’

i examples of a wider range of proper clinical activities can be used to demonstrate the narrowness of any disease oriented definition of health benefits

ii the example of infertility constituting a health need can be employed to explore the evolution of the character of health intervention

iii at the same time, the WHO definition is often criticized for being too wide; it is encompassing many situations that are not disease related and that can expand the area of work of medical doctors

Given the apparently limitless extension of the boundaries of health and consequently of needs and benefits indicated above, can we find some kind of general description which would secure a manageable range of benefits for which health care should aim?

The WHO, fully aware of the dangers of imposing narrow limits on the notion of health, has provided a definition which has been influential for many years. This definition certainly takes account of the extensions of health beyond the

boundaries imposed by disease related and physiological dysfunction related conceptions. It takes the psychological and social dimensions of people's conditions seriously. Insofar as this is the case the definition is valuable. However it is limited in its usefulness by the sheer immensity of the range of circumstances and conditions for which, by implication, health authorities should be regarded as responsible.

These would include the benefits of the provision of adequate defence capabilities to provide for the security of the population of a country and for the benefits of the provision of education to a population. A later amendment includes 'the ability to lead a socially and economically productive life'. However the amended definition remains open to the same criticism. In addition the amended definition might tempt us to consider that there are universal objective measures of health and consequently of health benefits. This would oversimplify the task of identifying and measuring health benefits.

So how do we proceed when we want to identify a health benefit? General definitions of health tend to be either too wide or too narrow to fit all cases to be of much assistance. It might therefore be helpful to look at the arguments that have been made for and against the identification of a particular condition as a candidate for being a health need and for the identification of the relevant concomitant health benefits attaching to the treatment of that condition.

What is harm?

It will not be surprising to learn that the task of identifying harms in health care delivery suffers from the same difficulties as the identification of benefits. It is not necessary to labour this point and one example of this relationship should be sufficient. Let us imagine that a surgical procedure to remove an ovarian cyst is carried out successfully on a patient. In the course of the procedure one of her fallopian tubes is inadvertently damaged and scarred. This damage results in infertility. Has a harm been visited upon that patient? The answer to this question is that it all depends on the patient. If the patient considers that she has completed her family and that she will not want any further children, then the inability to

conceive will not constitute a harm for her. Of course it might turn out that she will change her mind about this, given the possible circumstances which could develop in her life. In such an event she would come to consider that the surgical error did harm her. In other words we are obliged to consider the context of the surgical mistake in the life of the patient before we can determine whether it was harmful or not. The harm that is established in relevant cases, however, cannot be divorced from the kind of benefit which the provision or protection of fertility would constitute for the woman concerned.

Proceed with analyzing the various interpretations of 'harm', for example:
i physical harm ii psychological harm
iii moral harm (harm to interests, harm as unfairness, harm as disrespect)
iv social/economic harm (consequences for social role, stigmatization)

But there remain some interesting issues to consider around the question of identifying and avoiding harms in health care. If the ancient notion which asserts the primum non nocere (above all do no harm) principle is to be adhered to in practice, how can any surgical procedure be attempted, or indeed any medication be prescribed, when we can never know with certainty what the effects in total of that intervention will be in a given patient? In another context the wound inflicted by the surgeon in an abdominal operation would constitute a grievous bodily harm. Similarly the administration of cytotoxic drugs in other situations than in treatments of malignant disease would constitute poisoning. What justifies them in surgery and chemotherapy is the net balance of benefit over the harm which the treatments inevitably involve. Indeed any clinical intervention has to be undertaken only after the completion of a risk of harm/likelihood of benefit calculation. If a patient does not stand the chance of benefiting overall from an intervention, then that intervention is not indicated for him/her. That is, where the risk of harm outweighs possible benefit, then the treatment is not indicated.

These calculations are often very difficult to make for not only will the variety of perceptions of harm and benefit mentioned earlier come into play, but

the empirical and conceptual uncertainties of the possible outcomes will confound the procedure.

With respect to conceptual uncertainty we might consider the difficulties of making risk of harm/likelihood of benefit calculations in withdrawing or continuing intensive care treatments. In such circumstances is it the same to ask whether it can be of benefit to a patient to withdraw life prolonging treatment as to ask whether it can be harmful to continue life support where it precludes the possibility of a dignified death? We might well find that we cannot easily determine what can count as a harm or benefit in such cases.

In health care practice it is important to evaluate benefits and harms

Explore the difficulties of measuring harms and benefits in individual patients, involving:

i the assessment of degrees of harm and benefit

ii the incommensurability of harms and benefits

iii the social context of physical and mental suffering iv the subjective nature of suffering

Treatment choices also have to be made among patients; here an assessment has to be made between risk of harms and potential benefits for different patients. This will be particularly important for resource allocation; when time or material resources are scarce, different priorities can be selected; focusing on patients who are most in need because of the harm they are suffering or on patients for whom treatment will produce the greatest benefit.