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## The state of wellbeing: on the end-of-life care and euthanasia

Caring control takes place when medical professionals or public health authorities refuse to act according to the patient's wishes, or they restrict the patient's freedom or in other ways attempt to influence the patient's behavior, allegedly in the patient's own best interest.<sup>1</sup>

The previous chapter focused on the biological basis of happiness and wellbeing; this chapter focuses on justice and freedom when the process of dying has already begun. Freedom can be seen as the ability to decide for ourselves what happens in our lives without excessive constraints; that is, being in control. Of course, as social creatures, we are never totally free, even when we are not actively hindered from doing what we wish to do. The defining attributes of freedom have always collided with age-old debates on the meaning and value of human life which, in the contemporary context, have fuelled passionate discourse about the significance of abortion and euthanasia. Many contend that it is morally wrong to terminate an unwanted pregnancy or to give a lethal injection to a terminally ill patient who wishes to die expeditiously and without excessive pain. In the latter context, the act of euthanasia is understood as termination of life on request. Pro-life proponents see euthanasia as violating the principle of the sanctity of human life. Others maintain that such an inflexible stance is socially destabilizing because it is based on doubtful ethical principles and inaccurate understanding of the power of modern medicine. Most of us genuinely believe that human life has special value and that it is wrong to destroy it wantonly except, evidently, in

<sup>1</sup> Hayry, H. (1998). *Individual Liberty and Medical Control*. Aldershot, UK: Ashgate, p. 14.

specific circumstances, such as killing in battle which is considered by many as a 'sacred act' (Chapter 14).

The sanctity of life principle is recognized in the prohibition of unlawful homicide, which retains its absolute force irrespective of the quantity or kind of life in question. In this respect, all human life is absolutely inviolable and equally valuable. It follows, therefore, that doctors must never take life but are duty-bound to protect and prolong it whenever and however they can. By contrast, an alternative principle recognizes extenuating circumstances and maintains that sophisticated high-tech medicine needs to be balanced by imaginative insight, compassion and acceptance that conscious adjustment to awesome technological capabilities is inevitable. As a result, social, scientific and judicial preoccupations have moved away from an emphasis on preservation of life at any cost, favouring the inclusion of quality-of-life considerations. Consequently, in particularly difficult clinical situations, the medical profession has come to a form of consensus by supporting the ethical rights of doctors and others in the caring professions, not to undertake treatment which is contrary to their conscience. To this effect, 'do not resuscitate' orders are routinely utilized.

### **Life's balance sheet**

All organisms have finite lifespans where the core issue in ageing is to resolve environmental effects and endogenous ageing processes – to be alive means to be mortal. The seeds of individual ageing are found before birth and reflect genetically programmed regulatory systems which evolved hundreds of millions of years ago. These systems determine the level of molecular and cellular repair mechanisms in specific tissues and organs. Statistics show us that arterial disease and cancer are the main causes of death across ageing human populations yet are low until after 35 years of age, which was approximately the life expectancy in most human populations before the nineteenth century. Ageing increases the load of oxidative damage in DNA, lipids and proteins; for example, accumulation of oxidized lipids in the aorta and other central arteries begins during prenatal life and marks the beginning of arterial ageing which progresses to a greater or lesser extent depending on circumstance (Chapter 3). The main causes of early death are extrinsic risks such as infections, malnutrition and trauma. These extrinsic risks, until very recently, allowed just a minority of humans to survive to older ages.

In the course of the death process, nervous, endocrine and cognitive functions, in particular, display marked declines. Gerontologists refer to this phenomenon as 'terminal drop'. The terminal drop may linger for weeks or years

and is the critical period where the impending future, distant past and heavy present coalesce. It is a time for appraising the ideals of independence, participation, care, self-fulfilment, dignity and for gaining, hopefully, peace of mind. However, for the contemporary citizen living with limitless developments of modern technologies, the question is asked 'who should take responsibility for determining death?'

### **End-of-life care, advanced directives and 'do not resuscitate' orders**

There are valid reasons behind the search for new criteria which define the beginning and the end of a meaningful human life. Two such criteria can be found by focusing on consciousness, and by measuring the value of individual lives through directly consulting the individual concerned. Consciousness, generally regarded as the hallmark of a true existence, represents the ability to choose and decide to take action and assess reaction. Many argue that it is against this notion of conscious ability that quality of life should be measured. In essence, quality of life reflects an elusive individual perception about one's position in life within specific cultural and ethical contexts, and relates to one's personal goals, expectations, standards and level of awareness – it can be known only by the individual concerned. However, there is also total agreement that one of the most difficult issues in biomedical ethics today is the question of killing or letting people die.

While modern medicine has increased its capacity to cure and to prolong life, it has also generated serious bioethical difficulties. Scientific advances, including treatments for the extremely low birthweight infant, for example, are achieving cures or amelioration of many afflictions which in the past resulted in death or severe handicap. Assisted by complex life-supporting technologies, such as mechanical ventilators and dialysers, the functions of most failing organs can be maintained for prolonged periods of time. As a result, the previously incurably ill now have a chance of survival. There can be no doubt that modern high-tech equipment together with skilled surgery has significantly increased the survival rate and quality of life of the seriously ill, including neonates and infants with severe malformations. However, there are still many for whom modern technology achieves little more than delaying death or averting it at the cost of permanent ill health, unhappiness and lifelong handicap. Such case histories have magnified concerns, as demonstrated by the plethora of existing discussion papers on withholding and withdrawing life-prolonging treatments and do not resuscitate (CPR or cardiopulmonary resuscitation) orders. A 'do not resuscitate' (DNR) order is a written order from a

doctor that resuscitation should not be attempted in the event of a cardiac or respiratory arrest. The withholding or withdrawing of artificial life support is practised in situations where, despite all care, there is little or no hope of recovery; this includes patients in whom the quality of life is unacceptably poor, where the dying process is prolonged, causing severe distress, or where the patient is in a permanent vegetative state. In all of the above cases, reaching a satisfactory outcome involves addressing a number of difficult ethical and legal issues, including issues of over- or under-treatment towards the end of life.

It goes without saying that when life-support treatment is withdrawn, palliative care to relieve pain and distress is essential. Analgesics and sedatives are routinely given, even though they may coincidentally shorten life. On the other hand, despite technological capabilities to prolong life well beyond what is considered to be the limits of the natural term of life, physicians are still trying, in the Hippocratic spirit, to preserve human life whenever possible. This is in the face of a growing suspicion concerning the quality, or value, of the life counterbalanced against the procedures used to maintain bodily functions. Life-support systems are complicated and usually cause pain, sometimes to such an extent that patients openly express their wish to die rather than continue living under such extraordinary circumstances. Some physicians have been reluctant to come to terms with the validity of the patient's wish to die, but many patients label this intransigence as medical paternalism. Medical paternalism is characterized by an attitude that the patient's wishes may be ignored or not respected because patients, unlike the supervising physician, cannot know what is best for them. Particular criticism, however, is reserved for the indiscriminate use of medical technology on severely handicapped and dying neonates. Some critics have even maintained that the practice of indiscriminately treating and repeatedly operating on non-viable infants amounts to human experimentation and child abuse. The death of an infant is a devastating experience for the parents, made even more difficult by the burden of guilt associated with having to decide whether extreme medical intervention is appropriate for their critically ill baby. In a climate of accusation and counter-accusation, it becomes particularly difficult for all well-meaning physicians who, to protect themselves from prosecution, cannot risk forgoing reckless treatments. Doctors have a duty to give priority to patients on the basis of clinical need, while seeking to make the best use of resources using up-to-date evidence about the clinical efficacy of treatments. Doctors must also take care not to allow their views about particulars, such as a patient's age, disability, gender, race, colour, culture, belief, sexuality, social or economic status and lifestyle, to prejudice the choices of treatment offered or the general standard of care provided.

Because of the complexities of modern medicine, the sick, the frail or those in advanced old age are experiencing significant additional anxiety as they wonder whether they have lost the right to an earlier easier death, in harmony with human dignity. As a consequence, advanced directives, or living wills, have gained popularity among those who wish to maintain control over their lives. Advanced directives inform your doctor as to the kind of medical care you would like to have in the event that you are unable to make these decisions yourself. Living wills are one type of advanced directive. Living wills are legal documents by which individuals may direct in writing that they do not wish to receive treatment by extraordinary means, if in the future they become terminally ill or severely impaired. A durable power of attorney for health care is another kind of advanced directive, which states whom you have chosen to make health care decisions on your behalf and may include directions requiring that life-sustaining treatments be withheld or withdrawn. It becomes active any time the person responsible loses consciousness or is unable to make medical decisions directly. The concept of advanced directives first received legal acceptance in the 1976 Californian Natural Death Act, which was passed as a consequence of a number of right-to-die cases, such as the Karen Ann Quinlan decision. Ever since their inception, more formal legalistic documents have been developed, but, in essence, all advanced health directives are formal documents through which an adult may give directions about their future health care (both general health and special health care matters) and may appoint one or more individuals (an attorney or attorneys) to make decisions on their behalf. Advanced directives may be changed or cancelled at any time as long as the individual concerned is considered of sound mind. Evidently, such a document raises wider socioethical and legal problems relating to 'good medical practice' such as issues of limits on the operation of advanced health directives, protection for health providers relying on potentially invalid advanced health directives, validated copies of advanced health care directives, and the requirement to provide futile treatments in the absence of consent to withhold or withdraw life-sustaining measures. As if these dilemmas are not sufficient, recent research has suggested that, while a significant majority of terminally ill patients suffering unremitting pain supported euthanasia and physician-assisted suicide, only a minority of these patients considered these options for themselves.

In summary, the issues raised so far generally fall into two categories. The first deals with listing and defining the values that are challenged when human quality of life becomes the target of intervention and conflict. The second seeks to provide a social and political process that can mediate among those involved. The belief that it is permissible to withhold treatment and allow a

patient to die passively while it is never permissible to take direct action designed to kill the patient is endorsed by a majority of nations and accepted by their respective Medical Associations. This distinction, however, has been extensively challenged on the grounds that if one simply withholds treatment of a dying patient (or malformed infant), it may possibly take the patient/infant longer to die and so prolong the suffering. Is it as unethical to inflict unwanted pain and suffering on an ill and dying person as it is on a healthy living one? If so, active intervention may become the preferred humane course of action. If euthanasia is to make it possible for people to live together in reasonable security and peace of mind, medical technology has to work for and not against the ill. Death is not always avoided in the patient's best interests.

### **Euthanasia, an evolving concept**

One of the nagging ironies of modern medicine is that while it has enormously extended life spans, it has also stretched out the dying process.<sup>2</sup>

Traditionally, death was recognized 'on the cessation of blood circulation, respiration, pulsation, and other essential vital functions of the body'; that is, the irreversible cessation of function. Only in modern times has the concept of brain-death become central in biomedical discussions. A human being is brain dead if, and only if, the activity of his or her central nervous system has irreversibly ceased. The stimulus to redefine death in terms of brain activity emanated from the practice of organ transplantation. Evidently, if the patient were defined to be alive as long as the heart beats, organ transplantation would mean killing one patient to provide another one with the functioning organ. In ancient times euthanasia meant a 'good death' without severe suffering. Today one no longer thinks of this original meaning, but rather of some medical intervention whereby the sufferings of sickness, or of the final torment, are reduced; that is, the modern understanding of euthanasia is more akin to mercy killing for the purposes of putting an end to prolonged or extreme suffering which could impose too heavy a burden on the patient, the family or on society. Therefore, euthanasia in its modern terms of reference has its defining characteristic in the methods utilized. The distinctions which have become crucial in current medical ethics are 'active' or 'passive', 'voluntary' or 'involuntary' as described below:

<sup>2</sup> Horgan, J. (1997). Seeking a better way to die. *Scientific American* 5, p. 74.

- Active euthanasia refers to an act by another person intended to cause the death of a patient and may entail, for example, administering a larger-than-usual dose of an analgesic drug.
- Passive euthanasia generally refers to the act of letting someone die by withdrawing life-sustaining treatment or not implementing treatment in the first instance.
- Voluntary euthanasia refers to euthanasia that involves the fully informed consent of a competent person.
- Non-voluntary euthanasia involves a person who is not competent to give informed consent (for example, infants, the unconscious or senile) or one whose wishes are not, or cannot be, known.
- Involuntary euthanasia is the act of killing or allowing to die of a competent patient without the person's consent.

To the above can be added concepts like 'assisted suicide' which can occur when a fatal hypodermic syringe is left within easy reach of a patient who self-injects and subsequently dies, or 'indirect death', the necessary administration of drugs (painkillers, for example) that have the indirect effect of hastening the patient's death.

As defined above, active, voluntary euthanasia is the deliberate hastening of death, on request, of a competent person. Vigilance, however, is strongly advised in order to distinguish consensual euthanasia from active, involuntary euthanasia, in which patients' lives may be ended against their will. Opponents of euthanasia have expressed concern about the latter scenario, particularly in relation to the Netherlands where an increase in non-voluntary and involuntary euthanasia, following legal tolerance of the voluntary consensual form, has been claimed. They warn us against the 'slippery slope' into moral abuse, an argument that relies on the notion that allowing something in one situation opens the way for the same action to be used unacceptably in another different situation. It is in this context that a clear definition of the circumstances under which a sentient individual might be allowed to make the final decision concerning his or her own life is required. According to the standard medical interpretation, individuals should not be granted the right to full self-determination if they are very young, very old or are severely disabled mentally. Furthermore, individuals should not be given a decisive say in matters which have to do with their wellbeing if they lack sufficient psychological control over their choices owing to temporary emotional disturbances, lack of knowledge or undue coercion by other people. Admittedly, testing for full competency raises serious medico-ethical difficulties because the very act of testing implies the suspicion that the individual is incompetent, which

is itself a violation of the assumption of competency. The assumption of competency depends on understanding what is involved in making an autonomous informed decision. At the same time, health professionals are expected to protect those who are unable to make medical decisions in their own best interests – a difficult ask.

Restrictions of sentient individuals from full self-determination may be justified by reference to the needs of others, like those whose lives depend, directly or indirectly, on the person's actions. In these cases, the harm inflicted on self may harm others in the shared social environment, usually children or grandchildren, to an unacceptable degree. Otherwise, fully conscientious and autonomous beings should be allowed to determine the limits of their inner freedom on the basis of their own experiences and beliefs.

Chapter 7 reviewed modern insights into the essentials of healing and wellbeing. It was emphasized that, in biological terms, health and disease are not alternative states; rather they are part of the same continuum. This applies equally to the continuum of life and death. The urge to be in charge of one's destiny motivates those who hope to improve the quality of their dying by actively participating in a traditional, or physician-assisted, death far removed from the impersonal hyperactivity of hospital or nursing home. Increasingly, it is the hospice which is ministering to the needs of the terminally ill, either at the centre or at home. The modern hospice is a multidisciplinary system of family-centred supervision, designed to assist the terminally ill person through the phases of dying. Hospice care includes home visits, professional health care, education, emotional support for the family and physical care of the patient. A major landmark in society's increasing perceptiveness of the true nature of death was the publication of the book *On Death and Dying* by Elisabeth Kübler-Ross. Following her lead, a general awareness, including our bioethical responsibility to the dying, has matured. Prior to that time, death was the sole province of the priest, since doctors were expected to concentrate on the living. It is for this reason that modern medical education must ensure that physicians are trained in the art and science of improved terminal care of dying patients. An important goal in modern palliative medicine and hospice care is to promote an acceptance of death and gratitude for being allowed to live and transcend the present self.

The practice of 'protecting patients' best interests' against their expressed wishes or preferences, and rationalizing these unwelcome interventions on medical grounds, is often encountered. However, owing to changing ethical demands, these and similar medical attitudes are rapidly disappearing. In essence, the central requirement of professional medical ethics is that



physicians, nurses and others in the caring business must, under all circumstances, regard their patient's best interest as paramount. Unwarranted restrictive controls, such as the refusal to sterilize women with children who request it, are numerous, so a challenging request for euthanasia is even more likely to be refused. It is self-evident that when we act according to our inner directed principles we may not always be free from harming others, whose personal beliefs differ from our own. In respect of another's point-of-view or judgement, however, it may help to recall the three basic principles of bioethics: namely, the principle of autonomy or liberty, the principle of beneficence or responsible tolerance of difference, and the principle of justice, taking into consideration democratic decision-making. We respect autonomy when we refrain from interfering with people's opportunities to control their own lives and when we accept as worthy of respect the existence of individual values we do not share. In the modern medical context a physician's obligation to preserve life may conflict with the obligation to do no harm or to do good. It may also conflict with the patient's liberty; by refusing a request to end a suffering patient's life, the doctor is overriding the patient's right to choose death.

Ethical dilemmas such as the above cause justified unease; however, with the doctrine of individual autonomy replacing earlier medical authority, there is a stronger emphasis on patients' self-reliance and empowerment (refer back to Chapter 7 on wellbeing). Because of this biological association between self-empowerment and wellbeing, unacceptable restraint on the fully informed cannot be justified by appealing to the beneficiary's best interests. It is impossible to better the best interests of competent persons by violating their autonomy. Significantly, the principle of autonomy is closely related to self-determination, which states that persons should have the right to make their own decisions about the course of their own lives whenever they can. As reviewed in this chapter, self-determination - autonomy - over the important events in our life's choices and actions is a necessary pre-condition of genuine wellbeing. Therefore, there is only one sure-fire defence to unacceptable intrusion; that is, to include the dying individual in the final decision of his or her life.

### **Principles of bioscience ethics for discussion**

- In biological terms, life and death are not alternative states; rather they are part of the same continuum. Do you agree or disagree?
- Death is caused not only by injuries and pathological conditions, but also by programmed intracellular and extracellular signals. Therefore,

individual death is not a negative process; rather it is the natural process of adjustment to change. Discuss.

- Most individuals are appreciative of living longer, especially if modern medicine can treat the illnesses traditionally associated with old age. However, as a society have we seriously examined how we feel about longevity, and its local and global consequences? Discuss ethical solutions to the problem/blessing of increasing longevity. Do you think that older citizens are an asset or a drain on society?

# Bioscience Ethics



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