Chinese culture has believed that aging should be accepted. Death at an old age, after a long and full life, is simply sad, but it is a part of life itself. Leaving aside the thorny questions of euthanasia and assisted suicide, I am going to review some of the other ethical, legislative, clinical and economical aspects of end-of-life issues in the following paragraphs.

Medical ethics

\textit{I will neither give a deadly drug to anyone if asked for it, nor will I make a suggestion to this effect} - Hippocratic oath (5th century BC)

Ethics is also called moral philosophy; it is the discipline concerned with what is morally good or bad, right or wrong.

Beauchamp TL and Childress JF introduced the 4 principles of medical ethics in 1979. They are beneficence, non-maleficence, respect for autonomy, and justice. Beneficence is to provide benefits and balance against risks; non-maleficence is to avoid causing of harm; respect for autonomy is to respect the decision-making capacities of autonomous persons; and justice is fairness in the distribution of benefits and risks\(^1\).

However, these principles are not action guides and are not systematically related to each other. There is no priority ranking and there is no specified procedure to be used in resolving particular cases of conflict between the principles. For example, when a terminally ill patient requests the termination of life sustaining treatment, there is conflict between the principles of beneficence (to save the patient’s life) and respect for autonomy (in this case to respect the patient’s choice and terminate the life sustaining treatment). They do not help to clarify the moral issues involved in any particular moral problem nor in providing guidance towards a solution\(^2\).

To solve these problems, Clouser and Gert formulated another set of moral rules in 1990 (Table 1)\(^3,4\). These rules are not absolute and they can have justified exceptions. Answers to 9 questions should be sorted in order to determine whether or not a violation of a moral rule be publicly allowed (Table 2)\(^4\).

<table>
<thead>
<tr>
<th>Table 1: The 10 moral rules</th>
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<tbody>
<tr>
<td>1. Don’t kill</td>
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<tr>
<td>2. Don’t cause pain</td>
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<tr>
<td>3. Don’t disable</td>
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<tr>
<td>4. Don’t deprive of freedom</td>
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<td>5. Don’t deprive of pleasure</td>
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<tr>
<td>6. Don’t deceive</td>
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<td>7. Don’t break your promise</td>
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<td>8. Don’t cheat</td>
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<tr>
<td>9. Don’t break the law</td>
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<tr>
<td>10. Don’t neglect your duty</td>
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<table>
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<tr>
<th>Table 2: Justifying violation of the moral rules</th>
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<tbody>
<tr>
<td>1. What moral rules are being violated?</td>
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<tr>
<td>2. What evils or harms are being avoided, prevented, caused?</td>
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<tr>
<td>3. What are the relevant desires of the people toward whom the rule is being violated?</td>
</tr>
<tr>
<td>4. What are the relevant rational beliefs of the people toward whom the rule is being violated?</td>
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<tr>
<td>5. Does one have a duty to violate moral rules with regard to the person(s), and is one in a unique or almost unique position in this regard?</td>
</tr>
<tr>
<td>6. What goods are being promoted?</td>
</tr>
<tr>
<td>7. Is an unjustified or weakly justified violation of a moral rule being prevented?</td>
</tr>
<tr>
<td>8. Is an unjustified or weakly justified violation of a moral rule being punished?</td>
</tr>
<tr>
<td>9. Is the situation sufficiently rare that no one would ever plan or be in it?</td>
</tr>
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</table>

Most ethic codes of modern age follow Clouser’s format. For example, the international codes of medical ethics read as a doctor must always maintain the highest standards of professional conduct; must practice his/her profession uninfluenced by motives of profit; must bear in mind the obligation of preserving human life etc. These codes of conduct retain the brevity and generality of the Hippocratic oath.

Ethics tells people what they should do and embodies the ideals they should strive to attain. Unethical behavior leads to punishments that are related to how an individual is perceived, both by himself and by his fellow man. Law, on the other hand, provides boundaries of actions, set by society, beyond which a person may go only by risking external sanctions, such as incarceration or loss of a medical license. This explains why ethical codes...
usually involve generalities, while laws tend to be more specific.

Landmark cases in the United States

The Karen Ann Quinlan case in 1976 was the first to significantly address the issue of whether euthanasia should be permitted when the patient is terminally ill. Quinlan was a young woman who was in persistently vegetative state. Her parents petitioned the New Jersey Supreme Court to have her ventilator removed, so that she could die in a natural way. The Court granted their petition, and also held that an ethic committee could grant all parties concerned legal immunity for their actions. This widely publicized case prompted the enactment of the living will statute in the States, which was the Natural Death Act of California in 1976. The Act was considered to be revolutionary at that time. It contained a prescribed document, which to be legally enforceable, must be signed by the patient not earlier than 14 days after being diagnosed to be suffering from a terminal condition. The 14-day rule was intended to give the declarant a cooling off period to think about the issue. It was to remain valid for 5 years, or till the patient died, whichever was sooner.

In 1981, the mysterious death of a young woman in a Queens hospital intensive care unit sparked a grand jury investigation that lasted 2 years in New York. The hospital failed to provide the patient cardiopulmonary resuscitation because of a covert system in which purple dots were affixed to the charts of patients who were not to be resuscitated. The system had apparently been conceived in response to a staff decision against the use of explicit Do-Not-Resuscitate (DNR) orders, in order to minimize legal exposure. At the end of the investigation, the grand jury urged the state government to formulate policies governing the issuance of explicit DNR orders. In 1988, the New York Do-Not-Resuscitate Law became effective and New York became the first state to enact legislation governing the withholding of cardiopulmonary resuscitation.

In 1990, there was another landmark case: the Cruzan case, which introduced the concept of healthcare proxy. Nancy Cruzan was left in a persistent vegetative state after a road traffic accident in 1983. Her parents sought to have her feeding tubes removed. The Missouri Court, however, required clear and convincing evidence that this was what the patient would have wished for herself and the parents’ request was rejected. On appeal, the US Supreme Court upheld the Missouri Court’s ruling. The Cruzan case triggered widespread reaction from the public as well as medical professionals, calling for legal recognition of living wills and proxy directives, and resulting in the passage of the Patient Self Determination Act (PSDA) on 1 December 1991. The PSDA requires health care providers to inform patients about their rights to execute advance directives such as living wills and durable powers of attorney for health care. All hospitals, nursing facilities, home health care agencies, hospice, and health maintenance organizations participating in the Medicare and Medicaid programs must provide written materials for all adults who come to them as patients.

Advance directives

Like a will, everybody should have one.

Advance directive is a document that enables a competent individual to specify the form of health care he or she would like to have, in the event that he or she is unable to make such decisions in the future. This comes into effect when the person no longer has the mental capacity to decide on or communicate a treatment decision, usually due to being in the terminal phase of an illness, or being permanently unconscious. There are 2 kinds of advance directives: 1. Instruction directives, commonly known as living will which detail patients’ preferences regarding future treatment decisions; and 2. Proxy directives, sometimes known as ‘durable power of attorney for health care’, ‘health care proxies’, ‘medical powers of attorney’, or ‘living will designates’. Designated individuals are appointed to act on behalf of the declarants.

Instruction directive is most appropriate for those persons who do not have someone they can trust. This concept of advance directives originates from the right to die movement in the United States. Luis Kutner first proposed the idea at a meeting of the Euthanasia Society of America in 1967. He used the term ‘living will’ in 1969. It is a ‘will’ because it spells out a person’s directions, yet it is ‘living’ because it takes effect before death, though the execution of this ‘will’ usually hastens death. As mentioned above, California was the first to enact the Natural Death or Living Will Act in 1976. A living will is the legal document that describes those treatments an individual wishes or does not wish to receive should he or she become incapacitated and unable to make medical decisions for him- or herself. It should be signed and dated by two witnesses who are not blood relatives or beneficiaries of property. A signed copy should be placed in the patient’s medical record and a second
copy should be given to the individual designated to make decisions when the patient is unable to do so. By 1994, there was living will legislation in all states and the District of Columbia.

On the other hand, a health care proxy allows a person to appoint a ‘health care agent’ to make decisions for him- or herself. In contrast to a living will, a health care proxy does not require a person to know about and consider in advance all situations and decisions that could arise. Oral declaration is accepted only after the patient has been terminally ill. The declarant bears the responsibility of informing the physician to ensure that the document becomes a part of the medical record. Thirteen states in USA authorize the appointment of health care proxies.

Durable power of attorney

In general, power of attorney is a legal device that permits one individual known as the "principal" to give to another person called the “attorney-in-fact” to act on his or her behalf on matters like banking, real estate affairs and a wide range of legal affairs. However, this power of attorney automatically expires if the principal becomes comatose or mentally incompetent. Durable power of attorney, on the other hand, remains valid even if the principal becomes comatose. In the United States, all 50 states and the District of Columbia have durable power of attorney statutes.

Hong Kong law does not recognize the rights of proxy consent on behalf of an adult. Only in relation to children or mentally incapacitated persons incapable of giving consent, can people, providing they have parental responsibility or they are guardians with the requisite power, consent on behalf of others. Besides, under common law in Hong Kong, power of attorney would lapse if the person making it becomes mentally incompetent. The Enduring Powers of Attorney Ordinance in Hong Kong does permit powers to remain valid beyond this point but only in relation to the management of property and finance. Thus, proxy consents is not helpful in relation to medical decisions under the circumstances in Hong Kong.

Surrogate ruling

In the States, if a mentally non-competent patient has neither a living will nor a proxy directive, there is a backup system for decision making concerning health care issues. This is the Health Care Surrogate Law. The aim is to let decision making transfer from the courtroom back to the bedside. The physician should determine the patient has a qualifying condition, which is one of the followings: terminal condition, permanent unconsciousness, and an incurable or irreversible condition that will ultimately cause the patient’s death. Afterwards, the physician must make a reasonable inquiry to see whether a surrogate decision-maker is available. The possible surrogates, in order of priority as specified in the statute, are the patient’s spouse, and adult son or daughter, a parent, an adult brother or sister, and adult grandchild, a close friend, and the guardian of the patient’s estate. If none of these exist, it may be necessary to resort to courts. Although physicians have made such determinations routinely in medical practice in the past, such practice is now legally bound. By 1994, there was surrogate ruling in all but 2 states (New York and Missouri) in USA.

The physicians: non-treatment orders

Physicians are usually confronted with 2 situations. The first situation is treatments that, if not provided, lead to a bad outcome or even death for the patient at some time in the future (for example removal of feeding tubes). The second situation is procedures, which if not undertaken lead to immediate death, in particular the process of active resuscitation following a cardiac arrest.

1. Do not resuscitate (DNR) order

In the past, there was little to do for patients dying in the ward and their passing, although tragic, was regarded as a natural end point. This began to change since 1960 when Kouwenhoven in Baltimore described impressive recoveries after cardiac arrest with the new technique of closed chest cardiac massage, coupled with the newly described defibrillator. Over the next 10 years, virtually all large acute hospitals in Europe and North America set up rapid response crash teams to bring resuscitation skills to the bedside of anyone suddenly dying in the hospital. As the active management of cardiac arrest became commonplace, situations arose, where it was virtually impossible for a person to die in hospital from any cause without the application of active resuscitation.

Blackhall LJ in 1987 reviewed a number of studies on the outcome of cardiopulmonary resuscitation (CPR). He found that only one in seven of the cases survived to leave the hospital, and no patient with metastatic carcinoma, acute stroke, generalized sepsis or pneumonia left hospital after a cardiac arrest despite maximum therapy. Patients with acute myocardial infarction,
ventricular arrhythmia, and complications from anesthesia did better. The location of the patients undergoing cardiopulmonary resuscitation is important; patients in the emergency department or the intensive care unit gave a 19% survival rate, whereas patients on general wards have a survival rate of 2-6%\textsuperscript{15,16}. Those who survive are not infrequently left with serious neurological deficits\textsuperscript{17}, and when asked, 42% of the survivors stated that they would choose not to be resuscitated if they should have an arrest in the future\textsuperscript{18}. Recognizing the inappropriateness (not to mention the expense) of this course of action, hospitals begin to develop policies on the withholding of active resuscitation in certain patients.

The Hospital Authority in Hong Kong had also distributed guidelines on in-hospital resuscitation decision in July 1998. In case that a mentally incompetent patient’s wishes are not known, treatment decisions must be based on the patient’s best interests, taking into account: 1. Patient’s disease diagnosis and prognosis; 2. Patient’s known values, preference, culture and religion, which may influence treatment decision and 3. Information received from those who are significant in the patient’s life and who could help in determining his/her interests. The guidelines also state that doctors are not obliged to provide medically futile therapy when asked to do so by the patient or patient’s family. Medical futility in performing CPR in the guidelines is defined as a lack of reasonable hope in restoring or sustaining cardiopulmonary functions and clinical decision on resuscitation for this category of patients is normally made by the doctor-in-charge based on his/her judgement\textsuperscript{19}.

There are other more objective ways to define medical futility. Kanus et al. in Washington had derived scoring systems based on the degree of derangement of a number of physiological parameters, together with points for age and chronic health status, to produce a numerical APACHE score (acute physiological and chronic health evaluation) in 1985. The higher the APACHE score the more ill the patient. By amalgamating the results from a number of intensive care units (ICU) in the USA, they established a large database of patients and their scores. By looking at the outcomes of those patients who were having the best available therapy, it was possible to predict the mortality for certain scores\textsuperscript{20}. Chang in 1989 used a combination of absolute values of the score and the change over a period of time and was able to predict 109 out of 831 intensive care patients with no false predictions. Of the 722 patients whose predicted outcomes were uncertain, 181 also died\textsuperscript{21}.

2. Feeding tubes: case-specific guidelines in the United States

There is a distinction between ordinary and extraordinary medical care from the theological and ethical point of view. Such distinction is based on the belief that life is a gift from God that should not be destroyed deliberately by humans. Therefore, extraordinary therapies that extend life by imposing grave burdens on the patient and family are not required. A patient, however, has an ethical and moral obligation to accept ordinary or life-sustaining treatment\textsuperscript{22}.

Such distinction was challenged by the Conroy Case, which was heard by the New Jersey Supreme Court in 1985. The case involved an 84-year-old nursing home patient whose nephew petitioned the court for authority to remove the nasogastric tube that was feeding her. The court held that life-sustaining treatment, including nasogastric feeding, could be withheld or withdrawn from incompetent nursing home patients who will, according to physicians, die within 1 year. The court found that tubal feeding to be a medical treatment, as intrusive as other life-sustaining measures.

In 1986, the New Jersey Superior Court ruled that the husband of severely brain-damaged Nancy Jobes could order the removal of her life-sustaining feeding tube, which cause the 31-year-old comatose patient, who has been in a vegetative state in a hospice for the past 6 years, to starve to death. Despite medical experts testified that the patient could under optimal conditions live another 30 years.

Also, Elizabeth Bovia, a mentally competent cerebral palsy victim in the states, won her struggle to have feeding tube removed even though she was not terminally ill in 1986. The court found that her decision to let nature take its course did not amount to a choice to commit suicide.

To further complicate the issue, on March 17, 1986, the American Medical Association changed its code of ethics on comas. It states that physicians may ethically withhold food, water, and medical treatment from patients in irreversible comas or persistent states with no hope of recovery even if death is not imminent.

3. Non-treatment orders: the boarder arena

If a man who has a very poor quality of life, is not to be resuscitated when he has a cardiac arrest, does the decision not to resuscitate remove the need to provide dialysis or ventilation? What about cheap
and non-invasive therapy such as antibiotics? If we are not going to add therapies which will prolong life, what about procedures currently in place? If treatment is to be limited, what is the moral basis of doing this?

Schneiderman and colleagues pointed out that the benefit of a treatment should be judged by its ability to help progress the patient in the direction of an acceptable quality of life, not just by its physiological effect. For instance, dialysis that will correct the plasma electrolyte is irrelevant if having normal electrolytes will not help a patient wean from a ventilator. They do not regard merely getting a patient into a state where he is surviving with a total preoccupation with and dependence on medical treatment and monitoring to the extent that he cannot achieve any other life goals as a reasonable aim. Treatments, which can only achieve this, are in their view futile, and therefore not morally obligatory.

Economic considerations

It is costly when one is dying in a hospital, and even more so when one is dying in ICU. Eighteen percent of lifetime costs for medical care are spent in the last year. Twenty-nine percent of Medicare and Medicaid payments for those over the age of 65 is spent in the last year of life in the States. It is believed that these expenditure at the end of life seems an easy and readily justifiable way of cutting wasteful spending with the introduction of DNR and advance directives, freeing resources to ensure universal access to health care. However, such ethical means to limit costs may have undue influence to promote advance directive to limit health care inappropriately to the patient’s disadvantage, especially the elderly. Advance directives must be part of a clinical process not an administrative one.

Conclusion

Death is the greatest certainty of life

Physicians who care for the aged should have the knowledge and skill for counseling on end-of-life issues. Besides, they often have the opportunity to anticipate problems and help clients plan for their future. Although most people don’t enjoy considering the consequences of their dying process, it is a reality we all must face. The underlying philosophy of an advance directive is not the right to live or to die, but the right of self-determination, that is, ‘patient autonomy’. The appropriate involvement of an attorney can assist aged individuals in organizing their affairs, in exercising some control over how they will be treated. To date, no legislation has been enacted in Hong Kong Special Administrative District on advance directives and no court has yet had to determine the validity of a living will or an anticipatory decision made by a patient who is now incompetent. Doctors presently make healthcare decisions for incapable adults in the best interests of the adult concerned together with the relatives. As a longer life does not guarantee a better life, greater control by the elderly persons over their own dying - and particularly an enforceable right to refuse aggressive life-extending treatment - should be a minimal goal.

References