

# Ethics, Death and Dying

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## บทคัดย่อ

ความรู้และเทคโนโลยีต่างๆ ที่ทางการแพทย์นำมาใช้ช่วยชีวิตผู้ป่วยที่ในสมัยก่อนเป็นผู้ที่ไม่มีทางมีชีวิตรอดอยู่ได้นั้นถือว่าเป็น “ปาฏิหาริย์” สมัยใหม่ที่นำขึ้นขมยินดี ปัญหาจริยธรรมที่เกิดพร้อมปาฏิหาริย์นี้เป็นเรื่องเกี่ยวกับความหมายของ “ชีวิต” “ศักดิ์ศรีของมนุษย์” “คุณภาพชีวิต” “ความตาย” “วิถีตาย” และ “สิทธิมนุษยชน” ปัญหาเหล่านี้ยังไม่มีการตอบคําตอบที่แน่นอน เพราะเป็นเรื่องนอกเหนือขอบเขตของหลักจริยธรรมที่ยึดถือสืบต่อกันมาในการแพทย์/การพยาบาลจนเป็นประเพณี แม้แต่ศาสนาเองก็ยังหาคําตอบที่ทุกฝ่ายพึงพอใจไม่ได้ ไม่ว่าจะป็นกรณีของทารกแรกเกิดด้วยโรคร้ายแรงประเภทดาวน์ซินโดมส์หรือในกรณีของผู้ป่วยในโคม่าที่ไม่มีทางกลับคืนมาสู่สภาพปกติได้

ในกรณีดังกล่าว เรามักจะไม่แน่ใจว่า ควรใช้เครื่องช่วยชีวิตแก่ผู้ป่วยประเภทนี้หรือไม่? และจะใช้นานแค่ไหน? จะถือว่าชีวิตที่มีแต่มีติดทางกายภาพเท่านั้นและไม่ต่างอะไรกับพืชผักเป็น “ชีวิตมนุษย์” หรือเปล่า? “คุณภาพ” ชีวิตหมายถึงอะไร? ใครเป็นผู้พิจารณาตัดสินว่าชีวิตของผู้ใดมี “คุณภาพ” หรือไม่มี? ความตายหมายความว่าอะไร? “การชะลอความตาย” หรือการช่วยผู้ป่วยให้มีชีวิตต่อไปได้ด้วยเครื่องช่วยชีวิต และ “การปล่อยให้ผู้ป่วย (ในความรับผิดชอบ) ตาย” (โดยปราศจากการให้ความช่วยเหลือดังกล่าว) อะไรถูกหรือผิดกันแน่? การใช้เครื่องช่วยชีวิต (เพื่อชะลอความตาย) เป็นการทำให้ผู้ป่วยไม่มีศักดิ์ศรีของมนุษย์เหลืออยู่หรือไม่? เป็นการลิดรอนสิทธิของผู้ป่วยหรือไม่? “การปล่อยให้ผู้ป่วยตายโดยเจตนา” และ “การทำให้ชีวิตผู้ป่วยสิ้นสุดด้วยเจตนา” เช่นกัน เป็นการกระทำที่แตกต่างกันเล็กน้อยเพียงใด?

ปัญหาเหล่านี้เกิดขึ้นเพราะเป็นปัญหาในแดนสนธยาที่เส้นแบ่งระหว่างความถูกและความผิดที่ยึดถือกันมาไม่ชัดเจนไม่เหมือนกัน ความแตกต่างระหว่างขาวกับดำ จึงทำให้ นักจริยศาสตร์และ/หรือนักศาสนาต้องพยายามประยุกต์หลักจริยธรรมที่ตนยึดถือหรือที่ศาสนามีอยู่ให้มาเกี่ยวข้องกับปัญหาดังกล่าวเพื่อหาคําตอบที่ไม่ขัดกับมโนธรรมและ/หรือคําสอนในศาสนา

In few other areas have the recent advances in scientific knowledge and the new medical technologies raised more basic questions about the very nature, meaning and value of human life than in the whole area of death and dying. That health care professionals find themselves in conflict over ethical dilemmas which arise here is not surprising, since the problems are so recent and there is a lack of

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public consensus on what is morally acceptable. Already in the West, there has begun a groundswell movement of cultural change in which traditional attitudes and ideas about death and the dying process are being modified or rejected by many and the same developments are occurring now in Thailand. For example, in both Christian and Buddhist belief there has been a general prohibition against suicide; the taking of one's own life was considered an evasion of responsibility for the life that one had been given. Now the question is being raised whether the right to refuse treatments, which are life-preserving in cases of lingering terminal illness or chronic severe pain or disability, is a morally acceptable option or constitutes a kind of prohibited suicide. Reference has been made to a Buddhist text in which it describes two holy men who take their own lives to escape incurable illness and this is said to be an obstacle to their attaining *nibbana*, so perhaps this exception to the general rule against suicide is already part of Buddhist tradition.<sup>2</sup> This goes beyond the question of refusal of treatment to justify the direct taking of one's own life in certain medical circumstances. But the question is being taken even a further step. Is it morally acceptable that doctors or other health care professionals act upon the expressed desire of patients to assist them in committing suicide when they are unable to act for themselves or find the means to do so? For example, given the voluntary assent of patients may one give lethal overdoses of drugs or inject substances that will directly cause death? These would be cases of assisted suicide. But if these options are considered morally acceptable, what of the question of hastening the deaths of comatose or other incompetent patients who cannot or have not given voluntary assent or formerly expressed the desire to die? Is it morally acceptable for health care

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<sup>2</sup> The first precept in Buddhism prohibits the taking of life. Within this precept all killing for whatever reason is not allowed. The precept upholds the sanctity of life of all human beings regardless of the conditions of their lives. This is based on the Buddhist belief in the preciousness of human rebirth. As a rule suicide is prohibited. Even when one is suffering from a painful and incurable disease, or when one's life is unsatisfactory, one should bear it quietly and patiently while simultaneously trying to rid oneself of the pain and suffering in all possible ways. Suicide is not allowed. Yet in some cases, according to Buddhist scriptures, taking one's own life is allowed for noble ends. The giving of one's own life to save the lives of others, as a *bodhisatta* gave himself to a hungry lioness to save her from eating her own cubs, is one example of this exception. Another is suicide to escape from an incurable illness that is an obstacle to the attainment of *nibbana*. The Buddha was said to give approval to suicide of a monk named Godhika who, after attaining the state of spiritual release through meditation six times in succession and then falling away from it, committed suicide the seventh time he attained it, in order not to fall away from it again (*Samuyutta-Nikaya I*, pp. 120f.). This event has been used by Mahayana Buddhism to justify suicide. Whether there is another exception which would allow a sick person to refuse extraordinary measures to preserve life is an open question, and also whether health care professionals, requested by patients to assist them to end their own lives when there is no hope for recovery, would also be allowed to do so.

professionals to follow the wishes of family members to hasten the deaths of these people or for doctors or nurses to decide for themselves that such individuals are better off dead and thus directly act to cause their deaths? If doctors alone, or together with families, decide to withhold life-preserving treatments or to stop such treatments once they have begun them, are such actions the same as “killing” patients or are there important ethical distinctions to be made between “allowing to die” by withholding or stopping treatment and directly “killing” or causing death? The lack of public and professional consensus on these questions creates the possibility for emotionally laden moral conflicts within the general public, between families and their doctors and among medical personnel themselves. In many ways these unresolved moral issues have added to a general climate of mistrust of modern medical practice and the intent and motivations of medical personnel. Will they allow me to die, hasten my death or kill me—how can the public know?

Or to take another circumstance. I was once told by a young medical resident not to go to a certain teaching hospital if I were dying of an interesting disease. He said, “They will keep you alive just to study you”. “Being kept alive” --wasn’t that the goal of medicine, wasn’t that the blessing of modern medicine that it could keep more of us alive for longer periods than formerly? How had this blessing become a curse for some? Recent medical research and technology is a success story at keeping alive people who formerly would have had no chance for continued life: at the beginning of life, premature and defective infants; during the course of life, diabetics, those suffering from kidney failure and cardiac arrests, etc.; and at the end of life, those needing heart-lung machines, organ transplants, hyperalimentation, resuscitation procedures, etc. But each new success at keeping alive has raised questions about the worth of the lives saved.

Today some quality of life can be sustained, supported even indefinitely, but why do it? Who wants it? For what purpose? Is it worth the effort, the cost of suffering, and the expenditure, as well as time of health care personnel? Yes, people who are clinically dead can be revived, but why bother? Do they want to die? Should we leave people alone to die with dignity, not hooked to machines, not sustained at a meaningless level of human existence, not maintained so that we can study them, nor so their bodies can be used as organ banks for transplants? At what moment in the dying process (a process, biologically, and not an event) should we declare that “death” has occurred which is finally a matter of social, legal, philosophical and religious definition? Shall we continue with the traditional definition of “death”, the cessation of all vital signs, or declare “death” when we can, with our new measuring devices, detect the cessation of higher brain activity, “higher brain death”, irreversible coma, or when both the higher

and lower brain activities cease to function spontaneously, that is, unassisted by machines or procedures like hyperalimentation? Death with dignity! The right to die! In the midst of modern medicine's miracles in live-saving and life-preserving techniques and technologies came the cries of the public demanding that people be allowed to die! Initially, it seemed a very confused and ungrateful public response—and one shared by many medical personnel who witnessed the results of these new procedures. But out of more refined ethical analysis of what has been happening has come more clearly focused moral dilemmas and sharply defined positions on the questions of death and dying which at least make the discussion of them in the public and among health care professionals more rational and therefore more subject to resolution and possible consensus.

Life and death. The right to live and the right to die. How in concrete cases are we to decide which of these right is to be honored, which takes precedence? The old responses are no longer adequate. The dean of one medical schools in Thailand assured me that there were no problems here regarding this issue, since by tradition it was recognized by families, patients and doctors that the doctor's role was to do any and everything to preserve and prolong the life of patients at any cost. The case studies of actual hospital experiences told a different story; they reported instances of lethal overdoses being given, of no-code orders written, of the withdrawal of life-support systems or orders to withhold treatments all of which raised for them moral questions and/or placed them in conflict with other medical personnel. In Thailand, as in other countries, new medical developments and circumstances make necessary a systematic review of traditional ideas and attitudes, accepted practices concerning death and dying, and clarification of the moral implications of current new capabilities in medicine.

One of the most stringent general principles of moral obligation which can be used as an action-guideline for medical personnel, as well as for all of us, is the precept of non-injury. "*Above all do no harm*" or the duty of non-maleficence. This general moral rule is of particular application in medicine because patients are those already harmed by pain, suffering, disability and possible or probable imminent death and because medical personnel have within their power the means to prevent or alleviate further harm or, on the other hand, to permit or cause further harm to those already injured and vulnerable. It is true that all medical procedures and therapies carry a risk of harm in different degrees.<sup>3</sup> Any interventions in bodily and mental integrity and functions risk harm, but we morally accept these risks when the goals are important enough--to restore to health, to correct disabilities, to prevent death or prolong life. In regard to these

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<sup>3</sup> Beauchamp and Childress, *Principles of Biomedical Ethics*, p. 99

medical risks we ask only that medical personnel give us clear and full information about them so that patients and/or families can give informed assent this risk-taking and that doctors and nurses act thoughtfully and carefully to avoid negligence which exposes patients to undue and unnecessary risks. The “standard of due care” establishes the obligation, legal and moral, that doctors and nurses will not expose patients of further harm because of a lack of knowledge, inadequate skills or failure to be diligent in their actions. Within that moral framework, the normal risks of medical procedures are morally acceptable. What we are more concerned with here is intentional harming by causing, permitting or imposing death on patients (or increased needless pain, suffering or disability). When, if at any time, are such actions to be considered morally acceptable, that is, as not violating the principle of non-maleficence, as exceptions to the rule against non-injury and its secondary principle, the prohibition against killing?

In the continuing discussion of this issue, ethicists have drawn distinctions between *passive* and *active euthanasia* (a word meaning, literally, “a good death”) and *voluntary* and *involuntary euthanasia* in order to clarify the moral implications involved.<sup>4</sup> *Passive euthanasia* is defined as “allowing or permitting to die” by withholding or stopping treatments. It can be both voluntary or involuntary. Voluntary passive euthanasia is not starting or stopping treatment at the expressed desire of a competent patient even if these actions inevitably lead to the death of the patient. As we have seen, the right of competent patients to refuse treatment under certain circumstances has been made part of Patient Bill of Rights. The circumstances under which this action becomes morally acceptable include the careful assessment that the patient is in fact rationally competent to give genuinely informed assent in full awareness of the consequences of the decision (possible or probable death) and is acting freely, that is without external coercion or influence by others or inner compulsion or emotional disorder, e.g., depression.

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<sup>4</sup> Many books have been written about the moral issues and dilemmas involved in death and dying. Among those that give the most extensive coverage to these problems are :  
Carse, J. and Dallery, A., eds., *Death and Society* (New York : Harcourt, Brace, Jovanovich, Inc., 1977).

Veatch, R.M., *Death, Dying and the Biological Revolution* (New Haven : Yale University Press, 1976).

Steinbock, B., ed., *Killing and Letting Die* (Princeton : N. J. : Prentice-Hall. Inc., 1980)

Kohl, M., ed., *Beneficent Euthanasia* (New York : Prometheus Books, 1975)

Shils, E., et al.; *Life or Death : Ethics and Options* (Seattle : University of Washington Press, 1968)

Humber, J.M., and Almeder, R.F., eds., *Biomedical Ethics and The Law*, 2<sup>nd</sup> edition (New York : Plenum Press, 1979)

McGuire, D., *Death by Choice* (N.Y. : Doubleday, 1974)

There have been cases in which such competent patients have refused life-preserving treatments because they are not in accordance with their religious beliefs. This right of refusal has been upheld on the condition that their deaths would not inflict serious harm on others, for example, that their families or other dependents would not be unduly harmed. If that were a real possibility, then the moral principle of non-maleficence would override the obligation to respect persons and their autonomy, their desire to live only according to their own religious beliefs and values. But if no infliction of serious harm on others would result from the refusal of treatment then the duty of respect for persons and their autonomy takes precedence and such patients have been allowed to go untreated.

Still debated, but a kind of set of circumstances which increasingly commands moral assent, are cases in which terminally ill patients, who are still rationally competent and whose deaths are imminent, refuse further treatments, or express the desire not to be resuscitated but allowed to die, on the grounds that further treatments are only prolonging the dying process and will subject the patients (and/or their families) to increased and needless suffering. In cases of this kind both the principles of respect for persons and non-maleficence, preventing further needless suffering, would seem to be on the side of “allowing the patient to die”. Some have argued that such action is also in accord with the medical profession’s duty of fidelity to patient welfare, that death in these circumstances is in the harmed person’s best interests or that sustaining life, especially if the patient would suffer form unmanageable pain in his or her last hours or days, would itself violate the principle of “do no harm”. The prima facie duty of justice could also be invoked, arguing that it is unfair to burden patients and families with further suffering when is imminent, and the prognosis according to the best medical wisdom is hopeless. Here the rallying cry of “death with dignity” seems to make some moral sense; allowing the hopelessly terminally ill to die, unhooked to machines, subject to no experimental treatments merely to gain scientific knowledge, not kept alive merely to study them or allow interns to practice on them, but following their expressed wishes to decide, as their last human act, the manner of their own dying, appears to be the action most in accord with our prima facie obligations.

That more and more people are claiming this “right to die with dignity” in manner of their own choosing is evident in the United States where people are signing what are called “living wills”.<sup>5</sup> These declarations, made while people are still fully rationally competent and before the onset of any terminal illness, morally obligate family and health care professionals to allow them to die by

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<sup>5</sup> This issue is discussed in many of the books mentioned above.

withholding or ceasing “extraordinary means” to sustain life in accordance with their formerly expressed desire, freely given. This desire is to be honored especially if and when the person becomes incompetent or comatose as the result of a terminal illness and thus unable to give informed assent to further treatments. In some states the obligation to honor “living wills” has been enacted into law, legally binding families and doctors to follow the previously declared wishes of individuals should they become unable to express them later. For some ethicists, including myself, to make such “living wills”, perhaps written while a person is still young, healthy and unaware, legally binding is a mistake. It does not take into account possible future medical developments in treatments and cures nor that people who when they are actually facing dying might change their mind and, if they could, express the desire that everything be done to sustain and prolong life. Sometimes it takes the very threat of death for us to realize how sweet life is and possess the desire to live even at the cost of suffering.

It also gives a kind of legal license of families and doctors to hasten deaths by withholding or ceasing treatments prematurely for reasons that have nothing to do with patient welfare, for example, to insure inheritances, lessen taxes, use hospital equipment for wealthier patients, find organ transplants, etc. It has been argued in fact that some of the medical community’s support of the legal enactment of living wills had more to do with the self-protection of doctors than with patient benefit, since it could become a cover-up for negligence in the care of seriously ill and comatose patients; if they died it was a matter of following their wishes, thus saving doctors from malpractice suits!

When we move from the above cases which have been called instances of “passive voluntary euthanasia” to cases of “passive involuntary euthanasia” the ethical waters become even more muddy. Involuntary means not with the informed assent of the patient. It can be a matter of withholding or ceasing treatment for those who are incompetent either because they are at the beginning of life or are too young, or during life too lacking in rationality or at the end of life they are senile or comatose and therefore depend upon others to make the decisions for them. We will deal with this issue later and turn our attention first to arguments whether active voluntary or involuntary euthanasia (in the case of incompetents) is morally acceptable. Active euthanasia is defined as directly causing the death of patients, voluntary if they have expressed the wish to die, involuntary if others decide for them that death should be caused.

The first question that has been raised is whether there is a clear moral distinction between “*allowing to die*” and “*killing directly*”. The latter which has been called “*mercy-killing*” is in so many peoples’ minds attached to the term

“euthanasia” that for them the distinction between “allowing to die” and “killing” is a mere quibble over words since: the results are the same, the death of the person (by either passive or active means); the motive is the same because it is thought that death is in the best interests of the patients; and the intent is the same, to prevent further suffering. Since the end result is the same and the intentions are the same, those who find “mercy-killing” (active euthanasia) morally acceptable argue that direct killing is not in itself worse than letting die and may even be more right in that less suffering may be the result.

For example, if competent patients request the withdrawal of treatments to permit them to die sooner and that withdrawal means increased pain as they linger on, why not also act on their request that death be hastened by giving direct overdoses or injection of lethal substances which are painless? Or if we are going to allow defective babies to die by withholding treatments (which happens in many hospitals today) why let them linger of when we can painlessly put an end to their lives immediately? One can see that the basis of such an argument is an Act-Utilitarian approach where the end justifies the means only and therefore it is thought that the actions themselves of “allowing to die” or “killing” represent only a bare difference, not morally relevant. For the Rule-Utilitarian and Mixed Rule-Deontologist, the prohibition against killing directly is, for the one position, so important a social rule that it can have few classes of exceptions and medical practice can not be one of them and, for the latter position, it is thought that the practice of mercy-killing would fail to stand up under the weight of the prima facie duties of fidelity, respect for persons, beneficence, non-maleficence and justice in medicine.

It is true that sometimes “allowing to die” is just as immoral as killing directly. If parents passively allowed children to die by not giving them food available we would hold it be as horrendous an act as strangling them. When in our hospitals Downs Syndrome babies who have esophageal blockage are allowed to starve to death because parents refuse to give the necessary permission for the minor corrective operation which would allow them to feed and thus preserve their lives, it does seem to many as immoral an act as directly killing them would be. It is such cases which give support for those arguing that causing the death of these babies--active infanticide--would be more merciful than lingering deaths (some fourteen days) by starvation--passive infanticide. The prior question here is whether Downs Syndrome children ought to be allowed to die at all.

Those who see a very crucial moral difference between “allowing to die” and “killing directly” would argue that sometimes allowing to die is an immoral act, but that direct killing of patients is always wrong. The medical professions

ought to always be held responsible for killing patients, but they are not morally bound to preserve life in all cases. The American Medical Association also maintained the distinction. Only the cessation of treatment can be morally justified (not mercy-killing) and that only under certain circumstances:

*Those cases in which the patient and or immediate family with the advice and judgment of physicians decide to withhold or stop the use of extraordinary means to prolong life when there is irrefutable evidence that biological death is imminent.*<sup>6</sup>

This is under strict interpretation of what constitutes “extraordinary means”, though as we shall see the term is problematic, would not permit the “allowing to die” of Downs Syndrome babies.

They set three criteria then to justify stopping treatment and permitting to die:

1. the life is being preserved by extraordinary means;
2. biological death is imminent (irrefutable evidence);
3. patient and/or family consents,

The prohibition against “mercy-killing” is needed, it is argued, so that there can be maintained that basic trust which is fundamental between patients and health care professionals. That trust is dependent upon the mutual understanding that doctors will respect moral limits on how they will treat patients. And the moral limit which prohibits outright killing of patients cannot be weakened. The image of the medical professions as those dedicated to preserve life will be changed if they are allowed to become agents of death.

Beauchamp in his discussion of the issue uses two versions of the wedge argument (or camels’ nose-under-the-tent) to make the case for maintaining a strict prohibition against direct killing of patients for any reason:<sup>7</sup>

1) That the logical implications of the grounds used to justify one kind of act may also tend to justify others acts which we hold to be wrong. Following the principle of universality, like cases ought to be treated alike. Many fear this is already happening in the United States in regard to abortion. If the morally acceptable grounds for abortion are formulated in terms of saving the mother from hardship or inconvenience in raising the child, do not these grounds also justify

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<sup>6</sup> See Principles of Medical Ethics, American Medical Association.

<sup>7</sup> Beauchamp and Childress, op. cit., p. 117.

killing babies (or allowing them to die) after birth, if parents then believe it would be a hardship to raise them? Does it not justify infanticide, as in the case of Downs Syndrome babies? Or some of the general reasons for supposed “justified killing in medical contexts” might be too inclusive and spill over into non-medical contexts. For example, 14% of the deaths in the Yale special-care nursery were related to withholding treatment on the grounds that “prognosis for meaningful life was extremely poor or hopeless”. What constitutes meaningful life and according to whose values? If one can kill or permit to die newborn infants on these grounds, why not retarded children, or the severely crippled, or the deaf, blind and mute, or those who are senile, or paraplegics, or those at the end of life suffering from chronic and painful diseases? To withhold treatment or to kill simply on the basis that the prognosis for a meaningful life is poor justifies too much. It establishes the mentality that there are those whose lives are not worth living and should be ended.

2) The second version of the wedge argument asks us to examine the society to determine the probable impact of changing rules and making new classes of exceptions to basic social rules. Ethical decisions and the formulation of social policies do not occur in a social vacuum. One has to be aware of “the psychological and social forces at work that might push people to allow actions formerly thought to be immoral thus weakening the social sanctions against them.”<sup>8</sup> This was the fear expressed in regard to genetic screening and counseling, that social pressure would build up opposed to people giving birth to genetically defective children, even those who could be successfully treated medically after birth or those whose parents would otherwise be willing to care for no matter their afflictions, such that an element of social coercion would emerge in marriage and reproductive choices. It is the fear that many have regard to the policy of abortion on demand, since it permits abortion to be used as simply a form of birth control and thus weakens social sanctions against sexual irresponsibility. Here the fear is that permitting the killing of patients supposedly for their own good will open the door to killing patients for the sake of social benefits that active voluntary euthanasia will become in practice involuntary euthanasia, since it will lead to a general reduction of respect for human life. Some have argued that an increase in the quality of civilized life is correlated with the willingness of a society to care for the weak, afflicted and dependent peoples in its midst.

In a book called **Life or Death: Ethics and Options**.<sup>9</sup> Edward Shils argues that there exists in all of us a basic sense of the sanctity of life, of respect

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<sup>8</sup> Ibid., p. 110 – 113.

<sup>9</sup> Shils, *Life or Death : Ethics and Options*.

of life, which he believes acts as the basic sanction against destroying human life. But he goes on to say that:

*The protection necessary for the sanctity of individual life (and its integrity) depends in part on the strength of the ethical consensus of the medical and life-science professions and on the formation of a comparable ethical outlook among psychologists, social workers and related professions. It thus depends on the moral vigilance and responsibility of the universities and particularly of those who are in charge of training in biology, medicine, etc. It depends also on the vigilance of legislators and the courts.... The sanctity of individual life depends on public opinion.<sup>10</sup>*

*Without a widespread affirmation of the sanctity of life as a basic and guiding principle of social life, we will be hopelessly adrift.<sup>11</sup>*

And he tries to assure his readers that the kind of developments which occurred in Nazi Germany and Japan need not happen elsewhere.

*As long as a civil society endures, the civil authorities are reasonably humane and alert, and the present ethical traditions of the medical and scientific professions continue.<sup>12</sup>*

The wedge arguments against permitting any actions or policies that would undermine respect for the sanctity of life concern themselves with exactly the fragile conditions that Shils states--the "as long as" factors. His words were written in 1968 and already changes have occurred in the ethics of medicine and public opinion--open advocacy of abortion on demand, infanticide of defective newborns, living wills, changes in defining death to meet the need for organ transplants, exposures of inhumane medical experiments and now a cult of suicide and the right to die.

A. Kaplan in a concluding essay in this 1968 book had the following to say about American society:

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<sup>10</sup> Ibid., p. 36.

<sup>11</sup> Ibid., p. 37.

<sup>12</sup> Ibid., p. 38.

*What are problems of medical ethics with which (the symposium) we have been occupied...They are those that we would be coping with if we lived in a society which somehow feels that life is at best only a necessary evil. First is the problem of contraception--how to prevent life from coming into existence at all. If we do not succeed in that, we face the problem of abortion--how to destroy it once it has begun. Next we move to the problem of genetic engineering--how to reshape it in our own image, for apparently it is not quite acceptable as it is...And if all else fails, we come finally to the problem of euthanasia--how we can put an end to life which we have been powerless to prevent or improve upon.*<sup>13</sup>

*.....there is an irony in the fact that our deliberations on the sanctity of life take place against the background of a deep and widespread preoccupation with death that is characteristic of our culture.*<sup>14</sup>

*Our technology seems never to reach greater heights than when it is put to the service of human destruction.*<sup>15</sup>

*As long as a civil society endures, the civil authorities are reasonably humane and alert, and the present ethical traditions of the medical and scientific professions continue.*<sup>16</sup>

He went on to talk about the problem of war (now the acceptance by many of even nuclear war as possible and inevitable): the problem of wide spread starvation in the world (or as in Thailand, malnutrition); the problem of automobile safety (cars are the principle single cause of death in the prime of manhood); suicide which is on the increase, especially among young people---all evidences that in the United States people have become callow, hardened to accepting death, needless deaths, and not at all very concerned about the sanctity or preservation of life. Even science, biology (the name of life), he wrote, cannot hide from us that apparently a large part of the work of science is work of death—especially when the scientific values of prediction, efficiency and control of

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<sup>13</sup> Ibid., p. 154f.

<sup>14</sup> Ibid., p. 155.

<sup>15</sup> Ibid.

<sup>16</sup> Ibid., p. 156.

nature predominate over the claims of the sanctity and integrity of individual human lives and persons are not treated as ends in themselves, but merely as means. He concluded that, despite differences in religion or politics, we can all agree that life is to be sanctified “because for us, the living, it is the locus of value. If life is not sacred, nothing else could be.”<sup>17</sup> Since we have life, we have nothing to do but make the best of our lives; can we not accord this same privilege and responsibility to others?

The wedge arguments remind us that there is little enough conviction about the sanctity of life as it is in our societies and little zeal to preserve life given the many ways we already allow our fellow humans to die needless deaths. This is no time then in which to undermine further the general obligation to preserve life, especially in the medical profession whose role it is to be champions of life.

But there are other arguments that can be given against practices of hastening deaths by giving social sanction to suicide, or prematurely withholding or ceasing life-support systems or directly killing. There are, Beauchamp writes, two types of wrongly diagnosed patients (due to negligence or medical uncertainty). Some patients who are wrongly diagnosed as hopeless will survive even if treatments are stopped; other patients wrongly diagnosed as hopeless will only survive if the treatments are not stopped. If we have a rule which permits “allowing to die” under certain carefully formulated conditions, some patients may be lost in the second category, but if we have a rule which permits “mercy-killings” then patients will be sent to their deaths in the first category also.<sup>18</sup>

The reason most often given sanctioning suicide or in favor of active euthanasia (voluntary or involuntary) is that it shows more mercy or loving-kindness to help those suffering from unbearable or uncontrollable pain to end their lives quickly by suicide or direct killing than to let them linger on. But as we shall see in discussing the development of Hospice program, this advocacy of quick, supposedly, merciful endings to life to relieve pain diverts attention and resources away from other strategies and potentialities we already possess to see to it that no one need die in unbearable pain. We do possess the means to control suffering and the knowledge to maintain people without severe pain. There are only very exceptional cases, for example, accident victims hopelessly entangled in wreckage or fire victims unable to be moved, where the medical profession’s duty to relieve suffering might justify “mercy-killing” –or, at least, doctors

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<sup>17</sup> Ibid., p. 167.

<sup>18</sup> Beauchamp and Childress, *op. cit.*, p. 114.

administering sufficient dosages of pain-killers that death is hastened. But “hard cases make bad laws” –one cannot formulate rules for ordinary practice based upon infrequent emergency situations. The prohibition against the medical profession directly killing patients ought to be maintained, and in those rare instances where mercy-killing can be justified under exceptional circumstances, the courts should be left to decide whether mercy also ought to be shown to those who killed or assisted others to commit suicide out of compassion for their suffering.

Especially in regard to this argument that one is seeking to hasten the death of another in order to be merciful or show loving kindness, one has to be wary of paternalism and self-deception. People have different pain thresholds and psychological, emotional and spiritual factors play a great part in how much pain or suffering people can endure. There is some truth in what Nietzsche wrote, “The human spirit can endure any and all suffering if it can place a meaning on it.” We might think that another is suffering unendurable pain therefore ought to die because we are paternalistically imposing our values upon them. We would not want to go on living in such circumstances. But this does not mean that life, even a painful life, is meaningless to them. Secondly, the felt desire to end another’s suffering may derive from our own inability to cope with it, our own anguish in watching them suffer. We basically want to save ourselves from further suffering, not them.

Arthur Dyck is an ethicist decidedly opposed to “mercy-killing” which he thinks is what the public usually means when it uses the term “euthanasia.” To make a clear moral distinction between such “active killing of patients” and “permitting to die” he believes to be essential. Therefore, he proposed the use of the term “benemortesia” to talk about what we owe to the dying as humane treatment to permit them to die with dignity. He argues that there are four kinds of care to be given to patients who are considered to be imminently dying.<sup>19</sup>

1) Relief from pain. He argues that there are no legal, moral or religious objections to the administration of pain relief provided it is for that purpose and not for the purpose of killing anyone. This means that one does not knowingly give an overdose, but dosages only sufficient for the relief of pain—even when this sometimes means the shortening of the dying process. In fact, this is the position of the Roman Catholic Church.

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<sup>19</sup> Dyck’s essay in *Beneficent Euthanasia*, p. 117 – 129.

2) Relief of suffering. Suffering is not the same as pain. One of the major sources of suffering for dying people is loneliness and lack of companionship. To relieve suffering is to provide for these needs. There is also some evidence “that patients who know they are dying generally suffer less and are less inclined to ask for pain relief than those who do not know that they are dying”<sup>20</sup>—which recalls our arguments about truth-telling as good medicine.

3) A patient’s right to refuse treatment. Since “dying patients are also living patients, they retain the same right as everyone else voluntarily to leave the hospital or the refuse specific kinds of care.”<sup>21</sup> In the case of the irreversibly comatose and the severely brain-damaged, Dyck argues that since they cannot either assent to or refuse treatment, “there is a strong presumption to continue their support...until there is virtually no reasonable hope of sustaining life, apart from measures that go far beyond ordinary care.”<sup>22</sup> Benemortesia means not inducing death, but “as a last resort after making every effort to save and repair life, mercifully retreating in the face of death’s inevitability.”<sup>23</sup>

4) Universal health care. “In order to be merciful as well as just, no single person or family should have to bear alone the burden of extensive medical costs. It is notorious that poor people are more often and much sooner let go as dying persons than those who have more financial resources.”<sup>24</sup> The much higher mortality rates of the poor in infancy and throughout life are forms of involuntary euthanasia practiced upon them by society.

Dyck reminds us in this last point that *prima facie* duty of justice as well as fidelity to patient welfare and non—maleficence is very much involved in the issue of death and dying. He sums up his opposition to those who advocate suicide and mercy killing as “death with dignity” by arguing that the dignity that attaches to personhood by reason of the freedom we possess to make our own decisions and moral choices “includes the freedom to refuse noncurative, life-prolonging interventions when one is dying, but does not extend to taking one’s life or causing the death of another.”<sup>25</sup> While Kohl and Fletcher argue that there is such a thing as a life not worth living, a life that lacks dignity (for reasons of distress, illness, handicaps or sheer despair), Dyck argues that every life has some

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<sup>20</sup> Ibid.

<sup>21</sup> Ibid.

<sup>22</sup> Ibid.

<sup>23</sup> Ibid.

<sup>24</sup> Ibid.

<sup>25</sup> Ibid.

worth. His opponents tend to make the vague value of “human dignity”, as the capacity to choose and control life and death into an absolute; Dyck argues that human dignity is founded on what is right, merciful and just—moral obligations shared by the dying and those who care for them.

It can also be argued that the supposed rights to die—to commit suicide or to be killed—are too individualistically conceived. Deaths are not simply private affairs affecting the one individual. They occur within the human community and within the special relationships that people possess. One person’s death by suicide out of despair or suffering diminishes us all by undermining our own sense of the meaningfulness and sanctity of life and our courage to cope with life of which death is an inevitable part. A death does not occur in a social vacuum—it is the death of a parent, child, sister, patient. If rights claimed obligate others to act in certain ways, can by right people obligate us to stand aside while they kill themselves or are killed? Will this not work to undermine respect for life and for the principle of non-maleficence?

Many have written that the whole issue of the “right to die” or death with dignity” or mercy-killing” would not have emerged, if increasingly the setting in which most deaths occur were not our large, technologically equipped hospitals with their resources for keeping alive indefinitely, their research interest and their medical personnel as they are at present trained. Studies have indicated that many doctors, for example, by reason of both training and personalities tend to consider the dying patient as representing a personal failure of their skills and knowledge; they tend therefore to experience more “death denial” than other people, making them ill-at-ease with the dying and resistant to telling dying patients the truth about their condition. In general it has been said, dying patients in our large hospitals tend to be pushed aside and given less care. Because of these factors, in England and United States modern conventional hospitals are no longer believed by many to be the proper setting to ensure humane care of the dying. They believe that what we owe the irreversibly terminally ill are “human care, comfort, consolation and companionship” and help given to patients and their families in the grieving process which occurs before and after death. To these ends special institutions or special sections of hospitals known as Hospices have been established—now over 800 of them in the United States.<sup>26</sup> They are devoted to the full physical, psychological, social and spiritual care of the dying and their families. The specially trained personnel who staff Hospices are available on an out-patient basis also for those who would rather die at home amid familiar

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<sup>26</sup> Rossman, P., *Hospices* (New York: Fawcett Columbine, 1977). See also, *Hastings Center Report*, April, 1982.

surroundings. The doctors, nurses, spiritual counselors, social workers and volunteers who make up the team of Hospices specialists are especially trained to deal with all the kinds of suffering that people and families endure at the end of life—physical, mental, emotional, moral and spiritual. They have pioneered in pain-maintenance; through the use of-drugs, biofeed-back techniques, psychological counselling, etc., they have succeeded in demonstrating, not only that no one need suffer from unbearable pain relief which does not impair their faculties or cloud consciousness, but permits them to have meaningful lives to the end. In fact the Hospices movement has undermined one of the most powerful arguments used to justify all forms of euthanasia—including suicide, assisted suicide, hastening deaths or mercy-killing, namely, to spare patients and their families from unbearable suffering in the final stages of terminal illness. The success in pain relief and the atmosphere and policies of Hospices indicate that no one need die neglected, alone, shunted aside by doctors and nurses busy with the living, unconscious, hooked to machines, kept from their families—that death with dignity and humane treatment is still possible in our time. The question of the use of “extraordinary means” to keep alive does not arise in Hospices care, for the acceptance of death is one of the main tenets of this program when dying is the only option open.

It is the question of when to use “extraordinary” measures and when only ordinary care is justified which raises many ethical dilemmas in hospital settings. As Beauchamp indicates, the distinction between ordinary and “extraordinary” treatments (upon which the American Medical Society’s position is in part based) is too vague in practice and a moving target.<sup>27</sup> One year’s “extraordinary” measures to sustain life can become next year’s routine treatment as formerly experimental methods become accepted widely. He suggests that a better distinction is between optional and obligatory treatments: so-called ordinary care is understood to be mandatory, medically and morally required, while so-called extraordinary care would mean treatments which are morally optional or elective given the particular patient’s condition. To be obligatory, he suggests that treatments must offer a reasonable prospect of benefit to the patient and not involve excessive harm to the patient or anyone else. But if there is a reasonable hope of benefit, the amount of expense, pain, effort of medical personnel, etc. may be significant without being excessive. This means that the primary criterion to be used is patient benefit and other factors are only secondary considerations. It is competent and informed patients who ought to have the most to say about whether a treatment is to be considered obligatory or only optional because they are the one most vulnerable to harm. In the case of incompetent patients where

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<sup>27</sup> Beauchamp and Childress, *op. cit.*, p. 117 – 120.

others must decide, the criteria to be used to justify ceasing or withdrawing treatments as not obligatory are: 1) when there is no prospect of patient benefit; or 2) clear evidence that the patient is irreversibly dying. This means the use of all means to sustain or prolog life is not morally required when death is imminent: for example, resuscitation measures, respirators, hyperalimentation, etc., become optional. The best care of patients, that is optimal care, does not necessarily mean maximal care—the use of all possible measures to keep alive. A line should be drawn, on purely medical grounds, between treatments that prolong life or merely prolong the process of dying.

But what of cases in which the burden of treatments seems to outweigh the benefits for patients, e.g., comatose patients with seemingly irreversible loss of higher brain functions, cases where patients are conscious but so debilitated or mentally impaired that they cannot give informed consent, or cases of defective newborns? Now we are in the realm not only of purely medical decisions, about prolonging living or dying, but of judgements about the quality of life of those living under such conditions and whether, because of their present or future quality of life, therapeutic treatments ought to be withheld or stopped which would sustain that life. These decisions are about human value and individual worth; they are not purely medical judgements as such.

In the case of defective newborns, it has been argued that the criteria to be used in such decisions about when intensive care would be harmful and therefore not morally obligatory are: 1) the inability to survive infancy; 2) the inability to live without server pain; and/or 3) the inability to participate at least minimally in human experience. Or some have suggested the concept of “the injury of continued existence” which presupposes that life can be of such a negative value that “to do no harm” would require allowing to die.<sup>28</sup> But all these criteria are matters of value judgments, not purely medical judgments. Paternalism and self-deception can inform such judgments. Who is to decide that another’s life is not worth living? If we take just defective newborns, where do we draw the line—Tay-Sachs babies? Lesch-Nyhan? Spina befida babies? Downs Syndrome children? Beauchamp takes the position that in these and other cases, the basic presumption must be in favor of the prolongation of life; to assume otherwise is to violate the prima facie duty of non-maleficence. “Because of the possibility of error in diagnosis, prognosis and judgements about what is in the patient’s best interests, the prima facie duty to preserve life dictates erring on the side of sustaining life—at least in cases of doubt about the evidence.”<sup>29</sup> No one can say

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<sup>28</sup> Ibid., p.121.

<sup>29</sup> Ibid., p. 122f.

what is a meaningful human existence for anyone, except themselves. What would be agony to us, might be acceptable endurance for others. The lack of certain human abilities and awareness might make our lives seem pointless, but not necessarily the lives of others.

We are back to the issue of decisions to be made in terms of the “quality of life’ vs. “sanctity of life”. Ramsey fears that the practice of making decisions based on the “quality of life” to be sustained will move us in the direction of finding a policy of active involuntary euthanasia for unconscious or incompetent non-dying patients socially acceptable—a wedge argument. To avoid this, he maintains that we must hold the medical profession to the “undiminished obligation first of all to save life and second to use palliative treatments for non-dying patients where possible.”<sup>30</sup> Judgements based on the quality of life in the present or in the future are to be strictly avoided since they violate the principle of equality of life. He argues that the quality of life criteria “shifts the question from whether treatments are beneficial to patients to whether patients lives are beneficial to them”.<sup>31</sup> The fact that the practice of allowing even minimally defective newborn infants to die is increasingly widespread gives some weight to his wedge argument that quality of life judgements logically commit us to active, involuntary euthanasia for the non-competent, non-dying patients.

Beauchamp believes that criteria which are in part medical and in part value judgements on prospective quality of life can be stated with sufficient refinement to avoid the dangers foreseen in Ramsey’s wedge argument. For example, he maintains that the factor of retardation (unknowable at birth, in most instances) ought to be irrelevant in making decisions to withhold or stop treatment of newborns, but that such cases can be distinguished from anencephalic newborns whose lives ought not to be resuscitated or sustained. He agrees that only “patient-centered objectives” are relevant, in keeping with the medical profession’s fidelity to patient benefit, therefore, whether lives saved or sustained will be a burden to families or the society is not morally relevant when making decisions about incompetent patients—young or old. Only competent patients in accordance with their own value priorities can make factors, such as “the physical or mental burden involved on others, familial, social or economic concerns, or religious belief” relevant to their own decisions about refusing treatments.<sup>32</sup>

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<sup>30</sup> Ramsey, p. *Ethics at the Edges of Life* (New Haven : Yale University Press, 1978) p. 155.

<sup>31</sup> *Ibid.*, p. 172.

<sup>32</sup> Beauchamp and Childress, *op. cit.*, p. 125.

Beauchamp also argues that the distinction between withholding treatments and stopping treatments once started is morally irrelevant in deciding if a treatment is obligatory or optional.<sup>33</sup> Some of the most agonizing decisions that medical personnel face are ones involving the stopping of treatments which they had begun on newborns or the seriously ill which held out hope of preserving life. These seem much more emotionally difficult to deal with than decisions not to treat at all. Once having begun to treat there is the desire to go on to save at any cost; one experiences defeat and even guilt at stopping, at giving up. Yet, no matter how more heart-rending are these decisions. I think Beauchamp is correct, morally the criteria remain the same. No particular treatment as such can be said to be obligatory or optional; withholding or stopping any treatments depends upon the patient's condition and what would serve patient benefit. And in terms of competent patients, out of respect for their autonomy, what is obligatory treatment depends in part on the patient's own wishes.

But who decides for incompetent patients who cannot make their wishes known? Dr. Ray Duff has argued that the family ought to be the primary decision maker, in consultation with doctors, but finally responsible for deciding whether to treat, not to treat or to stop treatments. He maintains that family members can be expected to act in the best interests of patients and that they need a sense of control in the face of misfortune. His position would justify not treating the Down Syndrome babies with esophageal blockage if such is the parents' wishes. But isn't this position open to unacceptable abuses? Can family members always give impartial judgements? Can there not be cases of conflicts of interest here where family members decide in terms of what is good for them, rather than what is good for the patient? Family members can act paternalistically, imposing their own value perspective on the patient, or self-deceptively, thinking they are acting to save the patient from further suffering when they are really acting to protect themselves from further anguish. Or they may decide simply selfishly that it is in their own interests, to their own advantage, that patients die—and more quickly—to save money or to inherit money, for the sake of convenience and more leisure time. Doctors may abuse their positions of authority, but so might families if given sole power to decide life and death. How best to guard against all such abuses so that patients, young, disabled, old, sick or dying are not victimized?

It has been suggested that the decisions made for all incompetent patients be made serially and collectively in the hope of a more perfect justice. Because of imperfect medical knowledge and the frailty of even combined human wisdom, it cannot be guaranteed that decisions made for incompetent patients will always be

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<sup>33</sup> Ibid., p. 126.

in their best interests. For that matter, there is no guarantee that competent patients will always know what is in their own best interests and make treatment decisions wisely. The best we can hope for is that by following principles of right action, by establishing procedures to check flagrant abuses, we are coming as close as we can to doing “no harm” or preventing harm. What is clear is that doctors and nurses in accord with the principle of fidelity to patient welfare have a moral responsibility to participate in treatment or no treatment decisions and not simply assume the role of giving medical information or stand aside to allow families to have the final word. The duties of non-maleficence, beneficence and justice require health care professionals to prevent violations of the patient’s best interests and well-being which is clear from their professional codes.

Where there are family members present they ought to be first consulted, after careful explanations, about their wishes in regard to withholding or stopping treatments on incompetent patients since they are intimately involved. But if medical personnel have any doubts about their impartiality or conflicts of interests which would violate patient best interests, they ought to try to persuade the family to make a different decision. If they fail to change the minds of the family, they can invoke a special hospital ethics committee to mediate. And if that fails and it is appropriate, they can go to the courts for a legal decision to prevent patient harm. In cases where there is no family or the family is unconcerned with the fate of the patient, some hospitals have established the position of a “patient advocate” or ombudsman whose primary task it is to mediate between patients and hospital personnel when there is no one to speak for the patient and protect his interests. In other hospitals a special committee has been formed to make decisions regarding incompetent patients without family, a committee composed of members of the community—clergy, lawyers, social workers, teachers, etc., --as well as doctors to ensure an impartial decision about patient welfare.

To summarize: The whole area of death and dying today is filled with new ethical dilemmas. Here the prima facie duty of nonmaleficence is of central importance—that we prevent or remove further harm from those already harmed by defects, disabilities, severe pain and terminal illness. Nowhere else is the virtue of compassion more important. Doctors and nurses are required by their professional codes to do all they can to preserve and prolong life and not to hasten death or directly to end life. But for those who are, in the best medical judgement, in the process of irreversible dying, it is not required that doctors seek to sustain life indefinitely. What is owed to the dying which the Hospices programs are founded to provide is “care, comfort, consolation and companionship”. We have it within our power to allow people to die with dignity and without severe,

unbearable pain, therefore, most of the arguments for active euthanasia, mercy-killing, voluntary or involuntary, as a general practice are not persuasive. Fully competent patients have the right to refuse even life-preserving treatments, though their autonomy here can be overridden if their dying or deaths would be grossly unfair or seriously do harm to others, (or a case can be made out that soft paternalism is justified). Suicide or assisted suicide as a “right to die” cannot be absolute because people do not live alone but are members of communities who might be injured by their deaths or by a social policy that encourages such deaths. Above all, the welfare of incompetent patients unable to make life and death decisions for themselves must be carefully guarded. This is especially true of the treatment of defective newborns—who are living children. Those not facing inevitable death or not so grossly defective that they cannot enjoy life on some level deserve our loving care, humane maintenance and treatment.

In all decisions about death and dying, morally irrelevant factors, that is, social criteria, are to be avoided, for it is argued that in facing death we are all equal. Great care must be taken, that the procedures for decision-making take into account possible conflicts of interest (doctors seeking organs for transplants or families seeking to inherit, etc.) and therefore check abuses so that patients are not victimized. Finally, no practices or policies ought to be established which call into question the medical profession’s primary image and public trust that they are healers, dedicated to preserving and prolonging the life of all patients under their care, but when death becomes imminent they ought to become graceful acceptors of the inevitable and turn their full attention now to the compassionate care of the dying, their main concern to relieve the suffering of patients and families and ensure a “good death”.

