Euthanasia and assisted suicide – the illusion of autonomy
By Ole J. Hartling, M.D., D.M.Sc., former chairman of the Danish Council of Ethics.

Thank you for your call for evidence on The Scottish Parliament’s “End of Life Assistance Bill”. The reason for my answering your call as a Danish doctor is that should such a bill be passed in Scotland it may be used as a “benchmark” by other legislators in other countries to take similar initiatives.

Both as a physician and a worried citizen I think the drafted bill will not only be unnecessary (considering modern palliative treatment possibilities) but also detrimental to patients, doctors, and society.

In the following euthanasia and assisted suicide are taken together since the same arguments and mechanisms concerning suffering and putative autonomy will be relevant. Moreover, in e.g. Dutch jurisprudence the two are looked to be variants of the same matter. Hence, when I write euthanasia for short it should read “euthanasia and assisted suicide”.

In this letter I will contend the two typical arguments for euthanasia.

Arguments for euthanasia

Two arguments for euthanasia – i.e. for legalising euthanasia and assisted suicide – are constantly put forward. One is to respect the patient’s autonomy and the other is to avoid unnecessary or unbearable suffering. The second argument can be cloaked in words such as “letting die with dignity”. In my view the second argument is closely linked to the first. I shall deal with the arguments for legalising euthanasia from an ethical and philosophical point of view.

The concept of autonomy provides the seductively simple and lucidly logical central tenet of the proponents of euthanasia. It is based on the conviction that modern man is self-reliant. A person’s decisions can be taken only by himself and by no one but himself. It is generally thought that a competent person can always exercise autonomy, i.e. under any circumstances although this may not be the case (see e.g. Beauchamp and Childress 1994). According to the principle of autonomy (and according to usual medical law) the patient has a right to refuse a specific medicine, i.e. he has an unlimited right not to undergo a treatment even if the treatment is lifesaving. Consequently, it must also be the patient’s indisputable right to choose his or her own death. So the logic goes: Why should autonomy not be in force as regards the most important matter for the patient: the right to one’s own life and death, just as the patient’s autonomy is valid in all other connections? The logic is plausible and we physicians are confronted by this logic.
However, when something important appears to be obvious and logical and yet remains a question of controversy it may be worthwhile to look into it more closely. Logic may fail when you deal with the big questions of life. Some may add that ethical issues can never be solved through logic.

So let us consider the autonomy - consider how autonomous the autonomy is. First, the unrestricted right of a patient to refuse any treatment even if it be lifesaving does not imply a right to have any treatment, which the patient may desire. The patient has a right to be treated but does not have a right to demand any treatment to the extent that another person is obliged to comply with this right. The patient has autonomy but does not have autocracy. In other words, the patient has a right to refuse any interference with his soul and body but does not have a right to demand any interference with his soul and body. To be specific: It is not a violation of a patient’s autonomy to refuse to kill him or her. Therefore:

1. Autonomy is not synonymous with autocracy and it is not a violation of autonomy to refuse to kill the patient.

In the question of euthanasia autonomy is generally understood in the same way as autonomy with respect to one’s own course in life. Most people can to a great extent choose their education, work, friends, way of living, religion etc. Or at least – which is important – it is felt to be so. Self-determination about the end of life seems to be a mere continuation of an ideology and a conception that is characteristic of most people’s lives. This is the seductive argument. If you are master of your own life, why should you not be master of your own death?

It must however be remembered that this particular choice – the choice of one’s own death – is often made on a background of suffering, despair and hopelessness. Even an otherwise competent person may not be competent in deciding on his own death, because of despair, fear or perhaps a feeling of being weak, superfluous and unwanted. This is a very uncertain base for decision-making, especially in the irrevocable decision of euthanasia. Hence the choice of one’s own death is thoroughly unlike most other choices that are usually connected with the concept of autonomy.

Competent healthy people do not imagine that they can be in a situation where they cannot decide for themselves or where they do not want to decide. A patient in agony may be competent but he is not in a balanced state. A Dutch investigation that scored the psychological status of patients who requested euthanasia showed that very few of them were in a state of balanced self-determination. Most patients – more than 95% - were afraid, depressed or desperate. (Zylicz 2000)
2. It is questioned whether autonomy with respect to one’s own death can be exercised freely at all in a situation of suffering, despair and hopelessness.

Any decision involves responsibility. To what should the patient attach importance when she or he decides not to live any longer? A competent person usually makes choices in a responsible way and after due consideration; a 'good' decision should consider and respect the wishes and feelings of others. This will be no less the case in making a decision on the so-called free choice of euthanasia. I believe that there are people who would be able to make such a choice without letting him- or herself be influenced by others. Such people are undoubtedly strong personalities. But what about the less strong? Thus 'normal' behaviour in decision making will only add to the tendency of the already depressed person to feel a burden on his family, the staff, and even on society. That means that the very possibility of this decision forces the patient to consider whether he or she is a burden. In other words, it is the "right to be a burden" that is at stake should euthanasia be legalised. (see also The Danish ethical Council, 2003).

3. Autonomy with respect to the decision of one’s own death is not exercised free of consideration of others.

Can a person's decision on euthanasia be autonomous in the sense that it is voluntary? If euthanasia were legal everybody would be conscious of this option: the patient, the doctor, the family, and the nursing staff. Thus there could be an indirect pressure on the patient to make a decision. The choice is meant to be free but the patient is not free not to make the choice at all.

In some of the poor third-world countries you can sell for example one of your kidneys for money, which can be used for a dowry, seed corn, food etc. We know that this happens. So what is the problem? The contention might be that an individual should have autonomy in any case. He is free to do with his own kidneys as he pleases, isn't he? Is it not his own free choice? One answer is: The task of the community is to protect its weaker members. Society should not give its members every possible option including those that individuals ought to be protected against.

The Dutch physician Richard Fenigsen refers to a wife who no longer wished to care for her sick husband, and "offered him a choice between euthanasia and admission to a home for the chronically ill; the man, afraid of being in unfamiliar surroundings and in the hands of strangers, chose to be killed." That was his free choice. (Fenigsen 1989)

4. If the patient can freely choose euthanasia, she or he is not free not to make the choice.

An individual who uses his self-determination and chooses euthanasia precludes himself from determining or choosing anything thereafter. When it comes to death one can only use one's self-determination by giving it up forever. Daniel Callahan points to the analogy that self-determination
historically excluded the right to become voluntarily the slave of another. (Callahan 1989) He quotes the philosopher John Stuart Mill, who provides a compelling reason: “By selling himself for a slave a person abdicates his liberty; he forgoes any future use of it beyond that single act... The principle of freedom cannot require that he should be free not to be free. It is not freedom to be allowed to alienate freedom.”

5. From a philosophical point of view, autonomy cannot include giving up autonomy.

Not only is there a “fundamental discrepancy between the uncertainty of human and medical judgements, which are fallible, and the deadly certainty of the act.” (Fenigsen 1989), but self-determination is also halved with respect to one’s own death. We may decide to die if we do not want to live, but we cannot decide to live when we are about to die. The illusion may be that you can choose to die but in fact both birth and death are unavoidably a part of our condition.

6. Autonomy with respect to one's own death is halved: you can choose to die if you don’t want to live, but you cannot choose to live if you are about to die.

Autonomy is the inviolable principle of today within health care whereas paternalism is denounced. It is, however, not certain that the concept of euthanasia should always be looked upon as respect for an autonomous choice. A Norwegian study of the position of physicians concerning euthanasia revealed that physicians with the most paternalistic attitudes towards patient participation in medical decisions also held the most liberal attitudes towards euthanasia. (Førde et al. 1997) It looks like a paradox inasmuch as it is precisely autonomy that is maintained to be respected in euthanasia. But indeed the motive to give the patient the possibility of choosing euthanasia - or even encourage the patient directly or indirectly – may be a (paternalistic) belief that it is in the best interest of the patient to die. In the debate on euthanasia the view has been expressed that euthanasia should also be possible without the patient’s explicit request. The argument went that it can be too distressing for a patient to take a decision on euthanasia. It is more merciful to kill the patient surreptitiously, when it is after all in the best interest of the patient. A recent survey in Denmark showed that some people hold this attitude. What happened to autonomy?

7. Autonomy in connection with euthanasia may be disguised paternalism.

In the decision on euthanasia self-determination is not the only parameter. In other words it is not enough to say: “The patient asked me.” It is also required that the patient’s quality of life is considered to be sufficiently low. Thus the value of life is made relative and open to judgement. This means that the justification for “voluntary euthanasia” is based more on the fact that certain lives are not worth living than by the fact that there is a request.
8. **Patient autonomy is not the only or even the most important parameter in the decision on euthanasia.**

This leads to the other frequent argument for euthanasia namely that of unnecessary or unbearable suffering. This argument is also plausible. When life becomes unbearable and the agony insupportable it seems that there must be an easier way of getting around the suffering.

Here it must be remembered that euthanasia is not taking away the pain from a patient, it is taking the patient away from the pain. It is not alleviating the suffering of a person, it is removing the person who suffers. It is killing the pain by killing the patient.

9. **A choice that seeks to alleviate suffering and thus to improve life by annihilating it is in fact irrational.**

“When caring for a dying patient, the doctor can be overwhelmed by the patient’s suffering, along with their own sense of impotence and helplessness. The wish for relief from suffering for all involved may even include a wish for the patient to die.” (Kelly and Varghese 1998) Although euthanasia may be the poor response to suffering, it gives at least some power in the otherwise frustrating powerlessness felt in the face of terminal illness. In a situation where you do not any longer have the power to prevent death then the possibility of euthanasia will at least leave you the power to decide precisely when death should take place.

**Dying with dignity**

Avoiding unnecessary suffering is often expressed by saying that euthanasia allows death to occur when there is still dignity. It is “to enable a person to die with dignity…” as it says in the bill. I want to go into the notion of ‘dying with dignity’ because by using the term ‘dignity’ proponents of euthanasia would seem to hold a good hand. In the American state of Oregon a “Death with dignity act” has been adopted (1997) (Chin et al. 1999) A clinic for assisted suicide in Switzerland is called Dignitas – the Latin word. A society for promoting euthanasia in Denmark calls itself “A Dignified Death”, and states (as in the bill) that its aim is that people should be enabled to ‘die with dignity’. The argument for euthanasia is not only made convincing it is also seductive. The words ‘dignity’ or ‘dignified’ in connection with euthanasia have been chosen deliberately because it is then implied that euthanasia is the more dignified way to die, and because we all favour human dignity and agree that dying with dignity is right and must be achieved.

Indeed, the word dignity has only positive connotations because deep within us there is an idea of what dignity is. That a human being can choose and decide for himself, and that he is accountable to somebody or something and that he has responsibilities are all connected with dignity. Hence dignity is closely linked to the concept of autonomy and reflects the belief that each and every human being is a unique person whose decisions cannot be made by others nor be replaced by others’ decisions.
Was it not in the highest degree dignified when a group of four chaplains during the Second World War voluntarily abandoned a sinking lifeboat and drowned so that the other passengers could survive?

This shows that you can give your life for somebody or something. The dignity is based on the fact that there is something that is more valuable than life. Life is too good to throw away but it is not too good to give away. On the contrary, life is best when it is given away either in one final act or during the course of one’s whole life. The paradox about life is that it can only be given away when it is highly prized. When it is despised then it cannot be given away but may indeed be thrown away, which is something quite different. Only because life is great can it be great to give life away.

In the argument for legalising euthanasia and assisted suicide the concept of dignity has been changed – almost imperceptibly, but radically changed – so that the meaning becomes the opposite. To “die with dignity” now is not to give away life because it is of high value, but to get rid of it because it is of low value. As much as it is full of dignity to give one’s life it may be quite the reverse of dignity to define that the life of a human being is so poor that it is not worthwhile preserving it.

10. Death with dignity cannot be reconciled with throwing life away because it is despised.

If we maintain that dignity is connected with and even dependent on autonomy and self-determination, then it follows that we connect loss of autonomy, competence, and control with not having dignity. It is necessary to emphasize that you do not lose dignity by being needy and by being cared for. A baby cannot make autonomous choices, it does not have self-determination, and it needs care, indeed it would not survive if it were not taken care of. But it does have dignity.

11. Dignity is not based on autonomy alone.

All human beings have dignity but the people who surround a human being such as relatives and nursing staff may have a strong influence on how a person sees himself and his life. A patient can feel abandoned, discarded, and not wanted, and may therefore seek his own death. Therefore, a weak and despairing patient may accept an offer to be helped to die. Dignity will not diminish but self-esteem may dwindle because the latter is dependent on how you are regarded.

The implicit or explicit offer of euthanasia and assisted suicide to a weak patient may in itself be a repudiation and may convey a message to the patient that he is superfluous and unwanted. This may poison the patient-doctor relationship. The very assessment of the quality of life of a patient may bring about a reduction of its quality.
12. In conclusion, my contention is that autonomy is an illusion in the case of euthanasia and assisted suicide. A patient in great suffering may be more in need of compassion, care, and love than of someone kindly offering to help end his life if that is what he chooses at the point when others deem his condition to be sufficiently desperate.

Bibliography

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