

Oregon Health Authority Reveals Hidden Problems with the Oregon Assisted Suicide Model

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There is currently a discussion about medically assisted death here in Sweden. Advocates consider it a necessary right for certain patients whose palliative care does not help to relieve symptoms—a last resort for extreme cases. The idea presented to the public in opinion polls is that it should only apply to people with incurable diseases, those who have nothing else to look forward to but an imminent death.

The Swedish advocates recommend a law modeled on Oregon's Death with Dignity Act (DWDA). They explain to us Swedes that the Oregon practices are protected by strict safeguards which only allow people with an incurable and irreversible illness that will, within reasonable medical judgment, result in death within six months.

They assure us that it is a robust, well-proven and well-researched system that does not show any vulnerability to the development of a slippery slope. This is also the message that has been promulgated in Sweden by the Swedish National Council on Medical Ethics. In a recently published report, "Assisted Death: A Knowledge Compilation," the Council notes that Oregon's regulations have remained unchanged since the law was introduced. This, they argue, "negates the assumption that a slippery slope will occur, in the sense that expansion of the regulations for eligibility to more and more patients would be inevitable if death aid is allowed."

As a basis for their reassurance of no slippery slope in the Oregon model, the authors of the Swedish report note that there is one question that is "the crucial issue": **is anyone with a non-terminal, chronic disease granted medical assisted death?**

The report authors satisfy themselves and their readers: "When the study [resulting in the report] was made, there was no evidence that assisted death would have been granted to any patient in Oregon, who has not been judged by two doctors to have a maximum of six months of remaining life expected."

For Swedish readers of the report, this feels reassuring—but it states elsewhere that the six-month limit on expected survival time applies, **"if no treatment is given to slow down the course of the disease"** referring to a conversation with Professor Linda Ganzini, Oregon Health and Science University (emphasis added).

As I read this, I got the feeling that this interpretation of the six-month limit might complicate the whole idea that the law only applies to the "untreatable" sick where nothing could be expected to extend life beyond six months. Seeking clarification, I sent the following question to the Oregon Health Authority (DWDA.INFO@dhsosha.state.or.us):

1. In the law, "terminal disease" is defined as an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment (in the opinion of the patient's attending physician and consulting physician), produce death within six months.

Is this rule interpreted as "without administration of life-sustaining treatment"?

Craig New, Research Analyst, Oregon Health Authority, Center for Public Health Practice, Public Health Division, answered the question on 4 December, 2017:

- A. ...your interpretation is correct. The question is: should the disease be allowed to take its course, **absent further treatment**, is the patient likely to die within six months?
(emphasis added)

So under Oregon's assisted death law, one can achieve the status of being "incurably" sick even if the disease can be treated! Thus, all diseases which, **without treatment**, are expected to lead to death within six months are considered to be **incurable** and therefore qualify for assisted death. This is in fact an alteration of the traditional meaning of the concept of "incurable," which usually denotes an untreatable condition. Consequently, a far larger group of patients qualifies for medically assisted death than just the extreme cases for which the law was originally said to apply.

On further reflection, this subtle, new interpretation of "incurable" has profound consequences. In most Western societies, it is indeed an accepted right for patients to refrain from medical treatment. Since assisted death laws claim to be introduced with the purpose of expanding, not limiting, the autonomy and self-determination of the patient, therefore, the following questions arise:

2. If the doctor suggests, to an eligible patient, a treatment that possibly could a) prolong life, or b) transform a terminal illness to a chronic illness, or c) even cure the disease—and if the patient doesn't give his/her consent to the proposed treatment is he/she still eligible to take use of the Act?
3. If a patient with a chronic disease (for instance, diabetes) by some reason decides to opt out from the life-sustaining medication/treatment and by doing so is likely to die within 6 months, thereby transforming the chronic disease to a terminal disease—does he/she then become eligible to take use of the act?

On 6 December, 2017, Craig New gave the following answers to these questions:

- A. Interesting questions. While this is not addressed specifically in the law, the answer in both cases is **yes**—those patients would qualify.

The law is best seen as a permissive law, and states only that patients must have a terminal illness with six months or less to live. It does not compel patients to have exhausted all treatment options first, or to continue current treatment. It is up to the patient and doctor to discuss disease and treatment options. **But if the patient decides they don't want treatment, that is their choice.** (emphasis added)

My suspicions were thus confirmed by this officially sanctioned interpretation of "incurably" ill! A patient who has good or very good prospects of living for an additional number of years can therefore qualify for death assistance simply by refraining from curative treatment. In fact, it allows a sanctioned path to suicide, assisted by a physician, for **anyone** with a chronic illness who is likely to die within six months if they chose to stop treatment. This means that such a patient's decision to stop treatment will make them eligible for a lethal prescription from a physician.

A patient's motivation to refrain from treatment could be anything. One could fear the possibility of side effects or future disabilities. It could be a parallel life crisis that is indirectly or not linked at all to the disease. For example, a cancer patient who, due to her lost vitality, is abandoned by her partner and in her grief over this loss would rather die than fight the disease. A person, exhausted from his dependence on dialysis, terminates treatment and thus becomes eligible for assisted death. A young diabetic, in the despair of a broken relationship, wants to die and stops insulin so as to be able to obtain legal suicide assistance.

In such situations, an assisted suicide, advertised as a "comfortable falling asleep" may be a very attractive resort, an act that, due to legalization, has become socially accepted. However, if assisted

death is not available, it is more likely that patients will choose to undergo treatment—with the possible result that they experience an additional number of good years, in some cases after adaptation to new conditions. For a dead patient, that possibility ceases to exist.

Was it really this interpretation of "incurable" the voters said yes to in the Oregon Ballot Measure 16 (1994)? Is it not likely that they understood "incurable" to mean incurable in the obvious sense that the disease cannot be cured, and even with state-of-the-art treatment, death is likely imminent within six months? In order to bring clarity to the issue, I wondered how the term was defined when the Oregon law was presented in the 1994 ballot. I happened to find the "State of Oregon Official Voters' Pamphlet November 1994." From page 123 I read about Measure 16 and found in the Definitions section that "terminal disease" was defined as an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months. There was no definition in the pamphlet of "incurable and irreversible disease."

It seems to me the most straightforward and immediate interpretation should be a disease for which there is no treatment or medication, i.e. that all hope is gone.

Looking at the "State of Oregon Official Voters' Pamphlet November 1997" Measure 51 about repealing DWDA according to the previous Measure 16, I could not find among the Arguments in favour of repealing the DWDA any suggestions that "terminal disease" could be interpreted wider than the normal interpretation as stated above.

The fact that these laws are being promoted everywhere with the assurance that they will only apply to incurable diseases where death is expected to occur within six months—no matter what treatment might be tried, the conventional definition of "incurable"—indicates clearly that the voters in Oregon were deceived and so are many of those who vote yes to any law modeled after Oregon's.

An extension of the proposed range of the law is possible through this new interpretation of "incurable." Is this a slippery slope in the sense that there is a progressive enlargement of this concept? I suggest the answer is YES based on the fact that when the law was introduced, the impression was given that the usual and more obvious interpretation of "incurable" applied. But since the term was not clearly defined, a slippery slope was deceptively hidden in the law.

Worried about my discovery of how widely these laws are applied, some related issues began to rankle me and the following questions arose:

4. If the doctor suggests an eligible patient a treatment that could possibly a) prolong life, or b) transform a terminal illness to a chronic illness, or c) possibly cure the illness—and if the patient's health care provider/insurance company is not willing to pay for the proposed treatment—is the patient still eligible take use of the Act?
5. If a patient with a chronic disease (for instance diabetes) making the patient dependent on treatment/medication—and the patient's health care provider/insurance company is not willing to pay for the treatment/medication whereby the patient is likely to die within 6 months, does the patient then become eligible to take use of the Act?

Craig New answered these new questions on 15 December, 2017:

- A. In your two examples, both patients would qualify for the DWDA. Patients suffering from any disease (not just those that typically qualify one for the DWDA) may not be able to afford some treatments or medication, and may choose not to pursue some treatments or take some medication for personal reasons. This is the patient's decision and the law does not compel them to do otherwise. If the patient does not receive treatment or medication (for whatever reason) and is left with a terminal illness, then

s/he would qualify for the DWDA. **I think you could also argue that even if the treatment/medication could actually cure the disease, and the patient cannot pay for the treatment, then the disease remains incurable.** (emphasis added)

This information was deeply worrying to me. Could an insurance company become more inclined to deny life-sustaining or even curative treatment in favor of a much cheaper and supposedly humane and dignified alternative in the form of assisted suicide? In this light, assisted suicide laws of the Oregon type are potentially fatal to patients who could respond to treatment if given the opportunity. Keep in mind that these laws are being sold as a means of increasing the options for these patients, giving them more choice, not less or none at all. With a modulating interpretation of "incurable" arising from these laws, in the long run, the choices will be limited to committing suicide because they are denied treatment.

It seems to be the same with the assisted death law recently passed in the state of Victoria, Australia, which used the Oregon model. Debates that preceded the decision were said to be extensive and emotionally charged. Hesitant parliamentarians were convinced by a tightening of the safeguards, resulting in what has been described as the strictest law for physician-assisted suicide in the world. To qualify under this supposedly strict law:

"the person must be diagnosed with a disease that is incurable, progressive, and expected to lead to death within six months and which causes a suffering to the person who cannot be relieved in a manner that the person considers to be acceptable,"

The language gives a convincing impression of a patient incurably sick beyond all hope, but since the key term "incurable" is not defined anywhere, this "strict" law is wide open to the same novel interpretation as the Oregon law. This opportunity for "interpretation creep" is also facilitated by the principles of patient autonomy laid down in the law's preamble:

Principles 5 (h): "individuals are entitled to genuine choices regarding their treatment and care"

In summary, assisted death laws à la Oregon give the impression of being responsible and restrictively designed; but it is a deception. Since "incurable" is not defined but given an open interpretation, these laws apply to a wider population of patients. Those who would survive with treatment can convert themselves to a terminal state by refraining from treatment for any reason whatsoever. Alternatively, they may be forced into a terminal state by being denied treatment through lack of access to state-of-the-art treatment, or denial of insurance coverage. By these pathways, patients could end up with two doctors deciding that they have a maximum of six months left to live thus declaring them legally eligible for assisted death. The original vision that the law should only apply to "untreatable" illness with six months to live is lost.

We need to reconsider the significantly expanded dimensions as to who qualifies for assisted suicide under the Oregon model. The scenario being presented in the polls and in propaganda by advocates is deceptive. Proponents want to sell the Oregon model along with the assurance that medically-assisted suicide only applies to dying patients where all hope is lost. But it is completely misleading. Surely vulnerable people in Sweden and all over the world deserve better than laws with such inherent dangers hiding beneath the surface.