Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls

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ABSTRACT

Euthanasia or assisted suicide—and sometimes both—have been legalized in a small number of countries and states. In all jurisdictions, laws and safeguards were put in place to prevent abuse and misuse of these practices. Prevention measures have included, among others, explicit consent by the person requesting euthanasia, mandatory reporting of all cases, administration only by physicians (with the exception of Switzerland), and consultation by a second physician.

The present paper provides evidence that these laws and safeguards are regularly ignored and transgressed in all the jurisdictions and that transgressions are not prosecuted. For example, about 900 people annually are administered lethal substances without having given explicit consent, and in one jurisdiction, almost 50% of cases of euthanasia are not reported. Increased tolerance of transgressions in societies with such laws represents a social “slippery slope,” as do changes to the laws and criteria that followed legalization. Although the initial intent was to limit euthanasia and assisted suicide to a last-resort option for a very small number of terminally ill people, some jurisdictions now extend the practice to newborns, children, and people with dementia. A terminal illness is no longer a prerequisite. In the Netherlands, euthanasia for anyone over the age of 70 who is “tired of living” is now being considered. Legalizing euthanasia and assisted suicide therefore places many people at risk, affects the values of society over time, and does not provide controls and safeguards.

KEY WORDS

Euthanasia, physician-assisted suicide

1. INTRODUCTION

Euthanasia is generally defined as the act, undertaken only by a physician, that intentionally ends the life of a person at his or her request. The physician therefore administers the lethal substance. In physician-assisted suicide (PAS) on the other hand, a person self-administers a lethal substance prescribed by a physician.

To date, the Netherlands, Belgium, and Luxembourg have legalized euthanasia. The laws in the Netherlands and Luxembourg also allow PAS. In the United States, the states of Oregon and Washington legalized PAS in 1997 and 1999 respectively, but euthanasia remains illegal. The situation in the state of Montana is currently unclear; a bill legalizing PAS was passed by the state legislature in 2010, but was recently defeated by the state’s Senate Judiciary Committee.

In the Netherlands, euthanasia and PAS were formally legalized in 2001 after about 30 years of public debate. Since the 1980s, guidelines and procedures for performing and controlling euthanasia have been developed and adapted several times by the Royal Dutch Medical Association in collaboration with that country’s judicial system. Despite opposition, including that from the Belgian Medical Association, Belgium legalized euthanasia in 2002 after about 3 years of public discourse that included government commissions. The law was guided by the Netherlands and Oregon experiences, and the public was assured that any defects in the Dutch law would be addressed in the Belgian law. Luxembourg legalized euthanasia and PAS in 2009. Switzerland is an exception, in that assisted suicide, although not formally legalized, is tolerated as a result of a loophole in a law dating back to the early 1900s that decriminalizes suicide. Euthanasia, however, is illegal. A person committing suicide may do so with assistance as long as the assistant has no selfish motives and does not stand to gain personally from the death. Unlike other jurisdictions that require euthanasia or assisted suicide to be performed only by physicians, Switzerland allows non-physicians to assist suicide.

In all these jurisdictions, safeguards, criteria, and procedures were put in place to control the practices, to ensure societal oversight, and to prevent euthanasia and PAS from being abused or misused. Some criteria
and procedures are common across the jurisdictions; others vary from country to country. The extent to which these controls and safeguards have been able to control the practices and to avoid abuse merits closer inspection, particularly by jurisdictions contemplating the legalization of euthanasia and PAS. The present paper explores the effectiveness of the safeguards and the “slippery slope” phenomenon.

2. SAFEGUARDS AND THEIR EFFECTIVENESS

2.1 Voluntary, Written Consent

In all jurisdictions, the request for euthanasia or PAS has to be voluntary, well-considered, informed, and persistent over time. The requesting person must provide explicit written consent and must be competent at the time the request is made. Despite those safeguards, more than 500 people in the Netherlands are euthanized involuntarily every year. In 2005, a total of 2410 deaths by euthanasia or PAS were reported, representing 1.7% of all deaths in the Netherlands. More than 560 people (0.4% of all deaths) were administered lethal substances without having given explicit consent. For every 5 people euthanized, 1 is euthanized without having given explicit consent. Attempts at bringing those cases to trial have failed, providing evidence that the judicial system has become more tolerant over time of such transgressions.

In Belgium, the rate of involuntary and non-voluntary euthanasia deaths (that is, without explicit consent) is 3 times higher than it is in the Netherlands. (“Involuntary euthanasia” refers to a situation in which a person possesses the capacity but has not provided consent, and “non-voluntary euthanasia,” to a situation in which a person is unable to provide consent for reasons such as severe dementia or coma). A recent study found that in the Flemish part of Belgium, 66 of 208 cases of “euthanasia” (32%) occurred in the absence of request or consent. The reasons for not discussing the decision to end the person’s life and not obtaining consent were that patients were comatose (70% of cases) or had dementia (21% of cases). In 17% of cases, the physicians proceeded without consent because they felt that euthanasia was “clearly in the patient’s best interest” and, in 8% of cases, that discussing it with the patient would have been harmful to that patient. Those findings accord with the results of a previous study in which 25 of 1644 non-sudden deaths had been the result of euthanasia without explicit consent.

Some proponents of euthanasia contend that the foregoing figures are misrepresentative, because many people may have at some time in their lives expressed a wish for or support of euthanasia, albeit not formally. The counterargument is that the legal requirement of explicit written consent is important if abuse and misuse are to be avoided. After all, written consent has become essential in medical research when participants are to be subjected to an intervention, many of which pose far lesser mortality risks. Recent history is replete with examples of abuse of medical research in the absence of explicit informed consent.

2.2 Mandatory Reporting

Reporting is mandatory in all the jurisdictions, but this requirement is often ignored. In Belgium, nearly half of all cases of euthanasia are not reported to the Federal Control and Evaluation Committee. Legal requirements were more frequently not met in unreported cases than in reported cases: a written request for euthanasia was more often absent (88% vs. 18%), physicians specialized in palliative care were consulted less often (55% vs. 98%), and the drugs were more often administered by a nurse (41% vs. 0%). Most of the unreported cases (92%) involved acts of euthanasia, but were not perceived to be “euthanasia” by the physician. In the Netherlands, at least 20% of cases of euthanasia go unreported. That number is probably conservative because it represents only cases that can be traced; the actual number may be as high as 40%. Although reporting rates have increased from pre-legalization in 2001, 20% represents several hundred people annually.

2.3 Only by Physicians

The involvement of nurses gives cause for concern because all the jurisdictions, with the exception of Switzerland, require that the acts be performed only by physicians. In a recent study in Flanders, 120 nurses reported having cared for a patient who received life-ending drugs without explicit request. Nurses performed the euthanasia in 12% of the cases and in 45% of the cases without explicit consent. In many instances, the physicians were absent. Factors significantly associated with a nurse administering the life-ending drugs included the nurse being a male working in a hospital and the patient being over 80 years of age.

2.4 Second Opinion and Consultation

All jurisdictions except for Switzerland require a consultation by a second physician to ensure that all criteria have been met before proceeding with euthanasia or PAS. In Belgium, a third physician has to review the case if the person’s condition is deemed to be non-terminal. The consultant must be independent (not connected with the care of the patient or with the care provider) and must provide an objective assessment. However, there is evidence from Belgium, the Netherlands, and Oregon that this process is not universally applied. In the Netherlands, for example, a consultation was not sought in 35% of cases of involuntary euthanasia. In 1998 in the
Netherlands, 25% of patients requesting euthanasia received psychiatric consultation; in 2010 none did 19. Moreover, non-reporting seems to be associated with a lack of consultation by a second doctor 14.

In Oregon, a physician member of a pro-assisted-suicide lobby group provided the consultation in 58 of 61 consecutive cases of patients receiving PAS in Oregon 17. This raises concerns about the objectivity of the process and the safety of the patients, and raises questions about the influence of bias on the part of these physicians on the process.

Networks of physicians trained to provide the consultation role when euthanasia is sought have been established in the Netherlands (Support and Consultation on Euthanasia in the Netherlands) and Belgium [Life End Information Forum (LEIF)] 18. Their role includes ensuring that the person is informed of all options, including palliative care. However, most LEIF physicians have simply followed a 24-hour theoretical course, of which only 3 hours are related to palliative care, hardly sufficient to enable a LEIF member to provide adequate advice on complex palliative care needs 19. The development of expertise in palliative care, as in any other specialty, requires a considerable amount of time. In the United Kingdom, it involves a 4-year residency program, and in Australia and the United States, 3 years.

Oregon requires that a patient be referred to a psychiatrist or psychologist for treatment if the prescribing or consulting physician is concerned that the patient’s judgment is impaired by a mental disorder such as depression. In 2007, none of the people who died by lethal ingestion in Oregon had been evaluated by a psychiatrist or a psychologist 20, despite considerable evidence that, compared with non-depressed patients, patients who are depressed are more likely to request euthanasia and that treatment for depression will often result in the patient rescinding the request 21-23. In a study of 200 terminally ill cancer patients, for example, the prevalence of depressive syndromes was 59% among patients with a pervasive desire to die, but only 8% among patients without such a desire 21. Despite that finding, many health professionals and family members of patients in Oregon who pursue PAS generally do not believe that depression influences the choice for hastened death 24.

A recent Oregon-based study demonstrated that some depressed patients are slipping through the cracks 25. Among terminally ill patients who received a prescription for a lethal drug, 1 in 6 had clinical depression. Of the 18 patients in the study who received a prescription for the lethal drug, 3 had major depression, and all of them went on to die by lethal ingestion, but had been assessed by a mental health specialist.

There is evidence, therefore, that safeguards are ineffective and that many people who should not be euthanized or receive PAS are dying by those means.

Of concern, too, is the fact that transgressions of the laws are not prosecuted and that the tolerance level for transgressions of the laws has increased. Moreover, as the next section will explore, the boundaries of what constitutes “good” practices with respect to euthanasia and PAS continue to change, and some of the current practices would just a few decades ago have been considered unacceptable in those jurisdictions that have legalized the practices.

3. THE “SLIPPERY SLOPE” ARGUMENT

The “slippery slope” argument, a complex legal and philosophical concept, generally asserts that one exception to a law is followed by more exceptions until a point is reached that would initially have been unacceptable. The “slippery slope” argument has, however, several interpretations 26, some of which are not germane to the euthanasia discussion. The interpretations proposed by Keown in 2002 27 appear very relevant, however. He refers to these collectively as a “practical slippery slope,” although the term “social slippery slope” may be more applicable. The first interpretation postulates that acceptance of one sort of euthanasia will lead to other, even less acceptable, forms of euthanasia. The second contends that euthanasia and PAS, which originally would be regulated as a last-resort option in only very select situations, could, over time, become less of a last resort and be sought more quickly, even becoming a first choice in some cases.

The circumvention of safeguards and laws, with little if any prosecution, provides some evidence of the social slippery slope phenomenon described by Keown 5,28. Till now, no cases of euthanasia have been sent to the judicial authorities for further investigation in Belgium. In the Netherlands, 16 cases (0.21% of all notified cases) were sent to the judicial authorities in the first 4 years after the euthanasia law came into effect; few were investigated, and none were prosecuted 5. In one case, a counsellor who provided advice to a non-terminally ill person on how to commit suicide was acquitted 29. There has therefore been an increasing tolerance toward transgressions of the law, indicating a change in societal values after legalization of euthanasia and assisted suicide.

In the 1987 preamble to its guidelines for euthanasia, the Royal Dutch Medical Association had written “If there is no request from the patient, then proceeding with the termination of his life is [jurisdictively] a matter of murder or killing, and not of euthanasia.” By 2001, the association was supportive of the new law in which a written wish in an advance directive for euthanasia would be acceptable, and it is tolerant of non-voluntary and involuntary euthanasia 7,30,31. However, basing a request on an advance directive or living will may be ethically problematic because the request is not contemporaneous with the act and...
may not be evidence of the will of the patient at the time euthanasia is carried out.

Initially, in the 1970s and 1980s, euthanasia and PAS advocates in the Netherlands made the case that these acts would be limited to a small number of terminally ill patients experiencing intolerable suffering and that the practices would be considered last-resort options only. By 2002, euthanasia laws in neither Belgium nor the Netherlands limited euthanasia to persons with a terminal disease (recognizing that the concept of “terminal” is in itself open to interpretation and errors). The Dutch law requires only that a person be “suffering hopelessly and unbearably.” “Suffering” is defined as both physical and psychological, which includes people with depression. In Belgium, the law ambiguously states that the person “must be in a hopeless medical situation and be constantly suffering physically or psychologically.” By 2006, the Royal Dutch Medical Association had declared that “being over the age of 70 and tired of living” should be an acceptable reason for requesting euthanasia. That change is most concerning in light of evidence of elder abuse in many societies, including Canada and evidence that a large number of frail elderly people and terminally ill patients already feel a sense of being burden on their families and society, and a sense of isolation. The concern that these people may feel obliged to access euthanasia or PAS if it were to become available is therefore not unreasonable, although evidence to verify that concern is not currently available.

In Oregon, although a terminal illness with a prognosis of less than 6 months to live has to be present, intolerable suffering that cannot be relieved is not a basic requirement (again recognizing that the concept of “intolerable suffering” is in itself ambiguous). This definition enables physicians to assist in suicide without inquiring into the source of the medical, psychological, social, and existential concerns that usually underlie requests for assisted suicide. Physicians are required to indicate that palliative care is a feasible alternative, but are not required to be knowledgeable about how to relieve physical or emotional suffering.

Until 2001, the Netherlands allowed only adults access to euthanasia or PAS. However, the 2001 law allowed for children aged 12–16 years to be euthanized if consent is provided by their parents, even though this age group is generally not considered capable of making such decisions. The law even allows physicians to proceed with euthanasia if there is disagreement between the parents. By 2005, the Groningen Protocol, which allows euthanasia of newborns and younger children who are expected to have “no hope of a good quality of life,” was implemented. In 2006, legislators in Belgium announced their intention to change the euthanasia law to include infants, teenagers, and people with dementia or Alzheimer disease.

In Belgium, some critical care specialists have opted to ignore the requirement that, in the case of non-terminally-ill patients, an interval of 1 month is required from the time of a first request until the time that euthanasia is performed. One specialist reported that, in his unit, the average time from admission until euthanasia was performed for patients that seemed to be in a “hopeless” situation was about 3.5 days. Beneficence, this specialist argued, was the overriding principle.

Initially, euthanasia in the Netherlands was to be a last-resort option in the absence of other treatment options. Surprisingly, however, palliative care consultations are not mandatory in the jurisdictions that allow euthanasia or assisted suicide, even though uncontrolled pain and symptoms remain among the reasons for requesting euthanasia or PAS. Requests by the Belgian palliative care community to include an obligatory palliative care consultation (“palliative filter”) were denied. From 2002 to 2007 in Belgium, a palliative care physician was consulted (second opinion) in only 12% of all cases of euthanasia. Palliative care physicians and teams were not involved in the care of more than 65% of cases receiving euthanasia. Moreover, the rates of palliative care involvement have been decreasing. In 2002, palliative care teams were consulted in 19% of euthanasia cases, but by 2007 such involvement had declined to 9% of cases. That finding contradicts claims that in Belgium, legalization has been accompanied by significant improvements in palliative care in the country. Other studies have reported even lower palliative care involvement. It must be noted that legalization of euthanasia or PAS has not been required in other countries such as the United Kingdom, Australia, Ireland, France, and Spain, in which palliative care has developed more than it has in Belgium and the Netherlands.

The usefulness of a single palliative care assessment has been challenged—even when it is an obligatory requirement, as is the case at the University Hospital of the Canton of Vaud, Lausanne, Switzerland (the first hospital to allow, in 2005, assisted suicide in Switzerland). Among U.K. palliative care physicians, 63% feel that a single assessment is insufficient to fully evaluate and address the needs of a person requesting euthanasia or PAS. A similar number of U.K. psychiatrists have expressed similar concerns, and only 6% of Oregon psychiatrists are comfortable providing consultations for patients requesting PAS.
altered to allow access to euthanasia even if the person refused another available option such as palliative or psychiatric care. One consequence of the change is that, the appropriateness of suicide prevention programs may begin to be questioned, because people wanting to commit suicide should, on the basis of autonomy and choice, have the same rights as those requesting euthanasia.

There are other examples that a “social slippery slope” phenomenon does indeed exist. In Switzerland in 2006, the university hospital in Geneva reduced its already limited palliative care staff (to 1.5 from 2 full-time physicians) after a hospital decision to allow assisted suicide; the community-based palliative care service was also closed (JP. Unpublished data). Of physicians in the Netherlands, 15% have expressed concern that economic pressures may prompt them to consider euthanasia for some of their patients; a case has already been cited of a dying patient who was euthanized to free a hospital bed. There is evidence that attracting doctors to train in and provide palliative care was made more difficult because of the decrease, the rates are perturbing.

In Belgium, the rates of involuntary and non-voluntary euthanasia have decreased; together they accounted for 3.2%, 1.5%, and 1.8% of all deaths in 1998, 2001, and 2007 respectively (1800, 840, and, 990 people respectively in those years). In the Netherlands, the rate decreased from 0.7% in 2001 to 0.4% in 2005. The actual rate is probably higher, given the large number of unreported cases. Notwithstanding the decrease, the rates are perturbing.

Battin et al. examined data from Oregon and the Netherlands and concluded, as have others, that there was no evidence that vulnerable people, except for people with AIDS, are euthanized disproportionately more. “Vulnerable” was defined in that study as individuals who are elderly, female, uninsured, of low educational status, poor, physically disabled or chronically ill, younger than the age of majority, affected with psychiatric illnesses including depression, or of a racial or ethnic minority. Finlay and George challenged the study on the basis that vulnerability to PAS or euthanasia cannot be categorized simply by reference to race, sex, or other socioeconomic status. Other characteristics, such as emotional state, reaction to loss, personality type, and the sense of being a burden are also important. Patients are also vulnerable to the level of training and experience that their physicians have in palliative care and to the personal views of their physicians about the topic. For example, one study showed that the more physicians know about palliative care, the less they favor euthanasia and PAS.

The number of deaths by euthanasia in Flanders has doubled since 1998. Of the total deaths in this Flemish-speaking part of Belgium (population 6 million), 1.1%, 0.3%, and 1.9% occurred by euthanasia in 1998, 2001, and 2007 respectively (about 620, 500, and 1040 people respectively in those years). The requirement of the law to report euthanasia cases (aided by laxity in prosecuting cases that fall outside the requirement) may explain some, but not all, of the increase. Chambrae et al. reported in the Canadian Medical Association Journal that in Belgium, euthanasia without consent had decreased from 3.2% in 1998 to 1.8% in 2007. But a closer review of the original study shows that the rate had declined to 1.5% in 2001 and then increased again to 1.8% in 2007.

In Holland, the overall rate of euthanasia was 1.7% of all deaths in 2005, down from 2.4% and 2.6% in 2001 and 1995 respectively, but no different from 1990 when the rate was 1.7%. However, the Dutch government’s official statistics indicate a rise of 13% in 2009 compared with 2008; euthanasia now accounts for 2% of all deaths. Given the increasing numbers, interest in developing facilities that provide euthanasia (similar to those of the Swiss pro-assisted suicide group Dignitas) has recently been increasing. In Oregon, although the number of cases of PAS remain very small relative to the population, the rate has been increasing: 24 prescriptions were written in 1998 (16 of which led to deaths by PAS), 67 prescriptions in 2003 (43 of which led to deaths by PAS), and 89 in 2007.
4. THE RESPONSE

What can be done, then, when the best of palliative care is unable to address suffering?

Zylicz, a palliative care specialist who has worked extensively in the Netherlands with people requesting euthanasia and PAS, provides a taxonomy to understand the reasons underlying the requests and provides stepping stones for addressing the requests. The requests can be classified into five categories (summarized by the abbreviation ABCDE)\textsuperscript{54}:

- Being afraid of what the future may hold
- Experiencing burnout from unrelenting disease
- Having the wish and need for control
- Experiencing depression
- Experiencing extremes of suffering, including refractory pain and other symptoms

Strategies are available to begin to address severe refractory symptoms, to treat depression, and to deal with the fear that some people have of what the future with a terminal disease may hold. Approximately 10\%–15\% of pain and other physical symptoms (such as dyspnea and agitated delirium) cannot be controlled with first- and second-line approaches and become refractory. For these symptoms, there is the option of palliative sedation. Palliative sedation is defined as “the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the intent to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the intentions is defined as “the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the

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Studies have shown that losing a sense of dignity and hope and taking on a sense of burden prompt some people to seek euthanasia and PAS\textsuperscript{21–23,56}. Strategies to improve the sense of dignity, based on empirical studies that have explored the concept of dignity within palliative care, have been shown to work\textsuperscript{57}. Similar strategies need to be developed in the areas of hope and burden.

Given effective palliation, including palliative sedation for patients with refractory symptoms, the only remaining issue is that of legalizing “on-demand” euthanasia and PAS when there is no terminal disease or when the person is tired of living or has a mental illness. Legalizing euthanasia and assisted suicide in these circumstances is most concerning and would have major implications over time, including changing a society’s values and making suicide prevention programs redundant because people wishing to commit suicide would then be entitled to do so.

5. SUMMARY

In 30 years, the Netherlands has moved from euthanasia of people who are terminally ill, to euthanasia of those who are chronically ill; from euthanasia for physical illness, to euthanasia for mental illness; from euthanasia for mental illness, to euthanasia for psychological distress or mental suffering—and now to euthanasia simply if a person is over the age of 70 and “tired of living.” Dutch euthanasia protocols have also moved from conscious patients providing explicit consent, to unconscious patients unable to provide consent. Denying euthanasia or PAS in the Netherlands is now considered a form of discrimination against people with chronic illness, whether the illness be physical or psychological, because those people will be forced to “suffer” longer than those who are terminally ill. Non-voluntary euthanasia is now being justified by appealing to the social duty of citizens and the ethical pillar of beneficence. In the Netherlands, euthanasia has moved from being a measure of last resort to being one of early intervention. Belgium has followed suit\textsuperscript{37}, and troubling evidence is emerging from Oregon specifically with respect to the protection of people with depression and the objectivity of the process.

The United Nations has found that the euthanasia law in the Netherlands is in violation of its Universal Declaration of Human Rights because of the risk it poses to the rights of safety and integrity for every person’s life. The UN has also expressed concern that the system may fail to detect and to prevent situations in which people could be subjected to undue pressure to access or to provide euthanasia and could circumvent the safeguards that are in place.

Autonomy and choice are important values in any society, but they are not without limits. Our democratic societies have many laws that limit individual autonomy and choice so as to protect the larger community. These include, among many others, limits on excessive driving speeds and the obligation to contribute by way of personal and corporate income taxes. Why then should different standards on autonomy and choice apply in the case of euthanasia and PAS?

Legislators in several countries and jurisdictions have, in just the last year, voted against legalizing euthanasia and PAS in part because of the concerns and evidence described in this paper. Those jurisdictions include France, Scotland, England, South Australia, and New Hampshire. They have opted to improve palliative care services and to educate health professionals and the public.

6. CONFLICT OF INTEREST DISCLOSURES

The author has no financial conflict of interest to declare.
7. REFERENCES


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