

# Euthanasia: A Confounding and Intricate Issue

Isabelle Marcoux  
*Interdisciplinary School of Health Sciences, University of Ottawa*  
Canada

## 1. Introduction

Euthanasia is a term that often sparks heated debate, regardless of whether people are “for” or “against”. It is one of the most-debated ethical issues in recent decades as revealed by the considerable number of scientific publications, media coverage of specific cases, but also proposed bills in many countries. Despite its popularity and the fact that public opinion polls indicate increasing support, euthanasia is still illegal in most countries. Nevertheless, one of the most significant challenge in order to have an informed debate on this issue is to determine what euthanasia essentially is. In popular discourse, for example, euthanasia is often associated with expressions such as “wanting to die with dignity”, “not wanting to be kept alive against one’s wishes”, “not wanting to suffer”, and “wanting to die rather than live in a certain condition”. But, logically, if in most countries euthanasia is illegal, does this mean that these wishes run counter to current practices, or even that dying with dignity be against the law? Of course not, but in the context of the debate on the legalisation of euthanasia, it is legitimate to wonder about the meaning of this loaded term. Among members of the public and even health care practitioners, the term euthanasia is apparently used to refer to situations ranging from the last injection allowing a person to pass from life to death in a context of incurable illness, through withholding treatment that would do more harm than good (futile treatment) and withdrawing life support that keeps the person alive (mechanical ventilation, feeding and hydration tubes), to relieving the pain and other symptoms of persons at the end of life whose next breath may well be their last. The use of adjectives “passive” and “active” with the term euthanasia, to describe legal and illegal practices, is undoubtedly associated with this common clustering of concepts. Given this situation, the objectives of this chapter are to delineate exactly what is meant by the term euthanasia, and to see how the variable interpretations of this term can lead to confusion and misunderstanding that often render debate pointless. Part 2 describes what euthanasia is now considered to consist in, and puts it in perspectives with other types of end-of-life decisions that characteristically arise in medical practice. Part 3 lists studies that have attempted to clarify people’s understandings of euthanasia and particularly in relation to other end-of-life practices. Part 4 discusses the interpersonal, societal and political issues raised by these varied understandings of euthanasia according to various groups.

## 2. Meaning of euthanasia and end-of-life medical practices

Although the word euthanasia is derived from the ancient Greek *eu* (good) and *thanatos* (death), its general meaning of “good death” has changed over time. The first use of the

term euthanasia in the Modern Era is attributed to early 17th-century philosopher Francis Bacon, who wrote that euthanasia referred to “a fair and easy passage from life to death without pain and dolours” (Dick, 1955). Three centuries later, however, euthanasia took on a negative connotation with the introduction of Nazi “program euthanasia”, developed during World War II in order to eliminate “life unworthy of life”, including persons with illnesses and disabilities. In the 1960s, in reaction to the advances in medical technology and its intensive use, serious debate took place in the Netherlands (Kater et al., 2003). At that time, the term euthanasia was placed in the highly specific context of reaction against heroic treatment. Concerns focused on the best thing to do in a life-and-death situation where the patient’s wishes were central. Until the late 1970s, the term euthanasia designated a broad category of problems (for example, direct action, indirect action, refraining from action, and whether there was a request from the patient); since that time, however, it has been defined as “... the administration of drugs with the explicit intention of ending the patient's life at his/her request” (van der Mas et al., 1991). This is now the definition “officially” used in most industrialized countries. In particular, it served as a basis for regulating the practice of euthanasia in the Netherlands in the 1990s, when legislation was being amended in order to allow euthanasia in the Netherlands (2000), Belgium (2002) and Luxemburg (2009), and also for the systematic study of this practice. Thus we can see that the term euthanasia has been subjected to a variety of influences over time, and has recently been very strictly defined as a medical act that consists in intentionally bringing about the death of a patient at that person’s request. Practically speaking, euthanasia is usually accomplished by giving an injection of a barbiturate, combined with a neuromuscular relaxant which bring about the patient's death (Matersvedt et al., 2003).

In order to better understand what euthanasia exactly means (or not means), we must put it in perspective with other end-of-life medical practices. In fact, there are conceptual and practical distinctions among end-of-life practices; in recent decades in a number of industrialized countries, these distinctions have made it possible to differentiate between what is considered legal and what is not. The objective here is not to pass moral judgement on whether this situation is acceptable or not, but rather to provide a factual description of the situation. First of all, **withholding treatment** means not initiating treatment that may maintain or prolong life (for example, cardiac resuscitation or blood transfusion); **treatment withdrawal** means interrupting or ceasing life-sustaining treatment (for example, a ventilator, artificial nutrition or hydration, dialysis). These decisions, made in accordance with the patient’s wishes, are considered as good medical practices in most industrialized countries. Recognizing this right of refusal protects patients from possible heroic treatment and flows from physicians’ duty not to harm (non maleficence). Previously, these medical decisions were sometimes labelled as “passive euthanasia” since, for some people, they considered that the result (death) was the same as in the case of active euthanasia (lethal injection with intent to induce death), even though the means to the end was different. That terminology is not only confusing but also semantically meaningless.

A physician who respects a patient’s will to stop treatment that may prolong life, or that maintains life artificially, is not exonerated from the duty of providing the patient with adequate care to control pain and other symptoms. However, for some people, relieving pain with adequate doses of morphine may induce death and can therefore considered to be euthanasia. As a result, to ensure that patients receive the treatment needed for adequate pain relief, the principle of “double effect” was introduced. The “**double effect**” arises from

the fact that adequate pain relief sometimes calls for significant doses that could accelerate death as a side effect. In situations of this type, the intent is to relieve pain, not to induce death. Nevertheless, as we shall see, the results of recent research strongly challenge this principle of "double effect", indicating that, on the contrary, administration of medication needed for adequate pain relief would have the effect of prolonging, not shortening, life. Furthermore, and still with the objective of controlling pain and other symptoms at the end of life, we see increasingly frequent references to **terminal sedation** since the last decade. This practice consists in inducing sleep until death in persons at the end of life who have treatment-resistant symptoms such as pain, respiratory disorders, moral suffering, or delirium.

Relief of pain and other symptoms is one specific objective of palliative care. In fact, according to the World Health Organization definition: "**Palliative care** is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." (Sepùlveda et al., 2002). Dying with dignity is what palliative care professionals offer to persons at the end of life, but this is also the expression used by proponents of the legalization of euthanasia. Although the end is the same, in a number of countries euthanasia as a means to that end is considered irreconcilable with the concept of palliative care. In fact, palliative care is usually presented as antithetical to a debate on euthanasia: for example, persistent demand for euthanasia may be seen as a failure of palliative care; or palliative care may even be presented as the sole alternative to euthanasia. In endeavouring to counter the argument that better access to high-quality palliative care would eliminate the desire for euthanasia to end one's life, Belgium simultaneously passed two pieces of legislation: one on euthanasia (Sénat de Belgique, 2001a); and the other on palliative care, guaranteeing patients equal access to high-quality care (Sénat de Belgique, 2001b). In fact, access to palliative care is a major issue that must be addressed: for example, it is estimated that only between 16% and 30% of Canadians have access to palliative care, depending on their place of residence (Canadian Institute for Health Information, 2007), even though Canada ranks ninth out of 40 countries on a "Quality of Death" Index that takes into account factors including the availability of palliative care (Economist Intelligence Unit, 2010).

In general, withholding treatment, treatment withdrawal, relief of pain and terminal sedation are medically recognized as good practices and are legal in most industrialized countries, when implemented in accordance with the patient's wishes. However, except in a few European countries, euthanasia is still illegal, although its ethical justification is the subject of intense debate. Another practice usually considered to be illegal is **physician-assisted suicide**, which is distinguished from euthanasia by the concept of the person performing the act: in assisted suicide, it is the patient who takes the action that will induce that person's own death, while in euthanasia, it is the physician who assumes this responsibility. Three main concepts may be used to distinguish between these practices: intent; the act performed; and the person performing the act that results in death.

In theory, the current definition of euthanasia and the distinctions applied to other types of end-of-life practices have been accepted in legislative, research and medical circles. This consensus notwithstanding, groups each have their own justifications for acceptance. In legislative circles, the objective is to distinguish between legal and illegal practices on the

basis of societal values. The medical associations, consistently following the Hippocratic oath, have a duty to determine what is acceptable in terms of medical practice and to ensure their members' adherence to the profession's code of ethics. In research circles and particularly empirical studies, the objective is to obtain sound internal validity by using a recognized definition of the concept being studied. On that basis, study results can be reproduced and compared with the results of former studies, for which studies conducted in the Netherlands have been a reference point. As presented in this part, then, distinguishing among end-of-life medical practices and making them operational is essentially utilitarian.

### **3. Understandings of euthanasia**

Until now, there have been few specific studies on people's understandings of euthanasia, and these few studies have specific angles of analysis that can be classified under three headings. First, there are studies, often using a qualitative approach, on what people spontaneously think euthanasia is or how they identify components of a definition of euthanasia. Second, there are other studies on people's ability to distinguish between euthanasia and other end-of-life practices using vignettes. Third, there are studies on people's knowledge of whether euthanasia and other end-of-life practices are legally accepted in their respective countries. Aside from these different angles of analysis, these studies also diverge in two significant aspects of methodology: the country of the survey; and the target population of the survey (members of the general public; patients; significant others or natural caregivers; physicians or nurses). As well, the methods of data collection varied, as the way questions were formulated. Taking into account these significant challenges to the comparability of results, we will present these studies successively by angle of analysis; we will then endeavour to draw some conclusions about the current state of respondents' knowledge.

#### **3.1 Spontaneous definitions of euthanasia**

At a 1-day informative conference for Dutch medical students on the topic of “Dying on Request”, participants were asked, before and after the training activity, to define euthanasia (Muller et al., 1996). Although the objective was certainly to check the acquisition of knowledge after the training day, the results provide some indications of participants' initial concepts. This study is interesting from two standpoints: theoretically, the participants should have had good knowledge of what constitutes euthanasia because their future profession would call upon them to address this issue ; as well, they lived in a country where (in the mid-1990s) euthanasia was already broadly debated, regulated in certain circumstances, but not yet legalized. In order to assess participants' knowledge, the researchers used as a benchmark the definition adopted in 1987 by the Dutch State Commission on Euthanasia: “Active voluntary euthanasia is the intentional termination of life, by someone other than the patient, at the patient's request”. On that basis, the researchers were looking for three components of the definition of euthanasia: (1) intent to hasten death; (2) a person performing the act who is someone else than the patient; and (3) the existence of a request as evidence of compliance with the patient's wishes. Of the 137 student respondents, approximately two out of five initially provided the three expected components of the definition (41%; 39%; and 41% respectively, in regard to the components). Clearly the training day benefited participants, since most respondents'

knowledge of what constitutes euthanasia in medical practice in the Netherlands improved significantly (90%; 89%; and 84% respectively, in regard to the component). Unfortunately, there is no indication of the number of persons who combined the three components in their definitions, either before or after the training activity. Nor is there any indication of other components spontaneously put forward by respondents, which might have made it possible to determine whether there was confusion with other end-of-life practices. Still, we may posit that, despite respondents' special status and a context conducive to discussion of euthanasia, initial knowledge appeared to be limited.

During the same decade, an Australian survey of 10 nurses was designed in particular to shed light on nurses' understanding of euthanasia (McInerney & Seibold, 1995). When asked: "What is your understanding of euthanasia?", six respondents spontaneously provided what the researchers considered to be an accurate definition, that is, involving intent to induce death. In fact, the researchers applied the distinction between "active" and "passive" to assess whether the definitions provided by the nurse respondents were accurate; when questioned, further, by far most respondents appeared to support this distinction. As well, nine out of the 10 respondents did not consider the "double effect" to be euthanasia, in particular because of the concept of intent. Interestingly, six of the 10 respondents did not refer to the voluntary aspect of euthanasia; that is, they did not mention the importance of a request by the patient, as required by the Dutch definition of euthanasia. In conclusion, this study states: "It was conceded that the term passive euthanasia, particularly in relation to treatment withdrawal, has served to confuse the real debate centring around active euthanasia"; this debate did indeed take place in Australia at that time, and the 1995 legislative amendment allowing euthanasia in the Northern Territory of that country was overturned a few months after being effective (Dickinson et al., 1998). Participants in this study endorsed the idea of confusion created by the use of various adjectives with the term euthanasia, and appeared to distinguish readily between passive and active euthanasia. Nevertheless, one may wonder about the representativity of the findings of this study, since two broader surveys of nurses (Aranda & O'Conner, 1995; Davis et al., 1993) expressed significant reservations about the validity of their own results, specifically because of differing interpretations of the subject of the study. For example, in referring to euthanasia, nurses gave as examples of treatment withdrawal taking a patient off a respirator or withdrawing artificial feeding, and even pain relief through increased doses of morphine at the risk of hastening death. In short, even among professionals working with patients at the end of life, concepts of euthanasia do not appear to be altogether clear.

A similar open-ended question about what constitutes euthanasia was asked of 236 persons with cancer in Australia (Parkinson et al., 2005). Main topics identified included: "assisted death" (44%), meaning that another person is involved in the process; "suffering" (41%), identifying the context in which euthanasia takes place; and "ending life" (39%), raising the issue of intent, but not indicating exactly what respondents meant. In fact, very few persons appear to have referred to the "methods" of ending life; under this heading, the researchers grouped all sorts of activities including not only euthanasia but also other end-of-life practices/terms (such as lethal injection, tablet, withdrawal or withholding treatment, and active or passive measures). According to the study, the fact that a personal choice is involved, and the fact that this choice has to do with one's own death, were more frequently referred to than the concept of voluntary death, which was not often made explicit.

However, the fact that a high percentage of respondents referred to personal choice (request, wish, choice, decision) suggests that euthanasia flows from compliance with “the patient’s request” as set out in the Dutch definition of euthanasia. In summary, on the basis of the results presented, it is difficult to ascertain whether respondents distinguish between euthanasia and other end-of-life practices. In fact, the researchers indicate that people instinctively use euthanasia to mean a range of situations that could be described as active, passive, voluntary or even involuntary.

Lastly, respondents in a survey of 991 residents of Quebec, Canada, were asked: “In your opinion, what is euthanasia?” (Marcoux, 2003). First of all, one out of eight respondents indicated that they did not know what euthanasia is. Following an analysis of 825 codifiable definitions, nine initial themes were identified: (1) the type of subject (human or animal) to which the definition applied; (2) the intent underlying the act; (3) the act performed; (4) the person performing the act; (5) the existence of a request; (6) the existence of consent; (7) the presence of compassion; (8) the reasons underlying the act; and (9) the circumstances surrounding the act. However, in order to make people’s understanding of euthanasia operational and in order to compare the definitions, certain strongly correlated themes were combined (for example: act and intent; reasons, circumstances and compassion), and only some themes were selected, on the basis of the minimal semantic components inherent in the definition of euthanasia (intent; the person performing the act; and compassion). For example, for a definition to be classified as euthanasia, it had to include at least these three components, justified as follows: the intent is to induce death; the person performing the act is someone else; and indicators of compassion are present. When justification was used to cross-reference the response components, only 414 of the 825 definitions provided could be classified, under the following composite headings: (1) euthanasia (17.4%); (2) assisted suicide (4.2%); (3) treatment withdrawal (3.0%); (4) ambiguous practices, that is, those in which intent cannot be determined (17.1%); (5) suicide (4.3%); and (6) murder (4.3%). General observations are as follows: very few people spontaneously know what euthanasia is; over half have a fragmented understanding of the subject; and the rest appear to be confused about the difference between euthanasia, other end of life practices such as treatment withdrawal, but also physician-assisted suicide and even suicide. Some respondents spontaneously indicated that euthanasia means murder, citing intent to cause death and the fact that the act is performed by someone else, but included no component of compassion in the definition. Still, care must be exercised in interpreting the scope of these results since the telephone survey method does not readily lend itself to questions of this type (attempting to identify people’s understanding of euthanasia using an open-ended question) .

### **3.2 People’s ability to distinguish between euthanasia and other end-of-life practices**

The following studies used vignettes to focus on people’s understanding of euthanasia as compared with other end-of-life practices. The methodological details and brief results of these studies are presented in Table 1. As part of a public education event on death and dying, participants were asked first to complete a questionnaire on their knowledge of this subject (Gallagher, 2001: see box 1). Although a high percentage of participants already worked in palliative care (61 of 144 participants, or 42%), according to the results, 47% of participants thought that: “Euthanasia involves withholding life-sustaining treatments such as life support machines,” even though only 16% thought it is illegal to refuse treatment.

Although these results initially appear contradictory, they can be interpreted in two ways. First, it is possible that some persons think that the term euthanasia refers to a legal practice (which was not the case in Canada either when the study was conducted or when the book was published). Second, the lack of reference in the first vignette to a request by the patient could explain this variation between the two situations. Another interesting result of this study is the indication that 46% of participants believe in the principle of "double effect", that is, that pain relief using morphine may shorten a patient's life and even precipitate death, which is often a source of confusion with euthanasia, as we shall see.

Study	Year of realization	Country	Populations	Method	N (Response rate)	
Gallagher	1999 <sup>1</sup>	Canada (British Columbia)	Public	Questionnaire	144/ (not mentioned)	Withholding or withdrawing life-sustaining treatment is euthanasia: 47.30%
Marcoux et al.	2002	Canada (Quebec)	Public	Phone interview	991 (49.8%)	Withholding treatment is euthanasia: 38.1% Withdrawing treatment is euthanasia: 66% "Double effect" is euthanasia: 48.8% PAS is euthanasia: 71.9% Euthanasia is euthanasia: 79.7%
Neil et al.	2004	Australia	Physicians	Mail	854 (47%)	Withholding or withdrawing is euthanasia: 13% "Double effect" is euthanasia: 20% Euthanasia is euthanasia: 62% Provided own definition: 4%
Vilela & Caramelli	2003 <sup>2</sup>	Brazil	a. Physicians b. Caregivers	Interview	a. 30 (100%) b. 40 (100%)	Withholding or withdrawing is euthanasia a. 23.3%      b. 15% "Double effect" is euthanasia a. 6.6%      b. 20% Euthanasia is euthanasia a. 40%      b. 25% PAS is euthanasia a. 3.3%      b. 15% I don't know what is euthanasia (or other) a. 23.3%      b. 20%

<sup>1</sup> Personal communication with author

<sup>2</sup> Personal communication with author

Study	Year of realization	Country	Populations	Method	N (Response rate)	
Lindblad et al.	2007	Sweden	a. Public b. Physician	Mail	a. 1202 (48%) b. 1200 (57%)	Withdrawal of ventilator ( <i>no chance of improvement, but can live for many years</i> ) is considered as a type of euthanasia a. 16%      b. 26% Withdrawal of dialysis, depending of characteristics of the patients a. 16 and 17%   b. 8 and 13%

Table 1. Distinction between euthanasia and other end-of-life decisions

**Box 1.**

- "Euthanasia involves withholding life-sustaining treatments such as life support machines"
- "It is illegal to refuse treatment if you have a life-threatening illness"
- "Morphine doses sufficient to relieve pain may shorten the life of the person or contribute to their death"

Gallagher (2001)

Confusion between treatment withdrawal and euthanasia was shown among members of the population, and this confusion was even more widespread about various end-of-life practices (Marcoux et al., 2007). Vignettes of different end-of-life practices were used; for each vignette, respondents were asked to indicate whether the situation involves euthanasia or not (see box 2). Nearly three out of four respondents identified physician-assisted suicide as being euthanasia; 66% identified treatment withdrawal at the patient's request as being euthanasia; 49% identified the “double effect” as being euthanasia; and 38% identified withholding life-sustaining treatment as being euthanasia. Although there was no specific question about knowledge of whether these acts are legal in Canada (euthanasia and assisted suicide were illegal when the study was conducted and when the book was published), one may nevertheless assume that the recurring public debate on the acceptability of legislative amendments to allow euthanasia has numerous connotations in the popular imagination. In short, how should the results of public opinion polls on euthanasia be interpreted when respondents think, for example, that taking a patient off a respirator at his or her request (treatment withdrawal ) is *de facto* euthanasia?

**Box 2**

- "A dying person asks his doctor to give him a lethal injection because he could no longer stand suffering from his illness. The doctor agrees and this causes the patient's death" [Euthanasia vignette]
- "A doctor gives a terminally ill person medication the person can take to kill himself" [Physician-assisted suicide vignette]

- "At the request of a patient, a doctor disconnects machines which keep the person alive, for example, an artificial lung" [Treatment withdrawal vignette]
  - "At the request of a patient, a doctor respects the person's decision to refuse treatment which would prolong his life" [Withholding treatment vignette]
  - "A doctor gives a dying person drugs to relieve his suffering, but the drugs hasten his death" ["Double effect" vignette]
- Marcoux et al. (2007)

In the next two studies, respondents were asked to choose, from among proposed definitions, the one that best reflected their individual definition of euthanasia. As a result, unlike the previous study, here the responses were mutually exclusive, which makes it impossible to determine whether there is juxtaposition of confusion. Neil et al. (2007) proposed three vignettes to a group of physicians (see box 3); 62% of respondents chose the statement emphasizing the intent of "hastening death" underlying the act performed as an inherent component of what constitutes euthanasia (an accurate definition according to the researchers), in comparison with two other statements that referred instead to the "double effect" (20%) and to withholding or treatment withdrawal (13%). Moreover, 4% of respondents wanted instead to suggest their own definitions, most of which emphasized the etymological meaning of the term euthanasia: "good death". These results show that the term euthanasia can have different meanings even among physicians, 83% of whom have already cared for patients at the end of life.

### Box 3

Which of the following do you regard as euthanasia?

- Provision of medication or drug that doctor believes will hasten the patient's death
- As well as taking active steps, withdrawing or withholding
- Actions count as euthanasia only if acts with the primary intention of hastening death

Neil et al. (2007)

Unlike the study by Neil et al. (2007.), conducted in Australia where the legal status of end-of-life practices is the same as in most western countries, the study by Vilela & Caramelli (2009) was conducted in Brazil in 2003, a few years before that country's Federal Council on Medicine published standards of practice on the withholding or withdrawing life-sustaining treatment at the end of life (personal communication with the author). The comparison of responses by physicians and caregivers of persons with Alzheimer disease leads to different conclusions about what members of each of these two groups consider to be euthanasia (see box 4 for wording). Although the response choices were mutually exclusive, there was no real consistency in the responses by caregivers, since between 15% and 25% of them chose statements identifying treatment withdrawal, assisted suicide, "double effect", euthanasia, or "Don't know/Other". Responses by physicians were more limited, to statements identifying euthanasia (40%), treatment withdrawal (23%), and "Don't know/Other" (23%). In this context, the confusion between euthanasia and other end-of-life practices may be understandable since their legal status was not explicit at the time the study was conducted. Nevertheless, in comparison with the previous studies, this one still shows evidence of the conceptual mixture between withdrawal of life-sustaining treatment

and euthanasia, much like the former terms active and passive euthanasia, which are a source of confusion in medical practice.

#### Box 4

"What do you understand by euthanasia?"

- It is to let one die without any kind of medical assistance
- It is to let one die without sophisticated medical assistance (mechanical ventilation, dialyse, feeding directly in the vein...)
- It is to induce death by giving, for instance, a medication with lethal effect
- It is the attempt to reduce patient suffering by giving medications that control pain but shorten life
- It is to give the patient a lethal medication to let him/her take by himself/herself the decision to shorten his/her life
- I do not know/free answer/more than one option

Vilela & Caramelli (2009)

Although the next study was not designed to identify specific knowledge or possible confusion about end-of-life practices, it does indicate that certain situations of treatment withdrawal are considered to be, not as “defensible acts”, but rather as a type of euthanasia (Lindblad et al, 2010). This is true among approximately 16% of respondents from the general public, regardless of the vignette presented (see box 5). The same vignettes were also presented to physicians, who appeared to interpret the content of the acts differently depending on the vignette presented. For example, 8% and 13% of physicians respectively considered withdrawal of dialysis (case 1 and case 2) as a form of euthanasia, while one physician out of four (26%) considered withdrawal of a ventilator maintaining life (case 3) to be “a type of euthanasia”. However, that wording may be criticized since in fact it

#### Box 5

- "A 77-year-old woman, who as a result of type 2 diabetes and chronic renal insufficiency is dependent on dialysis three times a week. In recent months she has repeatedly expressed a wish to terminate the dialysis treatment. The woman is tired of life, but cognitively clear and not suffering from any mental illness" (case 1).
- "A 36-year-old man, who 5 years earlier attempted to commit suicide. He was saved without brain injuries, but as a result of a persistent chronic kidney disorder he is still dialysis dependent. Initially, he also received psychiatric treatment. The patient is in line for a kidney transplant. During the past 6 months he has repeatedly expressed a wish to decline the kidney transplant and to terminate the dialysis treatment. A psychiatric examination does not reveal any mental illness" (case 2).
- "A 34-year-old competent man who is tetraplegic and ventilator dependent as the result of a car accident 5 years ago. There is no chance of improvement, but the patient may live for many years in his current state. During the past 6 months, the patient has repeatedly asked for the ventilator treatment to be discontinued. Neither the physician, who knows the patient well, nor a consultant psychiatrist regard the patient as clinically depressed" (case 3).

Lindblad et al. (2010)

gives the impression that there are a number of types of euthanasia, and thus the wording of the question alone may create confusion. In the present state of affairs (when the study was conducted and when the book was published) in Sweden, treatment may be refused, although euthanasia is prohibited. The fact that more physicians considered treatment withdrawal in the case of a young quadriplegic man to be euthanasia provides food for thought. The possibility of this patient's living for a number of years in this condition may have influenced the physicians' interpretation of the request and invite us to reflect in greater depth on the balance between respect for the patient's autonomy and the physician's duty to do good.

### 3.3 People's knowledge about legal status of euthanasia and other end-of-life practices

The following studies focus more specifically on whether people are aware of their rights in terms of end-of-life care under the legislation in force in their respective countries of residence. The methodology details and brief results of these studies are shown in Table 2.

Study	Year of realization	Country	Populations	Method	N (Response rate)	Knowledge about the legal options
Gallagher	1999	Canada	Public	Questionnaire	144/( <i>not mentioned</i> )	Refusal of treatment: 84.5%
Silveira et al.	1999	US (Oregon)	Adult outpatients	Questionnaire	728/1000	Refusal of treatment: 69% Treatment withdrawal: 46% "Double effect": 41% Assisted suicide: 23% Euthanasia (illegal): 32%
Kopp	2002	US (Arkansas)	Public	Mail	300/( <i>not mentioned</i> )	Refusal of treatment: 61.5% Treatment withdrawal: 33.7% "Double effect": 27.6% Assisted suicide (illegal): 70.8% Euthanasia (illegal): 79%

Study	Year of realization	Country	Populations	Method	N (Response rate)	Knowledge about the legal options
Morita et al.	2004	Japan	a. Public b. Bereaved family members	Mail	a. 2548/4974 b. 513/738	Withdrawal: 32 à 45% “Double effect”: 50 à 63% Euthanasia (illegal): 66 à 75%
Mitchell & Owens	2000 <sup>3</sup>	New Zealand	a. Physicians b. Students c. Greypower	Mail (a & c) <sup>3</sup> In class (b)	a. 120 (40%) b. 205 (80%) c. 595 (30%)	Euthanasia (illegal) a. 94% b. 65% c. 64%

Table 2. Knowledge about legal options at the end of life

One study was conducted among outpatients at university-affiliated clinics in Oregon, USA, in 1999, that is, approximately two years after the passage of legislation allowing the practice of physician-assisted suicide under specific conditions (Silveira et al., 2000). For each of a series of vignettes (see box 6), respondents were asked to indicate whether the practice was legal or illegal under legislation in force in Oregon. Of the 728 respondent, 69% appeared to be aware of their right to refuse life-sustaining treatment, and fewer than half (46%) appeared to be aware of their right to have this type of treatment withdrawn. Only 41% considered the “double effect” to be consistent with the legislation. Despite public debate in preceding years about the legislative amendments to allow physician-assisted suicide, only 23% of respondents were aware that they had the right to ask their physician for assistance in ending their life if their life expectancy was less than six months. A somewhat lower proportion (17%) however, erroneously believed that euthanasia was legally allowed in Oregon. Moreover, according to this study, nearly two out of three persons made no distinction between euthanasia and assisted suicide. Having personally experienced illness or the illness and death of a significant other, or having written an advance directive, were unrelated to greater awareness of one’s rights in terms of end-of-life care. Nevertheless, having acted as a proxy in health care decisions for a significant other apparently had a positive effect on greater awareness of these rights.

#### Box 6

- "In Oregon, does a patient like John, who has less than 6 months to live, have the legal right to refuse treatment that might cure him or save his life"?
- "In Oregon, is it legal for a physician to turn off a ventilator when requested by a patient like John, with less than 6 months to live, even if it means the patient might die"?
- "In Oregon, is it legal for a physician to inject a medication that would cause a patient's immediate death if a patient like John, with less than 6 months to live, requests it"?

<sup>3</sup> Personal communication with author

- "In Oregon, is it legal for a physician to prescribe a medication and provide advice so that the patient can take the medication that will end his life if a patient like John, with less than 6 months to live, requests it"?
- "In Oregon, is it legal for a physician to give patients like John, with less than 6 months to live, pain medications with the goal of relieving pain and suffering even if death may occur sooner as a result"?

Silveira et al. (2000)

That study was replicated a few years later in 2002, in Arkansas, USA, among a sample of 300 persons (Kopp, 2008-2009). The results of this study differed somewhat from those of the previous study; possible explanations are the three-year time lag between the two studies, a difference in the type of respondents (outpatients at a medical clinic, as compared with respondents in households), sample size (728, as compared with 300), and the way the study was administered (a self-administered questionnaire, as compared with a mailed questionnaire). There was greater awareness in Arkansas whether euthanasia and assisted suicide are legal (79% and 71% respectively); both practices are illegal in that state. Nevertheless, for all practices there was a high percentage of "Don't know" responses, varying from 18% for euthanasia, through 31% for treatment withdrawal, to 35% for the "double effect". It should be noted that 21% of respondents believed they did not have the legal right to refuse treatment. A study conducted in Japan (Morita *et al.*, 2006) also shows a great deal of uncertainty about the legality of certain end-of-life practices, and indicates confusion that is proportionally similar to that shown by Silveira et al. (2000). However, it is difficult to draw any formal conclusions since at the time of the study the actual status of end-of-life practices in Japan did not appear to be very clear and had to be ascertained through consensus among experts. Still, it can be stated that there is significant confusion, regardless of type of end-of-life practice, although confusion appears to be more marked about withdrawing artificial hydration and the "double effect" (practices "supposedly" legally permitted in Japan at this time) than about euthanasia (illegal practice).

Mitchell & Owens (2004) focused on knowledge among physicians (n=120), students (n=205), and persons 55 and older (n=595) of whether acts of assistance in dying were legal in New Zealand. Four vignettes were presented, three of which showed situations of various levels of involvement in assisted suicide (supplying information; supplying drugs; assisting to take drugs) and one of which showed a situation involving euthanasia (see box below). Unfortunately, no situation involving treatment withdrawal was presented, which would have made it possible to compare knowledge of legal and illegal practices. According to this study, no physicians stated that it is legal in New Zealand to administer a lethal injection to a terminally ill person, at the patient's request, although 6% said they were not sure. This degree of uncertainty was even more marked among laypersons, who accounted for nearly one-third of respondents. Providing information on hastening death, and providing means to induce death, both at the request of a terminally ill person, were a particular source of confusion about the risk of legal action. In fact, in the first example, 18% of physicians believed that this practice is legal, while 26% were not sure. Among the two other respondent groups, not being sure about the legal status of these two acts ranged from 36% to 43%. In light of these few studies, then, we can see that awareness of legal rights in terms of end-of-life care is far from being optimal, among both physicians and persons who will eventually need to face these choices.

**Box 7**

- Patient B has a terminal illness (i.e. no hope of recovery), and pain is a constant problem, not alleviated by drugs. [...] The patient has difficulty swallowing and requests the doctor to administer a lethal injection to end the suffering. The doctor administers a lethal injection. In your understanding, is this action legal in New Zealand?

(Mitchell & Owens, 2004)

#### 4. Repercussions of confusion about euthanasia

This confusion about what constitutes euthanasia and what are the distinctions among end-of-life practices necessarily has interpersonal, societal and political repercussions, depending on the roles of groups in society. As a result, our objectives are to review these studies and to discuss issues that characterize this societal debate from the standpoints of the various groups.

##### 4.1 Laypersons

Public understanding does not appear to cover the subtleties of rights in terms of end-of-life care or the distinctions among end-of-life practices. In fact, when surveyed about these issues, people show a rather naïve approach: instead of distinguishing among end-of-life practices, often they consider all these practices to be euthanasia. In particular, many people appear to consider withholding or withdrawal of life-sustaining treatment to be an act of euthanasia (Gallagher, 2001; Marcoux et al., 2007), and appear to believe that they do not have the legal right to express that wish to a physician (Kopp, 2008-2009; Morita et al., 2006; Silveira et al., 2000). As well, in a context of public opinion polls, this confusion between treatment withdrawal and euthanasia appears to be associated with greater support for euthanasia (Marcoux et al., 2007). Similar conclusions were also shown in the study conducted by Kopp (2008-2009), which focused on the issue of physician-assisted suicide; the results of that study showed that greater awareness of the legality of certain practices, including treatment withdrawal and the “double effect”, was associated with lower support for physician-assisted suicide. In summary, caution is advisable in interpreting the results of public opinion survey about euthanasia: the questions asked must be valid, and the conclusions must take into account the undeniable effect of the wide range of ideas that the term euthanasia evokes. Of course, the media have a decisive role to play in disseminating accurate information and thus fostering enlightened debate. Nevertheless, the sensitive and at times sensational nature of this subject makes it a strong magnet for headline-grabbing reporting that does not always reflect reality (Schwartz & Lutfiyya, 2009; Seale, 2010) and that, regrettably, helps perpetuate confusion.

Unfortunately, there are practically no studies on the actual ideas of what constitutes euthanasia, or on which end-of-life practices are legal, among persons directly concerned by these issues. Only the study by Parkinson et al. (2005) suggests that the expansive understanding of euthanasia, as compared with the “official” definition of this term, is found among patients suffering from cancer as well and influences their responses to questions on this subject. On the basis of this broader definition of euthanasia, encompassing both practices that are currently legal and those that are illegal in most countries, then, we can assume that opinions on the acceptability of euthanasia and support for its legalization both depend on a

desire for a good death. This desire is influenced in particular by fear of suffering, fear of heroic treatment, fear of not having one's end-of-life wishes respected, and the wish to continue to be in control of one's life until its end. These concerns are legitimate and deserve to be heard, respected and addressed, not only by medical practice but also by means of a clear a political will, ensuring that persons do not receive medical treatment against their wishes and that no one is left in pain and suffering, and in anguish of death and dying. In this debate, there appears to be a message for the medical community about the limitations of the medical role in patients' lives; this message also raises questions about the changing therapeutic relationship between physicians and patients.

#### **4.2 Health care professionals**

Although most of the medical associations have adopted the "official" definition of euthanasia and proscribe this practice under their code of ethics (except in countries where euthanasia is legal), the delineation of what is or is not euthanasia is not always clear for physicians. In fact, some physicians appear to consider withdrawal of life-sustaining treatment, including withdrawal of a respirator or dialysis, to be euthanasia (Lindblad et al., 2010; Vilela & Caramelli, 2009). In the opinion of other physicians, the "double effect" also appears to constitute euthanasia (Neil et al., 2007; Vilela & Caramelli, 2009). These findings corroborate the conclusions of studies indicate that the prevalence of deaths by euthanasia as revealed by physicians may be inflated because of confusion, misclassification or misrepresentation of their actions (Emanuel et al., 1998; van der Maas et al., 1991), but also because of the wording of the questions (Seale, 2009; van der Maas et al., 1996). Thus we may question some physicians' capacity for enlightened discussion of the options available to patients and patient's rights in terms of end-of-life care, and even some physicians' comfort in providing appropriate patient care at the end of life. In fact, according to some studies, the principle of "double effect" is contested since increased doses of morphine might even prolong life (Sykes et al., 2003). Moreover, the unfounded fear of shortening life hinders good practices for appropriate relief of end-of-life symptoms (Bilsen et al., 2006). Among some physicians, then, this lack of awareness about what constitutes euthanasia and what distinguishes it from other end-of-life practices, and the resulting confusion between legal and illegal practices, leads to fear of legal action. As well, although according to some physicians their role includes providing assistance to die by euthanasia to patients who so wish, others see in that practice a risk of instrumentalization in which the patient's autonomy would take precedence over physicians' responsibility to do good. Clearly, this confusion about end-of-life practices is also found in some nurses and even among palliative care nurses (Aranda & O'Conner, 1995; Davis et al., 1993). While nurses are not directly responsible for medical decisions, they play an important role in educating patients and significant others because of their special relationship with these persons, not only in terms of informing them of their rights, but also in terms of reassuring them that they will receive appropriate care and relief (within the options legally available in their country of residence). Specific training for all physicians and nurses on the features of palliative care appears to be an objective of the utmost importance that needs to be achieved in the very near future.

#### **5. Conclusion**

In conclusion, as is shown by the results of a few studies conducted in various countries, there does not appear to be consensus on the official definition of euthanasia, with its

objectives of making end-of-life practices operational and standardizing language. In fact, the meanings attached to the term euthanasia by various groups in light of their particular concerns appear to be sometimes incompatible. In this context, arguments for legislative amendments to allow euthanasia are perceived, particularly by laypersons, as reflecting a desire for a good death, something that is apparently inaccessible at present. A good death, then, is perceived to be tied to euthanasia, and legalizing euthanasia becomes the *de facto* objective. Nevertheless, it has been observed that, in the view of a number of patients, caregivers, nurses, physicians and even members of the general population, euthanasia goes well beyond the possibility of dying following a lethal injection when suffering is considered to be unbearable by the person, as defined in the Netherlands. Unlike the institutional community, many people consider euthanasia to be as defined in the 17th century by Francis Bacon. If we want to have enlightened debate on this issue, then, would it not be appropriate to revisit the source of the present confusion and to opt for a term other than euthanasia to designate “... the administration of drugs with the explicit intention of ending the patient's life at his/her request”?

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