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Voluntary Active Euthanasia: The Debate

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1. Introduction

Voluntary active euthanasia refers to a clearly competent patient making a voluntary and persistent request for aid in dying (Brock 1999; Ogubanjo & Knapp van Bogaert 2008). In this case, the individual or a person acting on that individual's behalf (physician or lay person, depending on the law of the country) takes active steps to hasten death (LaFollette, 1997). That active step can be either the provision of the means (i.e. a lethal drug) for self-administration (orally or parenterally), or the administration by a tier. The provision of the means to die is called assisted suicide, assistance in dying, or physician assisted suicide. The patient acts last. With voluntary active euthanasia the assistant acts last. Doctor Jack Kevorkian's (dubbed "doctor death") "Mercitron" is an example of assisted suicide. The contraption is hooked to the candidate who initiates the delivery of the lethal drug. With voluntary active euthanasia the lethal drug needs to be administered by an assistant because the candidate is physically unable to proceed unaided. In both circumstances, the individual expresses a competent and voluntary wish to die, and the conditions that would make it right to allow or assist a suicide are satisfied. In both cases the aim is to spare that person pain, indignity, emotional and financial burdens. Yet, suicide is seen as morally reprehensible but is not prohibited by any law. Voluntary active euthanasia, on the other hand, is illegal in most countries and the object of conflicting and polarised moral debates.

Physician assisted suicide involves an affirmative act, writing a prescription or providing the lethal drug. Voluntary active euthanasia requires the acts of providing *and* administering the lethal drug. In physician-assisted suicide, the individual who wishes to die poses the final act; in voluntary active euthanasia, because that individual is unable to pose the last act, a proxy acts on his or her behalf. The difference is about the person who acts last. The intention and motivation are the same. Therefore, one might wonder whether the distinction is not a kind of hypocritical hair splitting. It reminds us of the omission/commission debates and of the doctrine of double effect.

The doctrine of double effect states that for an action with two consequences, one good and one bad, to be morally permissible the bad consequence may be foreseeable but not intended, and the bad cannot be used to achieve the good. The Dutch debate about indirect euthanasia is a case in point. "Terminal sedation" is legally permissible; it consists of administering large oral doses of barbiturates to induce coma followed by neuromuscular blocking agent to cause death on request of patients hoping their death to be hastened

(Veldink et al., 2002). Death is foreseen (and in fact wished by the candidate) but not intended. Furthermore, the candidate takes the first step actively; the second step inevitably requires the active intervention of an assistant. So, here we have two actors with the same motives. Both foresee the result. To claim that it is not intended is sheer casuistry.

Many red tapes need to be overcome by those wishing to die. The main reason is to avoid the legendary “What if?” In spite of good evidence against it, the most commonly advanced reason is avoiding the slippery slope. For instance, in Switzerland, where assisted suicide and voluntary active euthanasia have been tolerated (though not legal it is not prosecuted if the assistant has no hidden agenda, i.e. personal interest in the death of the assisted person) since 1918, it accounts for 0.45 percent of deaths, only a little more than the 0.3 percent in the Netherlands (Veldink et al. 2002; Van der Heide et al., 2007). The candidate has to activate the “death machine” or has to swallow the lethal drug; in other cases the candidate first ingests the drug but the final blow is administered by a tier. The death is foreseen but not intended. Who is the actor? What is active (commission) and what is passive (omission)? Removing a feeding tube is an act of commission; since the intention is death it is killing. Not pouring sustenance in the tube is omission, letting die. The intention is the same; the type of action is different. Does it really matter? As pointed out by Sullivan (1999), the debate places the doctor at the centre instead of the applicant, it leaves out the *good* of the person who wishes to die, which is the purpose of end of life decisions.

2. Facing death

Etymologically, euthanasia means a good or happy death. Many might wonder if death could ever be a happy event. To be good, death should be desired and ought to be peaceful and painless. The concept of euthanasia would not apply to a person who slips away peacefully and painlessly without any intervention after a fulfilled life. Euthanasia requires an intervention by the person wishing to die or by a person acting on her behalf to hasten a wanted death.

The word euthanasia has three meanings: 1) a quiet, peaceful, and painless death; 2) the means of procuring it; and 3) the action inducing it. What is missing is that the three definitions leave out the good of the person whose death is in question and that the death is desired by that person and for its own sake. Euthanasia cannot be morally justified unless it benefits the person who dies (Foot, 1996), and if no one else is harmed by it (Hook, 1995).

Some might consider that death is welcome after a happy and fulfilled life. Others who had an unhappy life or who are burdened with sorrow and suffering view death as deliverance. It seems, though, that for many who are clinging to life death is the last thing on their wish list. In other words, death is inevitable and is either wished or feared.

LaFollette (1997) has argued that we have not decided to enter life, but that we should be granted the right to choose to exit life. Such view, of course, is highly debatable and debated. Those who believe in the principle of sanctity of life argue that life is God given; therefore, God only can take it back. This argument does not hold for non-believers though. The principle that life is sacred, says Dworkin (1995), “that’s the easy part”; the crucial question is which decisions best respect it.

One must respect the wishes of those, believers or not, who wish to stay alive no matter what. On the other hand, to what extent should one respect the wish to die? One answer would be allowing them to commit suicide. Every one has the right to commit suicide; no

single law prohibits suicide. However, one may not have the courage or the means to take that step. Considering suicide one may be discouraged by the impact it has on one's loved ones. However, this argument is double-edged. The person who plans committing suicide may well make this decision because his entourage failed him. In that case, should he refrain from the act to avoid guilt feelings and remorse among the survivors?

Is there a right to die? Is there a duty to die? If there is a right to die, is there a correlative duty of a tier party to assist in dying?

In an attempt to answer these though questions the topic of euthanasia is riddled with inconsistencies and twists. Thou shalt not kill, of course, but it needs qualification: thou shalt not kill the innocent (Battin, 1995). It is legally and ethically impermissible to take some one's life against her will. Mass murder in war, camps, or campuses is fittingly condemned. Even if this was labelled euthanasia by the Nazi regime, it was murder of innocent and non-consenting persons. This is not negotiable. Then we have the debate whether killing and letting die are one and the same thing or not. Should active voluntary euthanasia be accessible only for intractable *physical* pain? What is the difference, if any, between early terminal sedation and terminal sedation? What is the difference, if any, between ordinary and extraordinary means to keep some one alive? And last but not least, what are the duties of health care providers towards terminally ill patients? As pointed out by Sullivan (1999), the euthanasia debate tends to place the doctor in the centre of the debate instead of the candidate. It too often leaves out the good of the person who wishes to die (Angell, 1998).

All these queries illustrate our concerns with death, our own and the other's. Death is inevitably part of life; we cannot avoid taking a moral position, because we can now choose to interrupt and delay nature's progress (Gorsuch, 2006). Euthanasia claims Moreno (1995), "appears as the ultimate postmodern demand for personal dignity".

3. Euthanasia's historical background

Rachels (1993) has given a historical overview of euthanasia from which some of the following is borrowed. In Ancient Greece, there was nothing similar to the current view on the sanctity of life. Infanticide of deformed newborns and infants was seen as benefiting them by avoiding a miserable life. Currently, such practices would be regarded as offensive and a deep lack of respect for differently able persons. This is not to say that every one believes that non-existence might be preferable to existence with different abilities. Peter Singer (1994), notoriously, has argued in favour of the permissibility of infanticide in such circumstances. Needless to say that Singer's view did provoke public outrage.

Hippocratic physicians represented only a small minority of all self-proclaimed healers. Markel (2004) claims that it is doubtful that Hippocrates would recognise most pledges ascribed to him because many revisions of the oath were written under Christian influence during the Middle Ages. In those early times, it was not uncommon for physicians to recommend suicide to a patient with incurable disease.

Even if great thinkers as Plato, Aristotle, and Pythagoras considered that suicide was mostly an act of cowardice, they admitted to exceptions. It should also be noted that the Pythagorean School of medicine did not follow Hippocrates' teachings with regards to physicians' duty to refrain from assistance in dying. Pythagoras of Samos (582-507 BCE) shifted philosophy from Asia Minor to Southwest Italy, where he founded a school, a religious and mathematical community where his intellectual and moral authority was absolute (*autos ephê, ipse dixit*, the master has spoken). Against the Homeric world-view, he

introduced features of the mystery religions. Pythagoras' community was influenced by Orphic mysticism. Pythagoras believed in the immortality of the soul (“*the body is a tomb*”, just like later Plato's “*body the dungeon of the soul*”). Therefore, one should strive to give priority to the soul and respect all living beings because they are all ensouled. Purity of the soul was important (because of his belief in metempsychosis) and can be only achieved through philosophy – the quest for knowledge, understanding, and competence.

During the following twenty centuries, Western Europe was so much under the influence of Christianity that there was a silent condemnation of suicide and no discussion on euthanasia (Curzer, 1999). During the Enlightenment, Immanuel Kant clearly rejected the permissibility of suicide. His argument was rooted in the belief that persons have an incomparable worth. Suicide degrades humanity. Even during the Enlightenment, it would have been risky to express personal liberal view on any topic, in this case to contest the sanctity of life that would upset the Church's fundamentalism.

It was not until the twentieth century that the legal and ethical aspects of euthanasia came to the public fore. In 1918, a comment by the Swiss federal government on Article 115 of the first penal code stated (quoted in Hurst & Mauron, 2003):

In modern penal law, suicide is not a crime ...
Aiding and abetting suicide can themselves
be inspired by altruistic motives.

This is why the project incriminates them only if the author has been moved by selfish reasons (Hurst & Mauron 2003). The act is called “murder upon request of the victim”, not euthanasia. *De facto*, a 1997 attempt to decriminalise euthanasia failed. The article does not require the involvement of a physician nor that the patient is terminally ill. Switzerland permits anyone to assist in another's death regardless whether the candidate is terminally ill or not (Ziegler & Bosshard, 2007). The Swiss Academy of Medical Sciences states that assistance in dying is “not part of a physician's activity”. Nevertheless, like any other citizen, a physician is allowed to altruistically assist in dying.

The argument from palliative care (including pain palliation) is often used against assistance in dying because of excruciating pain. The promoters of the argument claim that no pain is beyond palliation. A survey in Switzerland showed that 73% of palliative care physicians opposed the legislation of euthanasia; however, 19% would practice euthanasia if it became legal (Hurst & Mauron, 2003).

In the Netherlands, voluntary active euthanasia is “tolerated” since 1973 (it is not lawful but not a criminal offence) provided strict guidelines, called “due care criteria” (also referred to as careful practice, and standards of care) are adhered to: 1) the claimant must be sound of mind; 2) the request must be voluntary, independent, persistent and fully informed; 3) the pain endured must be intolerable and unresponsive to all pain relief methods; and 3) the physician must consult with another independent colleague (Battin, 2002; Sleeboom-Faulkner, 2006). The physician is free to participate or not (conscience clause) (Sleeboom-Faulkner, 2006). Note that, since the *Brongersma* case of “life fatigue or existential suffering”, the claimant needs not be terminally ill, and the pain must not be physical (Huxtable & Möller, 2007). The Netherlands since has formalised its policy in the *Termination of Life on Request and Assisted Suicide Act* 2001. The “due care criteria” including the intractable pain remain included. The *Euthanasia Act* was passed in 2003 to regulate ending of life by a physician at the request of a patient who is suffering unbearably without hope of relief. In 2005, 1.7% of deaths were the result of euthanasia and 0.1% of physician-assisted suicide; 80.2% of all cases were reported (*vs.* only 18.0% in 1990) (Van der Maas & Emanuel, 1998;

Van der Heide et al., 2007). Terminal sedation is legally permissible. It consists of the administration of a high dose of a sedative to relieve suffering without intending to hasten death, even if the patient might hope so (Quill, 2007). The Royal Dutch Association of Pharmacy technical guidelines of 1987 (revised in 1994 and 1998) recommend the oral administration of high doses of barbiturates to induce coma, followed by a neuromuscular blocking agent to cause death (Veldink et al., 2002). In the Netherlands, terminal sedation and the withdrawal of artificial feeding are regarded as “normal medical treatment” and thus different from euthanasia. Therefore, they cannot fall under the same legal regulation as euthanasia (Sheldon, 2003).

Australia’s Northern Territory was the world’s first jurisdiction to legalise euthanasia in 1996; four people were assisted under this legislation before the Australian federal government repealed it in 1997 (Parker, 2005). The Dutch practice is close to the requirements of the 1997 *Oregon’s Death with Dignity Act*, namely: 1) two oral requests separated by at least two weeks; and 2) a written request witnessed by two persons. From the part of the physician: the prescribing and the consulting physician must inform of alternatives such as pain control and hospice care (Dieterle, 2007). Note that in Oregon, the applicant must be at least 18 years old, competent, and suffering from a terminal illness with less than six months to live. As we know, this sort of prediction is alarmingly imprecise. Moreover, it might be tricky to determine one’s mental competency, but there is no obligation to get the opinion of a clinical psychologist or psychiatrist. Finally, any physician with a medical degree can assist.

In 2002, Belgium passed a Euthanasia Law. It carries most of the requirements and restrictions as those in the Dutch law (Lemiengre et al., 2007; Quill, 2007). In Germany, there is a legal “inconsistency” in the sense that voluntary active euthanasia is illegal but assisting in dying is tolerated. The preconditions are that the applicant should be competent and free. The *German Society for Humane Dying* provides the needed support provided the following conditions are met: 1) at least one-year membership; and 2) at least two years without treatment for depression or psychiatric illness. If these preconditions are met, the applicant is supplied with a list of drugs and their dosage for producing certain and painless death. It is recommended to acquire the drug through prescription from a physician and to sign a form where the decision is signed. A lay companion to assist is provided on request (Battin, 2002).

4. Definitions of euthanasia

Euthanasia is subdivided into voluntary and involuntary, active and passive. Involuntary means not under control of the will, unintentional, forced. Some add non-voluntary when a person has not expressed a choice (Beauchamp, 1996). Involuntary active euthanasia is killing an innocent person against his will. Since it does not refer to a “good” death, one should avoid calling it euthanasia.

There seems to be some confusion about the concept of active voluntary euthanasia, and its difference from physician assisted suicide. According to Dieterle (2007), in physician-assisted suicide “the patient him or herself is the instigator of death”; in active euthanasia “the physician is the instigator of death”. Brock (1999) writes “with physician-assisted suicide, the physician administers a lethal dose often because the patient is unable to do so”; but he goes on with the example of Janet Adkins (see below) who acted last. Brock (1999) opposes this to (voluntary active) euthanasia, where “the physician acts last”. Rachels (1975) writes:

The important difference between active and passive euthanasia is that, in passive euthanasia, the doctor does not do anything to bring about the patient's death. The doctor does nothing, and the patient dies of whatever ills already afflict him. In active euthanasia, however, the doctor does something to bring about the patient's death: he kills him. The doctor who gives the patient with cancer a lethal injection has himself caused his patient's death; whereas if he merely ceases the treatment, the cancer is the cause of death.

This, again, is unhelpful. To die from any terminal illness is a natural death. Whether it is accompanied by intractable and untreatable physical pain or psychological suffering is a different matter altogether. Notice the vocabulary: the doctor is the “killer”. In the euthanasia debate, the use of the verb killing should be avoided because it refers conventionally to taking a person's life against his will. The position of the American Medical Association, which Rachels tries to debunk, is “At stake is the intentional termination of life of one human being by another” (viz. of a person who did not express a consistent and free request of dying) (quoted in Rachels, 1975).

It seems that the debate has been confused by the fact that in the Netherlands, it has become common parlance to talk of active and passive while omitting the fundamental qualification voluntary and involuntary. Active voluntary euthanasia refers to a person who makes the free decision to end her life and takes the necessary steps to achieve death. The typical example is that of Janet Adkins. She was diagnosed as in the initial stage of Alzheimer's disease. She was devastated and wanted to die with dignity before the disease would take its full toll. At that time, she was a member of the Hemlock Society, and was living in Oregon where physician-assisted suicide and active voluntary euthanasia were then illegal. She flew to Michigan, where assistance in dying was not illegal. She went to Dr Jack Kevorkian who connected her to the “Mercitron”, a device composed of a pump containing a lethal substance connected to an intravenous line. The physician did install the IV-line but the candidate had to press the button to initiate the injection. In other words, Janet took the free decision to be connected to the contraption, and decided to initiate the procedure all by herself (Pence, 1995). The assistance provided by Dr Kevorkian was to make the device available. Although he was a physician and assisted by making the means available, this was not physician-assisted suicide but rather active voluntary euthanasia. It was voluntary and Janet executed the final act.

Kevorkian was prosecuted for murder by the local district attorney. A local judge dismissed the case but ordered Kevorkian to desist from using the contraption. It is unclear on what grounds the judge's ruling was based since assisting in dying was not against the law. In 1992, the governor of Michigan signed a law making assisted suicide illegal. In 1994, the Michigan Court of Appeals overruled the state's ban on assisted suicide on grounds of technicalities (Pence, 1995).

The striking down of a Washington state law banning assisted suicide followed this. The federal judge Barbara Rothstein held that the Fourteenth Amendment to the Constitution that protects individual liberties was broad enough to cover women's right to abortion *and* the right of the terminally ill to be assisted in dying. In *Quill v. Vacco*, 80 F.3d 716 (2d. Cir. 1996), the Second Circuit Court of Appeals declared unconstitutional New York's law against physician-assisted-suicide because it is a violation of the constitutional right of equal

protection under the law, since it denies help in dying to those without life-sustaining treatment, while permitting it for those receiving such treatment (Angell, 1998; Gorsuch, 2006).

In 1992, a referendum campaign aimed at toppling the California's law banning assisted suicide failed. In 1993, a similar campaign was successful in Oregon; legal challenges delayed the implementation of *Oregon's Death with Dignity Act* until 1997. Currently, in the vast majority of states' statutes have been retained or enacted expressly banning assisted suicides. In *Washington v. Glucksberg* (1997), the justices made it clear that there is no constitutionally protected right to physician-assisted suicide. However, they expressed concern about the inadequacies of access to and delivery of palliative care (Quill, 2004). Terri Schiavo was in the same condition as Quinlan and Cruzan. In 1990, at the age of 27 she went into permanent vegetative state. In 1998, her husband petitioned the court to withdraw the feeding tube. Florida's Supreme Court refused to hear appeals. A trial court judge ordered the removal. *Terri's Law* (2003) gave Governor Jeb Bush authority to order the feeding tube to be reinserted. The US Supreme Court refused to hear an appeal brought by Governor Bush. Despite the adoption by the senate of a bill *For the Relief of the Parents of Theresa Marie Schiavo* (2005), the tube was removed and Terri died (Annas, 2005).

Passive voluntary euthanasia refers to a person who makes a fully voluntary and persistent request to put an end to life but demands assistance from a tier person, either because she does not have the courage to do the needful to achieve her goal, or because she does not have the physical ability to do it. This is the same as assistance in dying. However, here again, Brock (1999) has a different definition; for him passive euthanasia (he omits the qualification of voluntary *vs.* involuntary) consists of withholding or withdrawing life-sustaining procedures.

The first assisted death on public record was the *Postma* case in the Netherlands in 1971. She suffered a severe brain haemorrhage that left her partially paralysed, deaf, and with gross speech deficits. She repeatedly begged for death. Her physician daughter Geertruda injected morphine to induce unconsciousness and curare (an agent that paralyzes all muscles including the respiratory ones) to kill her. She informed the authorities. She was found guilty of murder but was given a suspended sentence. In the aftermath, the Royal Dutch Medical association set down guidelines, the so-called "due care criteria", that were accepted by the Dutch prosecutors. Eventually, passive voluntary euthanasia or assistance in dying became rechristened as "terminal sedation", where deep sedation is induced to "an imminently dying patient". It is deemed permissible if it does not hasten death significantly (Varelius, 2007). Cellarius (2011) has argued that terminal sedation differs from early terminal sedation. He defines early terminal sedation as "palliative sedation in which deep, continuous sedation is combined with cessation of nutrition and hydration, orally or parenterally". Because it hastens death, he claims, it is "contentious but not unethical". What is contentious is debatable, disputed. This is unhelpful in the debate. Cellarius (2011) contends that deep and continuous sedation is acceptable to treat "intolerable and intractable pain", unless it hastens death. Sullivan (1999), on the other hand, states that a decision may hasten death, but that it does not follow from the fact that the intention is to bring about death that is intended. Death is only foreseeable.

This debate illustrates the contentious old doctrine of double effect, now rechristened "principle of proportionality". The doctrine states that if an action results in a foreseeable bad consequence (i.e. death), but that this end is not intended, it is morally permissible. It is quite clear that terminal sedation and early terminal sedation both aim at a single end,

death. To argue that the aim is the relief of pain or suffering is hypocritical. It seems that the same sophistry is used to permit withholding of treatment, i.e. letting die.

Passive involuntary euthanasia refers to a condition where the candidate is diagnosed irreversibly comatose. She either has a living will or not. If there is a living will that stipulates clearly the conditions in which she declines life-sustaining treatment, the decision should be respected. In the absence of a living will the decision has to be made by proxy. The proxy can be close relatives or friends who know what she would have chosen in the circumstances. In their absence, the decision is incumbent to the healthcare team and should be in the best interest of the patient. Now, this is more complex than it might appear. It raises the debate between killing and letting die. It raises the issue of the person's best interest and the possible hidden agenda of the proxy decision maker(s). We will come back to these issues.

Pickering (1993) has argued that an advance directive for “voluntary euthanasia” is a volatile combination. In brief, the argument stresses that the person who made advance directives was not psychologically the same at the time of the writing and at the time of the condition leading to coma. Perhaps, if she would regain momentary or permanent consciousness she would change her mind. One cannot foresee what type of condition one might be in and how one would judge it if one was conscious. It follows, so the argument goes, that advance directives should be respected only when the candidate is in a position to reiterate the decision made by advance directive.

The argument is often presented that one has to be suffering from depression to consider suicide or assistance in dying. One cannot fully exercise one's autonomy under the influence of depression. Therefore, one should never honour the request for assistance in dying. Along these lines, Brock (1999) discusses the “expressed-wishes euthanasia” based on what the patient would say if competent and rational. He contends that it is impossible to know what incompetent patients would choose if they were competent, even if they have previously expressed their preferences.

All these arguments have some truth, but they boil down to the infamous slippery slope: what if? Granted, all life and death decisions are controversial and may be abused. None the less, one cannot negate the fact that life and its quality may degrade so badly that death is deemed a better choice.

5. Killing and letting die

The ethical dilemma is about the difference, if any, between killing and letting die. The legal conundrum shows that, mainly in the US, the legality of letting die is variously interpreted. Similar cases, such as Karen Quinlan (1975) and Nancy Cruzan (1990), were treated differently. Karen was in permanent vegetative state and on a respirator; she was fed through a naso-gastric feeding tube. The New Jersey Supreme Court ruled in favour of Karen's parents' request to disconnect the ventilator to let her die. The importance physicians placed on the distinction between withholding and withdrawing life support surprised the Court. The Court applied the right to privacy to allow proxy decision of letting die. The Roman Catholic nursing staff, unbeknownst to Karen's relatives, implemented the weaning. Unexpectedly, Karen survived after having been weaned from the respirator. It is likely that without weaning she would have died when the respirator was disconnected. She ultimately died after 10 years in permanent vegetative state (Pence, 1995).

Nancy Cruzan was also in permanent vegetative state and fed through a naso-gastric tube. The Missouri Supreme Court overturned the probate court's decision to allow the withdrawal of the feeding tube. This was because, in the eyes of the judiciary, there was no clear and convincing evidence about Nancy's wishes not to be resuscitated if she were to be in permanent vegetative state. In reviewing the Missouri Supreme Court decision, the United States Supreme Court began to recognise a right of a competent patient to informed refusal. The tube was finally removed legally and Nancy died (Pence, 1995).

The importance of the Quinlan and the Cruzan cases was that they brought about the legal permissibility of informed refusal and the right to proxy decision-making about withholding and withdrawing life-sustaining procedures. In both cases the issue was the artificial feeding. Since food and water are basic human needs, the controversy arose whether artificial feeding is an ordinary or an extraordinary means. In addition, it ignited the debate whether removing the tube would be an act of omission (letting die) or commission (killing).

The legality of assistance in dying is mostly not recognised. The US state of Oregon, however, enacted the Oregon Death with Dignity Act. Oregon's Department of Human Services has the task of auditing a sample of the records regarding each act of assisted suicide on a yearly basis. At variance with the Dutch medical guidelines, in Oregon the right to assistance in dying does not require the existence of any pain, treatable or not. The distinction between killing and letting die has connection with the elusive distinction between omission and commission, as well as with the hair splitting and hypocritical doctrine of double effect.

In *Active and Passive Euthanasia*, Rachels (1975) has argued that there is no moral difference between killing (commission) and letting die (omission), but rather that it is "a grotesque perversion of moral reasoning". He opposes the American Medical Association's denial that the withdrawal of life-sustaining interventions equals the intentional termination of life. He contends that it is "patently cruel" to withhold a treatment (letting die) because it results in a prolonged agony; therefore, it is more humane to inject a lethal drug (killing). The American Medical Association's position is that in certain circumstances it is permissible to withhold treatment (letting die), but that in no circumstances a positive step can be taken to end a patient's life (mercy killing). Note that what the American Medical Association talks about is the withdrawal (i.e. "cessation", not withholding) of "extraordinary means" when it is clear that death is imminent. To withdraw is to discontinue something that was given; to withhold is to refuse to give. Rachels appears to be mixing both withholding and withdrawing treatment.

Thought experiments are often used as a fictional situation to underpin a moral argument. In his paper, Rachels (1975) argues that there is no difference if a person who has a personal interest in the death of a child, either witnesses it drowning in the bath tub (letting die) or actively drowns it (killing). In both cases the motive and the end in view were identical. Therefore, killing and letting die are the same. Now, as Rachels (1975) acknowledges, this is irrelevant to the issue under discussion, namely withholding and withdrawing life-sustaining procedures in medicine. If it is irrelevant to the issue under discussion, it should be omitted. He also points out that what matters in the moral judgement are the motives: personal gain or a humanitarian motive (which applies to the thought experiment he offers). The twist is that, as far as Rachels' case study is concerned, the problem is about the social and parental acceptance of Down's babies, rather than killing *vs.* letting die.

Now consider the following scenarios. Bill and his wife Nancy are clear about their mutual desire not to be resuscitated in case of irreversible coma. This is written down in their living will. Both drive weekly to their respective work place in two different and far away locations. Bill is involved in a car accident. He has a life threatening head injury and is treated by paramedics at the scene of the accident. He is put on emergency life-support and transported to the nearest hospital. On arrival, the casualty medical officer judges that Bill needs to be ventilated artificially to give him any chance of survival. Bill is intubated and connected to the ventilator. Nancy is informed about the situation and rushes to the hospital. She is told that the brain damage is most likely to be irreversible. She explains that Bill has a living will that is clear about “do not resuscitate” (DNR). The doctor acted according to his professional duty to preserve life. Nancy wants to respect Bill’s wishes, but the life-support procedures were initiated. There was no way the doctor could have known about Bill’s DNR wish. Now what would the decision to pull the plug be, killing or letting die? Bill had expressed the will to die if such foreseeable circumstances would occur. The life-sustaining procedure should not have been commenced if his DNR will have been known, but would it? Even if the doctor had known, would he have let Bill die? Let us now change the scenario. Bill and Nancy are driving on the highway to their log cabin at the lake. A drunk driver hits their car on the passenger side. Nancy suffers a life-threatening injury, but Bill is unscathed. The paramedics arrive on the scene. Bill tells them to desist from assistance. Bill lets Nancy die. This sounds similar to Rachel’s scenario where the person watches the child drowning in the bathtub. But is it? Nancy has no interest at all in Bill’s death. She only wants to respect his living will. However, it is doubtful whether she will be allowed. It is very likely that she would be charged of non-assistance to a person in danger.

6. The right to die: The limits of autonomy?

In 1973, an exploding gas line burned 67 percent of Donald (“Dax”) Cowart’s body. At the time, he was a healthy young jet pilot and amateur rodeo performer. At the scene of the accident, he begged for a gun to shoot himself when the emergency paramedics arrived. Dax’s prognosis for survival was approximately 20 percent, but his potential quality of life was deeply compromised. His request was denied. Against his will he underwent 232 days of treatment in Parkland Memorial Hospital in Dallas. Despite the fact that he was deemed competent, his repeated refusal of treatment and requests to die were consistently declined. Instead, the physicians honoured the wishes of his mother. The accident left him blind and gravely disfigured, with only partial use of his fingers. He later became a millionaire from an out of court settlement with the gas company. He graduated from law school in 1986 and got married. He also became a regular speaker for the Society for the Right to Die. His main argument has always been that his physicians had been morally wrong to treat him against his wishes (Andersen et al., 1996; Knapp van Bogaert & Ogubanjo, 2010).

The question is: Would it be an act of commission, sanctioned legally and morally, to provide someone the means to commit suicide? Recall Kevorkian’s Mercitron. Janet Adkins did operate the device herself knowingly and willingly. At the time, assisted suicide was legal in Michigan. And still, Kevorkian was requested to desist from repeating assistance. Dax, however, was unable to get hold of a gun without assistance. Isn’t there an inconsistency? One tends to admit that a terminally ill person has the right to assistance in dying, especially if she is in excruciating pain. When burns cover 67 percent of the body the

pain is excruciating and there is generally little hope to survive. Dax was in excruciating pain (and remained in that condition for the 32 following weeks). And yet, assistance was denied.

As we have seen, the US Supreme Court recognised the legal right to informed refusal of treatment or life-sustaining interventions. Unfortunately for Dax that was in 1993, twenty years after his ordeal began.

The right to die from one's personal perception of quality of life, as it was in Dax's case, was brought to the fore with Larry McAfee in 1985. Twenty-nine years old McAfee became almost totally paralysed in a motorcycle accident. In 1989, he decided to file suit in court for the right to die because the institutions he was placed did not provide what he judged an acceptable quality of life. He designed a switch to be connected to his IV-line that would allow him to self-inject a lethal drug by blowing in certain ways into the ventilator. The County Superior Court ruled in his favour. McAfee did not commit suicide as he was eventually placed in an institution where his quality of life was improved (Knapp van Bogaert & Ogubanjo, 2010).

As commented by Pence (1995), such cases suggest that society often gives severely disabled people only three limited, grim choices: to become a burden on their families or friends, to live miserably in a public institution, or to kill themselves. Even the last option is often denied. Is there any difference between a terminally ill patient requesting assistance in dying, given the hurdles of prognostication, and an almost totally paralysed person whose lack of quality of life is unbearable? Why would one oblige to the former's wish and not to the latter?

Like many others, Beauchamp and Childress (2001) remark that if autonomy is the corner stone of medical decision-making one has to admit that double standards regulate the granting and declining of patients' autonomy. On the one hand, a patient's informed refusal to life-sustaining interventions is viewed as an affirmation of and respect for his autonomy. That is the moral (and legal) permissibility of letting die. On the other hand, the right to assistance in dying by mutual agreement between the patient and her assistant is, with some exceptions mentioned above, unlawful and regarded morally impermissible. One does not always have the ability to commit suicide; for instance, if one is paralysed one cannot exercise one's autonomy. So, killing is not the same as letting die. Rachels (1993) has argued that it is the same. If he is right, the mentioned inconsistency must be redressed.

In the clinical context, autonomy and respect for patients are linked to the notion of informed consent or refusal. It is often regarded as a *loose* expression of patient's right to choose; the health care provider has to comply with whatever the patient decides as long as she is deemed competent and properly informed about the alternatives, the risks and benefits. This view places the concept of autonomy and respect for autonomy in a narrow or minimal perspective. This, writes O'Neill (1988), is a minimal conception of autonomy that identifies autonomy with the requirements of informed consent and that regards respect for autonomy as a sufficient rather than necessary ethical justification. Instead, she argues, autonomy should be understood as a capacity for independent decisions and actions. Autonomy is not exercised in vacuo. One is autonomous from something and from someone (the health care team, the entourage). Autonomy is exercised in a *relational* (after consultation, exchange) rather than in an adversarial context. And, finally, there are degrees of independent decisions. The mere fact of being ill places us in a vulnerable situation that may affect our level of independence and degree of willingness to accept the health care

professional’s plan of action. On the other hand, a stronger perception of one’s autonomy may easily conflict with the reasonable choices offered by the health care team.

7. Euthanasia and the slippery slope

One stands on the slippery slope when arguments against one position appear to equally apply to the counter position, leading to an undesired or undesirable situation. With euthanasia, it would mean that if assistance in dying becomes legally authorised the door is wide open to abuse. Corners will be bent so that euthanasia will be practised for other motives and outside of the requirements set by the law, let alone that people will be forced to die under false pretences. Granted that the risk cannot be denied, one should look whether the risk is real or of minimal magnitude.

Pence (1997) distinguishes three different types of slippery slope: 1) generalising to other kinds of cases; 2) unleashing the dark side of human nature; and 3) consistency. According to the first one, you first withdraw, say, the respirator, then you stop parenteral nutrition, and finally you kill. The slope slips from terminally ill patients, to formerly competent ones (e.g. senile dementia), to never competent adults (e.g. brain damaged at birth), and to infanticide. It does only if competence is disregarded or misconstrued. The second slope slips when proxy decisions are made that are not in the best interest of dying or terminally ill patient be it for material sake (e.g. the cost of terminal care, or greed) or out of convenience (e.g. the financial and emotional burden of terminal care). In this case, the person may be competent or not but coerced into accepting that she has the duty to die. In other words, the slope becomes slippery only if one calls voluntary active euthanasia what is not a willing and knowing request for help in dying.

The third slope slips if one uses criteria applicable in one case that are not applicable to another. This slippery argument, says Pence, is the weakest sometimes time and introspection will tell that criteria may have to change.

It is unfortunate that the country with the longest “experience”, Switzerland, has no validated statistics. Estimates, however, suggest that only 0.45% deaths are assisted suicides and that two thirds of the requests are rejected. In Oregon 0.09% of deaths represent assisted death, and in the Netherlands they amount to 0.3% (Hurst & Mauron, 2003). These data do not mean that “assistance” is not given without the patients’ explicit request. In 1990, a confidential enquiry run in the Netherlands showed that 0.8% of deaths were initiated without the patient’s request. A similar enquiry was run in 1995 and resulted in a value of 0.7% showing that toleration did not result in a ripple effect. The same questionnaire used in Australia estimated the occurrence of involuntary euthanasia at 3.5%. The difference suggests that different cultures may have different potential for misuse (van der Maas & Emanuel, 1998). As pointed out by Battin (1995), “It is unlikely that Americans can fully understand why the Dutch support their practice of euthanasia, and conversely it is unlikely that the Dutch will understand why the Americans are so ambivalent about its legalisation or why they are so likely to distort the Dutch practice, until these differences are incorporated into both sides of the debate”.

One of the slippery slope arguments claims that legalising euthanasia will result in pressurising the weak and the elderly to accept dying. In Oregon, however, data show that those who choose euthanasia are younger, highly educated, and used to be in control of their lives (Branthwaite, 2005).

As Rachels (1993.) comments, there is no denying that there are abuses of virtually all social practices. The question is whether the abuses would be so numerous as to justify the banning of that specific practice. Furthermore, slippery slope arguments provide no moral basis for the conclusion that some acts are morally wrong (Beauchamp 1996). With regards to assistance in dying, Pence (1997) remarks that claiming that it is immoral “only begs the question, it isn’t an argument”.

8. Conclusive remarks

It appears that more is written and argued against than in favour of voluntary euthanasia. This is understandable since most people wish rather to live than to die. None the less, there are people who wish to die. Their voice must also be heard. The nagging question is why, when, and how? As emphasised by Tristram Engelhardt (1995), “to establish the wrongness of voluntary euthanasia would require a hierarchy of values that subordinates the value of individual liberty to other special values”.

In this case, we encounter two potentially conflicting liberties: the autonomy of the person wishing to die, and the autonomy of the individual who is asked assistance in dying. Although Switzerland has, in my opinion, resolved that conflict by permitting legally any one who has no personal profit in assisting in dying, other countries like the Netherlands reserve this right strictly to physicians. The right to autonomy is equally applicable to physicians. Ann Davis (1996) contends that one cannot be autonomous if decisions can be overruled by people who do not share our values. Beauchamp (1997) asserts that to refuse assistance in dying is harmful because it denies a person’s autonomous wish. Self-determination, as long as it does not harm the other(s), is one of the main cornerstones of ethics. If the exercise of autonomy relieves us from an unacceptable lack of quality of life, it should not be morally wrong.

The legal and ethical permissibility of a patient’s right to withhold (not to allow) life-sustaining interventions is widely accepted. In this case, that person knows and willingly accepts that this will result in death. This has been dubbed “coming to peace with death” (Gorschung, 2006). It is the disease that kills (Callahan, 1999).

In the case of withdrawing life-sustaining procedures that have been initiated (killing), the intention, malevolent or not, is death. The irony is that this fuels a sophistical debate on omission and commission. For instance, the removal of a feeding tube is an act, commission. To keep the tube but not supplying fluids and nutrients is omission. In both cases, the patient will die. In both cases this was the motivation.

On the other hand, it is deemed legally and ethically impermissible to request assistance in dying (if one is unable to, say, press the button). It is killing if one is unable to press the button or suicide with some one’s assistance (otherwise called “mercy killing”) if one is the last person to act.

The so-called “joint view” that justifies voluntary euthanasia is based on two ethical principles: respect for autonomy, and beneficence (Huxtable & Möller 2007.). Varelius (2007) argues that respect for autonomy trumps the principle of beneficence, because the latter results in harm even if requested. However, the twist is that the defenders of terminal sedation deem it acceptable if the harm is needed to reach the intended goal, pain relief. On the other hand, by limiting the right of assistance in dying to physicians, one creates a potential conflict between the physician’s duties to preserve life, and to alleviate pain and suffering. In the case of euthanasia, one of both duties must be prioritised.

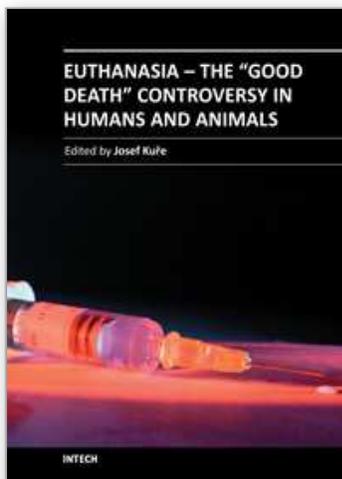
By placing the doctor at the centre of the ethical dilemma, the patient's request is often disregarded, minimised, or even put in jeopardy. Furthermore, the debate is all too often around generic patients, in ideal circumstances, where the arguments appeal to abstract principles (Donchin, 2000). In line with Beauchamp & Childress (1994), one should strive to reform ethics and the law to deal with an “apparent inconsistency” between affirmation and denial of autonomy. Autonomy is given to those who consciously and willingly refuse life-sustaining interventions; but autonomy is denied to those who consciously, willingly, and repeatedly ask for assistance in dying.

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No one really wants to die, or do they? From classical times to our post-modern era of medical high tech, societies have struggled with the thorny issue of euthanasia, and what it entails. Who shall be entitled to a "good death" and in what form shall it arrive? This book provides the reader with insight and enlightenment on the medical, philosophical, social, cultural and existential aspects of "good death" amid our digitized, individualized and ageing society, hampered by rising health care costs but unchained from one standardized level of care.

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